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**Conditionality, surveillance, and
citizenship: examining the impacts of
the 2010–2015 Coalition Government’s
welfare reform program on disabled
people living in Scotland**

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Submitted in fulfilment of the requirements for the degree
of Doctor of Philosophy (PhD) in Urban Studies

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For Pam, who got me started; and for Zaff, for whom I've finished.

Abstract

This thesis examines the impact of reforms to disability benefits enacted by the Coalition Government of 2010-2015 on disabled people living in Scotland. Situating the Coalition's reform agenda in the context of disability policies since the late Victorian era, it is apparent that the evolution of disability policy has not been a smooth, coherent, or strategic process. Nevertheless, it is possible to identify three trends that have been apparent since 2010. The first relates to the primacy given to participation in employment as the basis for 'active' citizenship, underpinned by a conditional approach to the receipt of benefits. The second relates to the conception of disability as an administrative category which is inherently expansive and therefore prone to crisis. Finally, the way in which reforms have been justified with reference to concepts such as 'independent living' is identified as a significant divergence from previous approaches to disability policy.

Based on semi-structured depth interviews with twenty-three working-age disabled people, this thesis explores the impact of the Coalition's reform agenda on disabled people living in Scotland across three dimensions. Firstly, it examines the extent to which behavioural responses to perceived 'welfare dependency' are based on a restrictive conception of agency that fails to capture the many and varied ways in which those in receipt of benefits act. Secondly, it explores the reforms as characteristic of a 'crisis' in the disability category, and considers the impacts of attempts to contain this crisis through increased reliance on medical testing. Finally, it considers the use of policy language derived from the disabled people's movement to ascertain whether these changes are reflective of a citizenship agenda in disability policy.

Key findings include that while the Coalition's approach emphasized participation in the labour market, and drew disabled people increasingly into conditionality, this had not resulted in a rise in labour market involvement for those in this study. Nevertheless, this study also demonstrated that disabled people can and do make a range of contributions to society whether they are in work or not. The findings presented here therefore stand in contrast to narratives that portray those in receipt of benefits as feckless and work-shy. They also serve to challenge some of the dominant assumptions about the agency of those in receipt of disability benefits, and highlight that structural barriers continue to shape individuals lives in many ways.

Furthermore, this work serves to illustrate the challenges of negotiating an increasingly complex process of accessing and being assessed for disability benefits. An important insight related to the way in which tighter eligibility criteria combined with a 'climate of fear' brought about by media reporting of the reforms to generate a form of 'hidden conditionality'. Participants

described being under surveillance by authorities and their own communities. Dominant narratives had served to foster feelings of resentment and indeed vindictiveness against a group who were seen to be receiving favourable treatment at a time of austerity. This was reflected in an increase in incidents of hate crime and violence against disabled people.

Finally, this thesis provides an evaluation of the extent to which the Coalition's linguistic support for independent living was reflected in the lived reality of their reforms. It finds that while the Coalition explicitly drew on the language of the disabled people's movement in the framing of policies, this discursive support had not been reflected in the experience of these policies. New approaches to the organization of social care in Scotland have also sought to advance the citizenship of disabled people living here. While the introduction of Self-directed Support (SDS) demonstrated considerable potential for a citizenship approach, the overall trend during this period was towards a reduction in the amount of choice and control disabled people were able to exercise.

This work is among the first substantive pieces of research to examine the impacts of the Coalition's reforms on disabled people living in Scotland. It contributes to knowledge in this area across four dimensions: firstly to debates around the agency and assumed agency of those in receipt of disability benefits; secondly to the understanding of disability as an administrative category, and the implications of this for policy; thirdly in connecting literatures concerning the narrative trends around reform to those concerning surveillance, vindictiveness, and resentment; and finally to the literature on 'personalization' in health and social care, and the emerging body of work on the impact of SDS in Scotland.

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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.

Name: Kainde Manji

Signed:

Date:

List of Abbreviations

AA	Attendance Allowance
ALMP	Active Labour Market Policy
BPS	Biopsychosocial model of Disability
CIL	Centre for Independent Living
CPI	Consumer Prices Index
DDA	Disability Discrimination Act
DLA	Disability Living Allowance
DP	Direct Payment
DPO	Disabled People's Organisation
DWP	Department for Work and Pensions
EHRC	Equality and Human Rights Commission
ESA	Employment Support Allowance
ESRC	Economic and Social Research Council
IB	Incapacity Benefit
ILF	Independent Living Fund
IVB	Invalidity Benefit
JSA	Jobseekers Allowance
MA	Mobility Allowance
NDDP	New Deal for Disabled People
NPM	New Public Management
PA	Personal Assistant
PIP	Personal Independence Payment
RPI	Retail Prices Index

rUK	Rest of United Kingdom
SB	Supplementary Benefit
SDS	Self-Directed Support
SNP	Scottish National Party
UC	Universal Credit
UPIAS	Union of Physically Impaired Against Segregation
WCA	Work Capability Assessment
WP	Work Programme
WRAG	Work Related Activity Group (of ESA)

Chapter 1 Introduction

1.1 Introduction

Between 2010 and 2015, the Conservative/Liberal Democrat Coalition Government embarked on an ambitious programme of reforms to social security in the United Kingdom. Their approach was intended 'to make the system fairer, more affordable and to tackle poverty and welfare dependency' (DWP 2010, p.6). The Coalition had come to power against the backdrop of the 2008 global financial crisis, an issue which had dominated the general election campaign. The Emergency Budget of June 2010 proposed public spending cuts of £30 billion per year until 2014/15, of which £11bn was to come from reductions in social security (HM Treasury 2010). Importantly, the Budget also outlined protections to the state pension, meaning that the majority of cuts were directed at working age benefits (Taylor-Gooby & Stoker 2011). Welfare reform was therefore both an agenda for bringing about behaviour change among those in receipt of benefits, as well as a strategy for managing the economy in the wake of recession (Lee 2011). Based on 23 semi-structured depth interviews with individual disabled people of working age, this thesis examines the impact of these reforms on disabled people living in Scotland. In doing so it focuses on three prominent trends in the reform of disability benefits during this period. Firstly it examines the extent to which behavioural responses to perceived 'welfare dependency' are based on a restrictive conception of agency that fails to capture the many and varied ways in which those in receipt of benefits act. Secondly, it explores the reforms as characteristic of a 'crisis' in the disability category (Stone 1984, Roulstone 2015), and considers the impacts of attempts to contain this crisis through increased reliance on medical testing. Finally, it considers the use of policy language derived from the disabled people's movement to ascertain whether these changes are reflective of a citizenship agenda in disability policy. This final section also provides an early insight into the impact of changes to the organization of social care in Scotland in the form of Self-Directed Support (SDS) on social care users.

This work is among the first substantive pieces of work to examine the impacts on disabled people living in Scotland. It contributes to knowledge in this area across four dimensions: firstly, to debates around the agency and assumed agency of those in receipt of disability benefits; secondly, to the understanding of disability as an administrative category, and the implications of this for policy; thirdly, in connecting literatures concerning the narrative trends around reform to those concerning surveillance, vindictiveness and resentment, and; finally, to the literature on 'personalization' in health and social care and the emerging body of work on the impact of SDS in Scotland.

This introductory chapter provides a brief justification for this work, and discusses and defines key terms. It also provides a brief pen profile of disabled people living in Scotland and the United Kingdom at the start of the period under examination. Finally, the chapter provides an overview of the thesis structure, and briefly highlights the key arguments that will be made in each chapter.

1.2 Justification for research

This thesis examines the impacts of the Coalition Government's welfare reform programme on disabled people living in Scotland. In doing so it seeks to answer the following questions:

- 1) *Policies promoting a conditional approach to the receipt of benefits are based on certain assumptions about recipient's agency. To what extent are these assumptions reflective of individual disabled people's attitudes to benefits and the labour market? In what ways have disabled people been affected by the intensification of conditionality?*
- 2) *The reform of Employment Support Allowance/ Incapacity Benefit (ESA/IB) and Disability Living Allowance/Personal Independence Payment (DLA/PIP) has been characterized as a redrawing of the*

disability category in response to a perceived crisis. In what ways has this reform impacted on the experience of claiming and using disability benefits? In what ways have disabled people been affected by popular and media narratives supporting the reforms?

- 3) *Policies adopted both at Westminster and at Holyrood between 2010 and 2015 drew heavily on the language of the disabled people's movement, emphasizing concepts like independence. To what extent have these policies enhanced disabled people's citizenship status during this period?*

Many of the changes undertaken during this period were targeted at benefits received by long-term sick and disabled people of working age including DLA and the ILF. Likewise, the coalition were also responsible for overseeing the reassessment of existing IB recipients introduced under the move to ESA, which was initiated by the previous Labour Government (1997-2010). Though the scale of reform was significant, the philosophical basis for the changes that were embarked upon during this period was consistent with the overall trajectory of UK government 'welfare' policy since the 1980s (Deacon & Patrick 2011, see also Chapter 2). This approach emphasized the need to 'activate' people into employment by making the receipt of benefits conditional on certain behaviours. Nevertheless, disabled people had been largely protected from these trends in the past as a result of having been viewed as more broadly deserving of state support (Roulstone & Prideaux 2012). The Coalition's reforms, however, saw a marked expansion and intensification of conditionality to disabled people (Patrick 2011a). This period also saw an increased focus on 'independent' medical assessment in order to determine eligibility to these benefits (Shakespeare et al. 2016). These changes were supported through the cultivation of a public narrative which increasingly described those in receipt of benefits as 'scroungers' (Briant et al. 2013; Garthwaite 2011). While the coalition's reform program was expected to impact on a range of different groups of benefit recipients (Lister & and Bennet 2010), early analysis of these changes suggested that disabled people would be disproportionately affected (Wood & Grant 2010).

Demographic differences between Scotland and the rest of the UK (rUK) meant that it was reasonable to expect that the experience of reform might well have been particularly intense here. The impact of the 2008 recession saw a greater rise in unemployment in Scotland compared to rUK, and in 2010, Scotland also had a larger proportion of where no one was in work at 22.6% compared to 19.1% (Scottish Government 2011). Tackling this issue was a central focus of the Coalition's welfare reform agenda (DWP 2010). Likewise, the proportion of individuals in receipt of disability benefits was slightly higher in Scotland than rUK. A higher proportion of individuals in Scotland received IB or ESA in 2010 at 8.3% of the population compared to 6.7% respectively (Scottish Government 2011). Similarly, the proportion of the Scottish population in receipt of DLA was slightly higher in 2010 than in rUK at 6.6% and 5.2% respectively, though this difference was small. Overall, this meant that the reforms were expected to be experienced particularly acutely in Scotland.

Since 1999, changes in the constitutional settlement have also created a different context for the implementation of the reforms in Scotland. While the UK retained control over policies such as defence, and social security, powers over health and social care as well as education and skills were devolved to the newly created Scottish Parliament. The extent to which this resulted in the development of a uniquely 'Scottish approach' (Cairney et al 2016) to social policy has been the topic of considerable debate since the advent of devolution. For example, while Scotland has operated under its own framework for the delivery of social work since the 1960s, this has not resulted in a significantly divergent approach, even following devolution of powers in this area (Rummery & McAngus 2015). One notable exception to this was the introduction of 'free personal care' for adults aged over 65 in Scotland in 2002 (Bell et al 2007). The general lack of divergence from UK policy approaches taken in the rest of the UK has tended to be explained by the lack of concomitant welfare powers that would enable a more systemic reform to be possible. However, closer analysis has also pointed to a conservatism or even path dependency in the Scottish approach to policy

making (Rummary & McAngus 2015). This has been particularly evident in Scotland's approach to more personalized social care policies including those pioneered by disabled people themselves such as Direct Payments (Rummary & McAngus 2015, see also 2.6.2.2). While Direct Payments were embraced by English local authorities, uptake in Scotland has historically been low, largely due to local authorities' resistance to a policy process they perceived as a form of privatisation of care (Pearson 2004 see also section 2.6.2.2 for a discussion of this). As a result the period of devolution has not been marked by significant policy divergence from the rest of the UK, providing a remarkably similar social policy context across the two nations. Nevertheless, Scottish politicians since devolution have still sought to emphasise a more social democratic orientation to social policy in the Scottish context. The reputation that Scotland has for delivering a unique and different approach to social policy may therefore be based more on rhetoric, than on policy (Cairney et al 2016, Rummary & McAngus 2015).

The period in which this study was conducted saw the rhetorical differences between Scotland and the rest of the UK amplified in the lead up to the 2014 Independence Referendum. Although the Scottish Parliament did not have powers over social security spending in this period, the Scottish Government took a keen interest in the reforms taking place. This was in no small part due to their desire to appear more socially progressive by curbing the excesses of the Coalition Government in Westminster. This led to the adoption of a number of small scale interventions to mitigate some of the impacts, including changes to Council Tax Benefit and elements of Housing Benefit (Beatty & Fothergill 2013, 2015). Similarly, Scottish Local Authorities were responsible for delivering frontline services such as social care to disabled people. However, as will become evident in chapters 3 and 7, their ability to offset UK level reforms with more generous social care policies was hindered by the context of an ever-tighter financial settlement, compounded by the decision to freeze council tax in 2007 (Spowart 2011), significantly reducing local authorities' revenue raising powers. This freeze remained in place until 2017 when the Scottish Government introduced a 're-banding' exercise for properties in bands E-H, increasing the rates levied to households in these

bands (Scottish Government 2017a). Local authorities were then also given power to increase bills across the bands at this time. However, the freeze had been in place for a decade by this time, representing a significant reduction in local authorities' revenue raising powers during this period. Research for this thesis was conducted in the very middle of this period. Furthermore, changes to the framework for delivery of social care in Scotland initiated at Holyrood provided an additional level of policy change that disabled people were having to negotiate at this time. The Social Care (Self-Directed Support) (Scotland) Act (2013) aimed to transform traditional service provision by the local authority in favour of more a personalized approach emphasizing values such as empowerment and co-production (Leadbetter 2008; Pearson et al. 2014). However, it could be argued that this change has simply brought Scotland further in line with approaches to personalization across the UK rather than representing a significant divergence (Rummery & McAngus 2015 see also 2.6.2.2 and 3.4.1). Nevertheless, these and other factors discussed above have made Scotland an important and interesting case study for the examination of impacts of the coalition's welfare reform agenda on disabled people.

1.3 Key concepts

This thesis speaks to two particular concepts that are significant within social policy: citizenship and conditionality. It is helpful therefore to provide a brief definition of each of these terms. Citizenship as a concept relates to the relationship between individuals and the state, and has its roots in ancient Greek democracy (Dwyer 2010). Crucially it draws a clear boundary between 'insiders' and 'outsiders'. It is also characteristically marked by a balance between obligations and attendant rights (Lister 2003). Citizenship as it is understood in the present day has evolved to incorporate three strands: political, civil and social (Marshall 1949/2006). The first relates to the right to take part in the democratic process, while the second relates to rights around ownership of property. Social rights emerged as a concept in the Elizabethan

period, and related to state poor relief. As will be apparent in section 2.3 at this time the receipt of social support often necessitated exclusion from the other forms of citizenship (Stone 1984). It was only in the post-war period where social democratic governments sought to mitigate the impacts of cyclical unemployment inherent in industrial capitalism, that social rights became reconnected with citizenship (Marshall 1949/2006). Social citizenship as conceptualised by Marshall acted as a means of enabling those facing social inequalities to access the support necessary to realise civil and political citizenship. However, the balance between the rights and duties of citizenship has continued to be a significant debate in social policy, particularly with regards to the obligations to participate in the labour market (Lister 2003). Central to this has been the question of whether individuals should expect to meet the obligations of citizenship, for example participating in paid employment, before enjoying the attendant rights (Dwyer 2010). As will become evident in 2.6.1, for many disabled people, the ability to fulfil their citizenship obligations is dependent on access to the appropriate social rights to make these possible (Morris 2005). In the context of this thesis citizenship will relate to social rights and the extent to which the ability to access these either facilitates or hinders disabled people's potential to live independently (see 2.6.1 for a discussion of this).

The debate about whether individuals should enjoy the benefits of citizenship before they have met their obligations has given rise to the second key concept under consideration in this thesis, that of conditionality. This concept arose from the political and economic movement known as the 'New Right' which emerged in the 1970s and 1980s in the UK and in the US as a direct response to the social citizenship rights embodied in the Post War Welfare State (Dwyer 2010 see also section 2.5.2). Proponents of New Right perspectives have argued that the state had become too powerful through the development of welfare institutions and bureaucracies that have interfered with the free functioning of the market. As a consequence, civil rights of freedom to participate in the market had been infringed (Rummery 2002). The New Right viewed individuals as inherently self-interested, arguing that the post-war welfare settlement had introduced perverse incentives that made it

more appealing for individuals to become dependent on the state, than to seek employment. As a result the welfare state caused individual citizens to fail in their obligations to participate in paid work (Lister 2003). Conditionality policies therefore placed conditions on individuals in exchange for the receipt of benefits, and are often intended to 'activate' individuals into employment. These included the requirement to provide evidence to demonstrate that they were genuinely seeking work, as well as participating in schemes related to finding paid employment, for example attending training courses. These policies are often accompanied by sanctions which are used to address non-conformity with expected conditions. This can include the suspension of benefits until the claimant 'complies' with the conditions imposed. These policies have been critiqued for pushing the balance too far against the interests of the citizen, causing the state to overlook its own obligations to the citizenry (Lister 2003).

The introduction of conditionality in the UK was also strongly influenced by the communitarian tradition, which has tended to emphasise the ordering of obligations before the enjoyment of rights (Dwyer, 2010). This conception was influential in policies adopted by the Labour Government of 1997-2010 (Lister, 2003). Again, these have been criticised for giving the citizen little in return for meeting the conditions imposed, while overlooking structural barriers that exist within the labour market (*ibid*). There are also concerns that focusing narrowly on employment as the hallmark of citizenship inevitably undermines the value of other forms of citizenship contribution, for example through volunteering within the community, (Morris 2005) or through providing unpaid care for family members (Rummery 2002). This thesis focuses on conditionality policies broadly, but is particularly interested in some of the behavioural expectations implicit in conditions imposed on benefit recipients since 2010 (see section 3.2). For a more detailed discussion of the evolution of conditionality in the UK see section 2.5.2. The Coalition's approach to these policies is discussed in section 3.2.

1.4 Defining disability: key debates

Before examining the impact of reforms on disabled people, it is important to first be clear about how disability is defined and understood in this thesis. Disability is a highly contested concept and an important argument outlined in the following chapters is that the way in which it is understood by policy makers has a significant bearing on the way in which policy is experienced by disabled people (Drake 1999). This section provides a brief overview of key debates in disability studies that form the basis of 'models' of disability. It also briefly outlines alternative ways of defining and measuring disability that are commonly used in policy.

For much of the twentieth century, research on disability was driven by disciplines such as medical sociology or epidemiology (Barnes 2012; Stone 1984). The object was to consider the development and treatment of disease in the latter case, and deviations from perceived 'normal' behaviours (Waddel & Aylward 2010) in the former (Barnes 2012; Barnes & Mercer 2005). This approach as tended to treat disability as a case of 'personal tragedy' (Barnes 2012). Disability policy has therefore focused on 'cure', and where this has not been possible, on rehabilitation (Barnes 2012) rather than on including disabled people within citizenship. As a result, disabled people have tended to be viewed by policy makers not as autonomous individuals or citizens in possession of agency, but at worst as examples of social deviance, and at best as objects of pity (Barnes 2012; Barnes & Mercer 2005). This approach to disability has come to be known as the 'Medical Model' (Barnes 2012).

From the 1960s, the emergence of social movements lead by disabled people resulted in a reframing of disability. Instead of being viewed as objects of pity, disabled people sought to position themselves as a minority group experiencing oppression, discrimination, and exclusion from citizenship (Barnes 2012). Political organizations of disabled people began to challenge the traditional conception of disability as 'personal tragedy'. This framing of disability has come to be known as the 'Social Model' of disability (Oliver 1981). The social model distinguishes between two separate but frequently

conflated concepts: 'disability' and 'impairment'. While individuals may experience impairments such as cerebral palsy or mental ill health, it is society, by creating barriers to their full involvement, that disables people. This is encapsulated by the fundamental principles outlined by the UK-based Union of the Physically Impaired Against Segregation (UPIAS 1975):

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (p.4)

Because this definition emerged through the UK disabled people's movement, the model has become associated with a particular political or philosophical approach to understanding society. This has emphasized a materialist or structuralist analysis, which viewed disability as a consequence of economic factors such as the organization of industrial capitalism (Barnes 2012). People with impairments are disabled or excluded from society because they are unable to meet the demands of an industrialized labour market (Stone 1984).

As will become clear in Chapter 4, the social model spurred the creation of the disability studies discipline within academia, but retained close links with activists in the wider Disabled People's Movement (Watson 2012). It had also had some influence on the way in which disability was viewed in policy terms by the start of the period under consideration in this thesis (see section 2.6). Nevertheless, the approach taken by proponents has faced some criticism both from within and outwith disability studies. This has included those who have argued that the by focusing on disabling barriers, the social model ignores the lived experience of impairment (Morris 1992). This serves to disempower disabled people by denying discussion of important aspects of the embodied experience of disability, such as the management of pain (Shakespeare & Watson 2001). This debate has been partially resolved by the further distinction between impairment in the medical sense, and

'impairment effects' which capture some of the social-relational experience of impairment (Thomas 1999).

Other critiques of the social model have included debates as to whether the aims of the social model can ever be achieved, or indeed whether their achievement would be desirable (Shakespeare & Watson 2001). Those writing from a critical disability studies perspective have argued that the removal of a disabling barrier for one person may result in the creation of a different barrier for another (ibid). While these critiques are not intended to dismiss the contribution made by the social model, they highlight some of its limitations, and perhaps the need to develop a more sophisticated approach that recognizes the diversity of disabled people (Shakespeare & Watson 2001).

A further approach to defining disability has emerged through disability studies in the United States (US). This relates to the idea of disability as an administrative category, as conceptualized by Stone (1984). Defined in this way, disability emerged as part of the process of industrialization in order to distinguish those with a legitimate claim to financial aid, from individuals seeking to avoid the obligation to work. While society has an obligation to support those who are unable to work for legitimate reasons, this inevitably creates a tension: supporting people who are unable to work may create an incentive to others to withhold their labour. A mechanism is therefore required to create a boundary around those with a legitimate claim to societal or state support. In most cases this is a straightforward exercise. Exclusion from the obligation to work on the basis of childhood or old age is relatively easy to assess. However, as will become apparent, claims of incapacity to work due to sickness and disability have often been subject to allegations of fraud or misuse. The categorical resolution is therefore attractive, Stone argues, because it draws the boundary between 'work' and 'need' in such a way that retains cultural legitimacy. While this is a neat resolution, defined in this way, disability ultimately becomes a political concept. As a result, it is inherently expansive and therefore prone to periods of crisis, the typical response to which is retrenchment and redefining of the boundaries of the category. This

thesis explores the reforms which took place between 2010 and 2015 as characteristic of one such crisis.

Theoretical debates as to how to define disability have continued to dominate discussions within academia and the disabled people's movement. However, while these remain useful heuristic or analytical devices, it is also useful to consider the ways in which disability has been defined and measured by policymakers. One such approach is the definition used in the Equality Act (2010), legislation which exists to protect certain groups within society who may be more likely to face discrimination:

*A person (P) has a disability if—
 (a) P has a physical or mental impairment, and
 (b) the impairment has a substantial and long-term
 adverse effect on P's ability to carry out normal day-
 to-day activities. (section 6)*

Though the creation of anti-discrimination legislation was an important achievement for the disabled people's movement (see section 2.6.2.1), the framing of this definition has been critiqued for being reflective of the medical model of disability (Morris 2011). Disability is derived from impairment, and impairment is viewed as a deviation from 'normality'. As a legal test, it is also individualizing because it places the onus on the individual to meet the definition (Morris 2011). Nevertheless, it remains an important definition in policy terms, because it provides the legal basis for identifying disability discrimination.

A further definition or measure of disability is one commonly used in large-scale quantitative social surveys, for example the General Household Survey (Berthoud 2011). According to Berthoud, this defines disability as someone with a limiting long-standing illness (LLI). Again, the focus on impairment means that this is a largely medical approach to defining disability. Nevertheless, it is important to be aware of because of its prevalence in policy

papers examining the incidence of disability, particularly in relation to employment.

This section has demonstrated that disability is a highly contested concept with a range of different approaches to defining, measuring, and understanding the experience. In the interests of clarity, it is therefore important to be explicit about how disability will be defined for the purpose of this study. This thesis adopts a critical disability studies perspective to understanding disability. In doing so it draws on key insights from the social model which continues to provide a powerful heuristic, if simplistic, device for the understanding of disability (Barnes 2012). It is also more important for having been developed and pioneered by disabled people themselves (Barnes & Mercer 2005). The thesis will therefore distinguish between disability and impairment using *disability* to refer to the barriers disabled people experience within society. However, it will also strive to include a social-relational understanding of the embodied experience of impairment. *Impairment* will therefore be further distinguished from '*impairment effects*' (Thomas 1999). The thesis also draws on Stone's (1984) insights into disability as an administrative category. Although developed over three decades ago, this means of conceptualizing disability remains highly relevant (as will become apparent in the coming chapters) and provides a useful analytical lens for examining reforms to disability policy. Many of the large scale social surveys on which official statistics are based use LLI as the basis of defining disability. This definition will therefore be used when citing statistical data that have used this measure to define disability, although its use in this way will be made explicit.

1.5 Barriers to the inclusion of disabled people in Scotland and the United Kingdom

A major contribution made by the Social Model of Disability is to the understanding of discrimination against and exclusion of disabled people within society. This section briefly outlines some information about the

experience of disabled people living in Scotland at the time that this study commenced. Data came from a range of statistical publications, so it is therefore not possible to provide baseline data for the exact year that the reforms commenced. The year to which the data relate is therefore made explicit. Where possible, comparisons will be made with equivalent data from the rUK. Where Scottish data is not available, this will be substituted by UK-level data.

In 2011, towards the start of the period under consideration in this study, 19.6% of people living in Scotland reported an LLI in the Census (Scottish Government 2014a). This was slightly higher than for the UK as a whole (ibid). One of the greatest barriers to their inclusion identified in Census data for Scotland is the relationship between disability and deprivation. Individuals in the lowest income decile were twice as likely to report an LLI as those in the top income decile (Scottish Government 2014a). Children in households with one disabled person were also more than twice as likely to live in poverty as those with no disabled people (Papworth Trust 2013).

The link between disability and poverty at a UK level is largely a result of disabled people's reduced labour market participation rates as compared to non-disabled people (Berthoud 2011). In March 2013, only 49% of working age disabled people in the UK were in employment, compared to 81.8% of non-disabled people (Papworth Trust 2013). Disabled people across the UK were also four times more likely to be economically inactive than non-disabled people. They are also particularly prone to geographical variations in local labour market conditions (Berthoud 2011). This is borne out at least indicatively in Scottish data which links prevalence of disability (LLI) with deprivation by area. The most deprived areas of Scotland had the highest rates of reported disability according to the 2011 census (Scottish Government 2014a).

The likelihood of disabled people participating in employment is affected by a range of factors, including the 'severity' (sic) of their impairment, the type of impairment, and the length of time they had experienced impairment for

(Berthoud 2014). Disabling barriers such as education level and the willingness of employers to hire disabled staff suggest that issues such as discrimination also strongly influence employment prospects (Berthoud 2011). As Chapter 2 demonstrates, the segregation of disabled children from 'mainstream' education has a long history in disability policy. This was often based on the assumption that disabled children would not engage in the labour market in the future (Drake 1999, Roulstone & Prideaux 2012). However, this has resulted in lower levels of educational qualifications. Disabled people across the UK are twice as likely to have no formal qualifications as non-disabled people (Papworth Trust 2013).

Attitudes of employers are also an important influence on disabled people's likelihood of entering the labour market. This has been found to have worsened over time with employers less likely to be willing to employ disabled people in 2009 than they were in 2001 (Berthoud 2011). Disabled people also face significant pay inequality once in employment. Disabled men receive 11% less pay than non-disabled men in equal or equivalent work. For disabled women, the pay gap is double that of men at 22%.

Other factors may also contribute to the ease with which disabled people are able to find work. Self-identified barriers to employment include the availability of inaccessible public transport networks (Papworth Trust 2013). Disabled people are less likely to drive or own a car than non-disabled people, and therefore public transport is often the only means of transport (ibid). The speed of growth in new technology has also put disabled people at a disadvantage in the labour market compared to non-disabled people. In 2013 one-third of disabled people had never used the Internet (Papworth Trust 2013), which demonstrates that many disabled people also face digital exclusion.

1.6 Structure of the thesis

This final introductory section provides a brief overview of the structure of this thesis while highlighting some of the key findings from the study. Beginning with an examination of the history of disability policy in Chapter 2, followed by a more detailed analysis of the details of the Coalition's Reform programme, the first two chapters of the thesis provide a critical thematic review of literature on this topic. Chapter 2 is structured around Drake's (1999) typology of disability policies, and examines the history of disability policy in the UK since the Victorian era. It begins by exploring policies which sought to 'contain' disabled people in institutions, before briefly discussing the emergence of compensatory benefits in the interwar period. The chapter then examines the era of 'social welfare' policy in the post-war period, and in particular the expansion of social security and the shift away from institutionalization in favour of community care. Discussion of social security also provides an insight into growing pressures for contraction that emerged in the 1980s under the influence of neoliberal economics. This provides the background to the shift towards a more conditional benefit system that has been at the centre of the Coalition's approach. Discussion of care in the community explores the introduction of a 'mixed economy of care' and the introduction of market mechanisms in the delivery of social care, as well as the emergence of the nascent disabled people's movement. The final section of Chapter 2 identifies the emergence of a citizenship agenda within disability policy, and highlights key successes for the disabled people's movement in the 1990s such as the introduction of Direct Payments (DP) in social care, as well as the first anti-discrimination legislation for disabled people. Chapter 2 highlights three important trends in the evolution of disability policy in the UK. The first trend relates to the primacy given to participation in employment as the basis for 'active' citizenship, underpinned by a conditional approach to the receipt of benefits. The second relates to Stone's (1984) conception of disability as an administrative category which is inherently expansive and therefore prone to crisis. The final trend outlined in Chapter 2 relates to the citizenship agenda and the influence of the language of the disabled people's movement on social policy.

Chapter 3 is structured around the three trends highlighted in Chapter 2, and examines the Coalition's approach to 'welfare' reform between 2010 and 2015. It begins by discussing whether the Coalition's approach can be seen as indicative of a perceived crisis in the disability category (Stone 1984). This section examines the role of 'independent' medical assessments as a mechanism to determine eligibility to disability benefits. The creation of ESA under the previous Labour Government, and the Personal Independent Payment (PIP) introduced by the Coalition are both presented as important examples. The theoretical underpinnings of this trend are briefly examined. The second section of Chapter 3 considers the intensification of conditionality and sanctions under the Coalition. Expanding on analysis of the theoretical basis for conditionality discussed in Chapter 2, this section discusses the way in which assumptions about individual agency have shaped policy. Policies based on conditionality are critiqued for presenting a limited understanding of how individuals can and do act. Alternative conceptions of agency are also explored. The third section of Chapter 3 considers the way in which the Coalition have adopted the language of the disabled people's movement in their reforms, emphasizing concepts such as 'independent living'. The extent to which this is reflective of either the success of the disabled people's movement, or the appropriation of its terms, is discussed in relation to policies such as PIP, ILF, and SDS. Finally, Chapter 3 reflects upon the scale and scope of reforms embarked upon by the Coalition during this period, in particular, the way in which some of the discursive elements of reform played out in official and media narratives at the time. It is contended that this served to contribute to a 'climate of fear' (Pearson & Trevisan 2015) for disabled people. The emergence of new activist movements in opposition to the changes, as well as policies adopted by the Scottish Government to mitigate the impact of the reform agenda, are also examined.

Chapter 4 provides an overview of the methods employed in conducting research for this thesis. It begins by outlining the three research questions listed above, which form the basis for discussion in the rest of the thesis. The chapter then outlines some of the key methodological and epistemological

debates that have relevance to this study, before situating myself as a researcher in relation to these. The remainder of Chapter 4 outlines the way in which data were conducted and analysed. The key ethical issues that arose through the research are explored before introducing the sample and discussing the way in which it was achieved. The process of conducting interviews with research participants is also described. Finally, the approach taken to analysing the resulting data is detailed.

Three empirical chapters follow, which present findings for each of the three research questions in turn. Chapter 5 examines the question of agency and conditionality policy through Lister's (2004) taxonomy 'getting by', 'getting (back) at', 'getting out', and 'getting organised'. It finds that, contrary to the narrow conception of agency on which a conditional approach to benefit receipt is based, participants expressed a range of different forms of agency. The chapter begins by exploring the ways in which those involved in this study used their benefits to meet their needs. An interesting distinction emerges between those who used benefits to meet every day living costs, and those who used them to meet additional costs arising from disability or impairment. The flexibility of payments like DLA meant that many were able to use considerable flexibility to meet their particular needs. However, this became more difficult as a result of the changes experienced, meaning that participants were increasingly using payments like DLA to meet everyday living expenses. The second section of Chapter 5 explores respondent's attitudes to and experience of the labour market. All but one interviewee had some experience of employment, and the vast majority spoke positively about the role of work as a contribution to society. However, they were also keen to express that this was not the only contribution, with a large proportion actively involved in volunteering whether or not they also worked. This section also explores participants' experiences of conditionality and the Coalition's Work Programme (WP). Surprisingly, only a small proportion of those interviewed were subject to conditionality; nevertheless, their experiences, of the WP in particular, had not been positive. The third section of Chapter 5 discusses participants' responses to the coalition's reforms. While some had a history of political activism, and others had been inspired to get involved in new activist

groups, the vast majority felt powerless to change their situation. This was exacerbated by the climate of fear generated by government and media discourses surrounding welfare reform at this time. This theme is expanded on in the final section of Chapter 5. It finds that those in receipt of disability benefits were preparing themselves for an increasingly uncertain future.

Chapter 6 addresses the Coalition's reforms as an attempt to redraw the disability category, and focuses in particular on the experience of negotiating this new category. The chapter begins by discussing the processes involved in gaining access to the disability category through mechanisms such as application forms and assessment centres. The majority of participants found this to be a difficult and un-transparent process, which many experienced as demeaning and degrading to their sense of self. The chapter goes on to explore the extent to which the behavioural expectations increasingly imposed upon those seeking access to the disability category were being experienced as a form of 'hidden conditionality' or surveillance. This was evident not only in the assessment process, but also significantly in the course of everyday life. The final section of Chapter 6 explores a worrying consequence of this trend, in the form of resentment and vindictiveness against disabled people in the form of harassment and hate crime. This was fed by some of the discursive elements supporting the reforms highlighted in Chapter 3. These experiences notwithstanding, it finds that respondents remained positive about the role of that benefits played in their lives.

Chapter 7, the final empirical chapter, explores the experience of policies which have drawn on the language of citizenship. It focuses in particular on the creation of PIP, and the proposed closure of the ILF. It finds that while the coalition repeatedly emphasized concepts such as 'independent living' in their reforms, this was not reflected in disabled people's realities. Although the move to PIP had been delayed and was therefore only in the early stages of implementation at the time of interviewing, it was striking how little participants knew about the changes taking place, or how they might be affected. It will be argued that this compounded the sense of powerlessness highlighted in Chapter 5. The second section of Chapter 7 then provides an insight into the

experience of a new approach to the organization and delivery of social care in Scotland in the form of SDS. It finds that while the policy had considerable potential to empower new groups of service users to increase choice and control over their care arrangements, the majority had not benefited from this change. This was largely as a result of the context of financial constraint in local government as a result of reductions to the local government block grant from the Scottish Government. Those who already exercised choice and control through DPs were also facing re-assessments and reductions in their existing provision, as well as having to meet more complex reporting requirements.

The thesis concludes in Chapter 8, which provides an overview of the main findings from the study as well as detailing the contribution to knowledge made in this thesis. It also highlights some key policy recommendations arising from the findings, and suggests areas for future research.

1.7 Summary

This chapter has provided a brief introduction to the topic area and justification for the research presented in this thesis. It has also provided a number of definitions of disability and outlined the way in which they will be used throughout this text. A brief pen profile of barriers to inclusion experienced by disabled people living in Scotland and the UK was presented. Finally, this chapter has briefly outlined the structure of the thesis and content of each chapter. The following chapter begins the thematic review of literature by exploring the evolution of disability policy using Drake's (1999) typology of disability policies.

Chapter 2 from containment to citizenship: the evolution of disability policy from 1834 to 2010

2.1 Introduction

This chapter provides the background and context to the reforms that took place between 2010 and 2015. The detail of the reforms themselves is outlined in Chapter 3. This chapter concentrates instead on the evolution of disability policy up to May 2010. It begins by discussing what is meant by 'disability policy' with reference to Drake's (1999) typology. Using this as a framework, the rest of the chapter goes on to outline the development of policies within each of the dimensions of this typology. The history of approaches intended to contain and segregate disabled people from the rest of society are briefly discussed. The chapter then considers the evolution of social security benefits from the earliest social insurance schemes designed to 'compensate' for industrial injury.

The third section of this chapter addresses the development of policies related to social welfare, in particular the expansion of social security benefits for disabled people 1970s. This period of growth was short lived, with the rise of concerns that generous benefits were making individuals 'dependent' on state support. The section goes on to explore the introduction of policies intended to 'activate' disabled people back into the labour market. Discussion of social welfare policies also includes an examination of the move away from institutionalization towards 'care in the community' (Roulstone & Prideaux 2012) in the 1980s. This focuses in particular on debates around the shifting balance in the provision of care by the state and the market.

The final section of this chapter considers what Drake (1999) identified as policies intending to bring about equal citizenship for disabled people. This includes the introduction of anti-discrimination legislation, as well as policies seeking to increase the amount of choice and control disabled people were able to exercise in relation to the organization of their care through

independent living. This chapter lays the foundations for an important argument in this thesis: that the way in which disability is defined and understood by policymakers has a major bearing on how policy is experienced by disabled people (Drake 1999).

2.2 A typology of disability policy

The history of social policy for disabled people can be traced back as far as 1750 (Borsay 2005). However, the complex network of payments, benefits, and social welfare provision that we now understand as disability policy have many of their roots in the late Victorian period (Drake 1999, Warren 2005, Roulstone & Prideaux 2012). These emerged as a result of a number of often unconnected responses to different challenges over the course of time (Drake 1999). It is therefore difficult to define 'disability policy' as a coherent agenda (Berthoud 1998, Drake 1999). In his book *Understanding Disability Policies*, Drake (1999) discusses the development of disability policy as having proceeded along four dimensions that follow an overlapping but broadly historical trajectory (Table 2.1). Though developed in the 1990s, the themes discussed are still highly relevant for assessing the framework of state support for disabled people today.

Table 2.1: Drake's typology of disability policy

Type	Description
Containment	The segregation of disabled people from wider society, often in institutional settings such as workhouses and asylums, in order to 'cure' or correct.
Compensation	Payments made to disabled people in recognition of impairment arising from war or industrial injuries that prevented their participation in the labour market.
Social Welfare	The provision of social services such as community care, and the expansion of social security.
Citizenship	Policies aimed at securing equal rights for disabled people by reconfiguring both society and the built environment.

(Adapted from Drake 1999, p. 45)

The ways in which disability has been conceptualized by different governments over time has had a significant influence in shaping these dimensions. Drake outlines a spectrum of responses ranging from those that actively sought the annihilation of disabled people at one end, through to policies that sought to 'radically change the contours of daily life' (1999, p. 40) at the other. Policies that sought to contain disabled people were based on a concept of disability as a medical aberration that needed to be 'cured' in order to prevent its spread to the rest of society. Compensation and social welfare policies, by contrast, were intended to integrate disabled people into society. However, consistent with containment policies, it was not society but rather individual disabled people who were expected to change. The first three of these dimensions, then, are underpinned by understandings of disability that are underpinned by the medical model of disability (see section 1.3). The social model of disability is evident in the framing of the final dimension of Drake's typology, relating to policies that sought to achieve equal citizenship. The rest of this chapter discusses the development of policies within the four dimensions in turn.

2.3 Containment policies

Policies intended to contain or segregate emanate from a response to disability that views them as a threat, and are based on a desire to bring disabled bodies (or minds) back into line with societal expectations of normalcy (Drake 1999). Borsay (2005) has highlighted the role played by asylums in the history of medicine as sites for experimentation and the development of procedures intended to torture patients into 'sanity'. Disabled people were contained and segregated from society until they conformed with expectations around 'sane' behaviour (Borsay 2005). Interestingly, Borsay defines this behaviour as having applied not just to the mind, but also to the body, with physical impairment viewed as emanating from mental incapacity.

Containment policies were also evident in Victorian approaches to poverty. The Poor Law Amendment Act of 1834 (1845 in Scotland) established the principle of less eligibility, that people seeking poor relief should not receive support to lift them above the situation of the poorest labourer (Borsay 2005). This principle underpinned policy throughout the Victorian period and beyond (Stone 1984). Additionally, the act introduced a distinction between 'indoor' and 'outdoor' relief, whereby able-bodied individuals in need of assistance could only receive this within the workhouse (Borsay 2005). Workhouses were to stand as a deterrent to requests for assistance, and to enforce the work ethic.

The relationship between disability and work has always been a complex one, as will be evident throughout this thesis. While the Poor Law ostensibly exempted disabled people deemed eligible for assistance from the obligations of work, participation in the labour market has long been viewed as a major prerequisite to citizenship (Stone 1984, Borsay 2005). Policy has therefore focused on requiring, or indeed compelling, individuals into work. Indeed, the concept of less eligibility was based on the belief that generous payments would make people lazy and unwilling to find work. In other words, that they would become dependent on support from the state, and would start to view it

as an entitlement. Having to seek recourse to poor relief by entering the workhouse was therefore highly stigmatized. Workhouses therefore stood as a deterrent to malingering, compelling those who strayed to return to work (Borsay 2005). Policy initially placed disabled people outside of workhouses on the basis that they were unable to work for legitimate reasons and therefore viewed as more 'deserving' (Stone 1984). However, disabled people were still excluded from the mainstream in the sense of being held separate from society as incomplete citizens (Borsay 2005). The idea of 'deservingness' was based on exclusion from the obligations of work, rather than a benign status indicating better treatment. In this sense, desert operated as a form of 'stigmatised social privilege' (Soldatic & Meekosha 2013 p199).

By the 1860s, rising costs saw institutionalization become the default policy response to claims for poor relief, blurring the boundaries between indoor and outdoor relief (Borsay 2005). As a result, many disabled people were contained in workhouses, with little difference in the conditions they faced compared to non-disabled people (*ibid*). Disabled people living outside of institutional settings may have been viewed as more 'deserving', but still faced exclusion from full citizenship (*ibid*). Disability has therefore always been a contested status, treading a treading fine line between paternalistic conceptions of desert and accusations of indolence (Stone 1884).

Containment has also operated in the field of education. Prior to the introduction of compulsory education in 1880, it was assumed that children with sensory, physical, or cognitive impairments would be unable to work (Borsay 2005). The report of the Royal Commission of 1885–89 saw the establishment of 'special schools' as charitable institutions with a strong religious ethos (Drake 1999). Drake (1999) has argued that this represented an important step away from containment, albeit one based on paternalistic notions of philanthropy. However, Borsay (2005) has argued that educational institutions simply perpetuated the exclusion of disabled people. Again, conceptions of citizenship as participation in paid work were an important factor in special education, with religious instruction combined with basic employability skills (Borsay 2005). However, separating disabled youngsters

from 'mainstream' education served to reinforce the assumption that disabled children would be unfit for the world of work.

Discussion in this section has highlighted an important tension that exists across welfare states when defining the boundary between the requirement to participate in work, and identifying and meeting needs (Stone 1984). Stone (1984) has argued that disability emerged as an administrative category in order to resolve this dilemma. This conception of disability is underpinned by three important factors: the prevalence of social or moral understandings about who is deserving of support and why; the existence of incapacity for work; and the ability to apply objective criteria to assess incapacity for example through medical testing. Importantly, she argues that the boundary is flexible and will be subject to pressure to expand or contract at different times according to different understandings of acceptable need. The Victorian Poor Law was therefore one approach to resolving the work/need dilemma. Crucially, Stone has argued, the category is a political construct, and is therefore inherently expansive. As will be evident in the following section, this leaves it open to periods of crisis. While there has been a shift in recent years away from policies that physically segregate and contain disabled people, discussion in the next two sections and in Chapter 6 demonstrate that containment principles have continued to influence public policy in subtle ways.

2.4 Compensation policies

An important challenge to the principle of participation in the labour market arises when the inability to work is caused by injury sustained through industrial accidents or by the state's involvement in war. Policies designed to compensate disabled people for the inability to work as a result of the acquisition of impairment through industrial or war injuries emerged in the late 1890s, however the advent of World War I saw considerable expansion of this approach (Drake 1999). Again, eligibility for support was heavily influenced by social norms relating to who was and was not deserving of support. The large

numbers of war-wounded soldiers returning from the front led to legislation for wounded service men and families of those killed in action between 1914 and 1920 (Drake 1999). However, this also introduced a hierarchy of desert, with disabled veterans being viewed as more worthy of support than those affected by industrial injury (*ibid*). Individuals with forms of impairment (including mental ill health or learning disabilities) that prevented participation in the labour market were either ignored by public policy altogether or were still subject to containment at this time (Drake 1999).

The aftermath of World War II, and the creation of a welfare state following recommendations contained in the Beveridge Report (1942) saw a further expansion of policies relating to compensation. These included the National Insurance (Industrial Injuries) Act 1946, the National Insurance Act 1946, and the National Assistance Act 1948 (Roulstone & Prideaux 2021). Beveridge's ultimate goal was full employment, and these policies (with the exception of industrial injuries) were therefore largely intended to address temporary cyclical exclusion from the labour market. Social security measures introduced in this period were also designed to rehabilitate and support individuals into employment (Drake 1999). The Disabled Person's Employment Act 1944 saw the introduction of disability quotas as well as the creation of sheltered workshops (Roulstone & Prideaux 2012). Quotas were rarely enforced, however, and supported employment schemes were often experienced as effectively a continuation of containment policies (*ibid*). Roulstone and Prideaux (2012) have also criticized the quest for full employment that underpinned policy in this period, for overlooking the barriers that many disabled people face to entering and remaining in the labour market. While the introduction of means-tested national assistance represented some acknowledgment that not all disabled people would be able to qualify for the insurance-based schemes, this was paid at a significantly lower rate in order to discourage dependence. In the post-war welfare state work continued to function as the major pre-requisite to citizenship.

2.5 Social welfare

The third element of Drake's typology relates to 'social welfare' and the expansion of social services in the post-war period. The post-war period saw significant expansion of the disability category, with the creation in the 1970s of a number of benefits specifically aimed at disabled people who were unable to work (Burchardt 1999). This was not as a result of a coherent effort to address unmet need among disabled people, but rather a number of ad hoc responses to different needs arising at different times (Berthoud 1998). Again, primacy was given to labour market participation, with more generous payments being made to those who had some history of employment. This period also saw the recognition that that higher rates of poverty among disabled people had resulted in part from the additional costs they faced in daily life, and not just lower labour market participation (Burchardt 1999). However, in keeping with Stone's (1984) conception, efforts to reduce eligibility to out-of-work disability benefits soon followed (Roulstone 2015). This section explores the expansion into the 1970s followed by the contraction of the welfare state from the 1980s, under the influence of social and economic theories emanating from the US. It highlights two important trends that underpin much of the rest of this thesis: firstly, the introduction of policies designed to 'activate' people back into the workplace, and secondly, the increasing role given to medical testing in reducing eligibility to disability benefits. The medical model of disability, therefore, continued to be highly influential during this period.

This section also briefly examines the emergence of social welfare policies in light of the expansion and professionalization of social work in the post-war period (Drake 1999). In particular, it explores the move away from containment towards policies placing a greater emphasis on 'care in the community'. The influence of new models of public sector management in the organization of care are explored. While these were pioneered in the interests of the market, policies in this period also began to shift the balance away from local authority provision, giving greater opportunities to individual service users to exercise choice and control.

2.5.1 The expansion of social security in the 1970s: the era of disability benefits

The previous section focused on the expansion of the welfare state in the immediate post-war period. However, it was not until the 1970s that policies began to focus on support for people who were unable to work due to sickness or disability unconnected to war or industrial injury. Means-tested national assistance (see section 2.4) did not distinguish between those who were sick and disabled, and those out of work for other reasons. The introduction of means-tested Supplementary Benefit (SB) in 1966 provided a higher rate for those who were long-term unemployed, but again this was not specifically for disabled people. It was not until 1971, with the creation of Invalidity Benefit (IVB), that those who had to leave employment due to sickness or disability received specific recognition within the benefits system (Burchardt 1999). Eligibility for IVB was calculated on the basis of national insurance contributions. This meant that disabled people (and particularly disabled women) who had not enjoyed consistent labour market engagement were often unable to claim (Burchardt 1999). The creation of Invalidity Pension, which did not take account of NI contributions, in 1975 saw some recognition of this. However, it was paid at a much lower rate than IVB (ibid).

From the 1960s, social research into the experience of poverty also demonstrated that disabled people's disproportionate experience of poverty was not only due to lower levels of employment, but was also a result of facing additional costs, such as for accessible transport or personal assistance (PA) (Burchardt 1999). These needs were not being met within the existing framework of means-tested and insurance-based social security provision (Roulstone & Prideaux 2012). In 1971, Attendance Allowance (AA) was introduced for those needing PA, followed in 1975 by Mobility Allowance (MA) for those who required assistance with transport (ibid). This was an important breakthrough for disabled people (Drake 1999), although by the 1990s concerns had emerged that the payments were providing insufficient support

to those with the highest needs, while those with lower needs were going unsupported (Roulstone & Prideaux 2012).

AA and MA were replaced in 1992 by the Disability Living Allowance (DLA) for those aged under 65. Payments were made in two parts: the Mobility Component, paid at a higher and lower rate; and the Care Component, paid at the high, medium, and lower rate (Burchardt 1999). Importantly, unlike most means-tested social security benefits, it was paid to individuals both in and out of work (ibid). As a result, the benefit did not attract some of the stigma associated with out-of-work benefits (Roulstone & Prideaux 2012). The creation of DLA was therefore of symbolic as well as financial value to disabled people (Drake 1999). By working to create more of a level playing field between disabled people and non-disabled people, DLA implicitly adopts a social model perspective on disability (Morris 2011). The creation of DLA therefore represented an important step towards a citizenship model of disability policy (Drake 1999, Roulstone & Prideaux 2012). However, it was initiated without the involvement of disabled people themselves, and is therefore more of an example of progress by default (Morris 2004) than an example of citizenship policy in action (see section 2.6 below). Nevertheless, the policy became widely used and popular among disabled people, providing much-needed assistance towards the additional costs they faced in daily life (Burchardt 1999).

2.5.2 Tackling 'cultures of dependency': the pressure for contraction

The expansion of social security during the post-war period was possible as a result of the high rates of employment and economic growth (Roulstone 2015). However, from the mid- to late-1970s a period of financial insecurity generated pressure for contraction. This was underpinned by the re-emergence of concerns that 'generous' unemployment benefits had caused people to become 'dependent' and therefore unwilling to meet their obligations to participate in paid work (Dwyer 2010; Wiggan 2012). Though initially not primarily concerned with disability benefits, these ideas have been

increasingly applied to policies for disabled people. The theoretical underpinnings of these concepts are therefore worthy of consideration here.

Concerns relating to 'cultures of dependency' have been primarily associated with the emergence of the 'New Right' and in particular ideas inspired by neo-liberal economics (Dwyer 2010). These perspectives have asserted that the development of welfare institutions and bureaucracies interfered with the free functioning of the market, and have caused the state to become too powerful inhibiting individual freedoms (Rummery 2002). The post-war welfare settlement therefore introduced perverse incentives that led individuals to act not as independent agents, but caused them instead to become dependents on the state, undermining the obligation to participate in paid work (Lister 2003). These concerns are primarily motivated by a change in the economic model in modern welfare states away from Keynesian economics, which sought to curb the excesses of capitalism through protection of workers from periods of cyclical unemployment (Pierson 2006). The neo-liberal approach instead focused on increasing the supply of labour in order to boost productivity and control inflation (Standing 2011). This is partly due to the process of deindustrialization, which moved away from production as the major economic base towards an economy based on the delivery of services (Pierson 1998). However, Pierson (1998) has argued that this model is inherently less productive than one based on manufacturing. This required an increase in supply of labour and a simultaneous driving down of wages in order to sustain it (Standing 2011). The perception that generous welfare payments were leading to the emergence of an 'underclass' unwilling to participate in paid employment (Murray 1990) was therefore a major concern for the neo-liberal project.

Two solutions to the problems associated with 'dependency' are commonly identified (Dwyer 2010). These ideas gained prominence through the work of American conservatives such as Charles Murray (1990) and Lawrence Mead. Murray (1990) argued that America was facing the emergence of an 'underclass' living on the generosity of hard working taxpayers, but unwilling to play an active role within society. His solution was to call for benefit cuts,

making fewer people eligible for support and at less generous rates. This would serve to 'reactivate' people into the labour market (Dwyer 2010).

The work of American academic Lawrence Mead (1997) has also been influential in this debate. Unlike Murray, Mead argued against the reduction of benefits for the purpose of reactivating those out of the labour market. Instead he attributed blame to the organization of the welfare system rather than its relative generosity. Social security had created a 'culture of dependency' by failing to provide the correct incentives to work. His solution was to retain benefit generosity, but to make the receipt of support conditional on certain expected behaviours. Such an approach would create incentives to work without reducing support for those genuinely in need. This approach is embodied in so called 'workfare' approaches popular in the US and other liberal welfare states, such as Australia (Wiggan 2012). Under these programmes benefit recipients were expected to fulfil certain expectations, such as providing evidence that they are actively seeking work or participating in work schemes, in return for receiving benefits. These approaches often include the imposition of sanctions for non-compliance with conditionality (Wright 2012).

The New Right approach to social welfare has been critiqued from many quarters. Concerns have included that the economic model of neo-liberalism has led to a growth in low-wage and casual labour resulting in an increasingly precarious labour market (Standing 2011). This shift has been viewed as a restructuring of the social contract. Conditional approaches emphasize the requirement to meet the obligations of citizenship before the attendant rights can be granted (Lister 2003). Lister (2003) has argued that this serves to tip the balance of power too far against the interest of the citizen. She argues that the citizen gets little in return for the level of conditionality expected, and that the conditional approach overlooks structural barriers that many individuals face within the labour market. While it is right for the state to expect citizens to meet certain obligations in return for the granting of social rights, the state has obligations in return. These include ensuring that there is

an adequate supply of jobs to meet the needs of citizens looking for work (Lister 2003).

2.5.2.1 The emergence of a 'crisis' in the disability category

Though heavily influenced by New Right thinking, the Conservative Governments of 1979-1997 explicitly excluded disabled people from their approach to Active Labour Market Policy (ALMP) (Dwyer 2010), implying that they may have been viewed as more legitimate or deserving of state support at that time. This is significant, given the growing narrative around fraud and the abuse of benefits that were prevalent during the period (Roulstone & Prideaux 2012). However, by shifting large numbers of people from unemployment benefit on to IVB in order to disguise escalating unemployment during the 1980s and 1990s, the Conservative Government sowed the seeds for one of the major challenges to disability benefits in the present day (Roulstone & Prideaux 2012). Drawing on Stone's (1984) analysis, this move can be viewed as simply an example of the state expanding the 'disability category' to meet new political needs (Roulstone 2015). However, it also set in motion the beginnings of a crisis in that category, which persists to the present day.

Many of the individuals who were moved on to IVB did indeed experience long-term illnesses or impairments that made it difficult for them to participate in employment (Beatty et al. 2010). However, the geographical distribution of claimants in former industrial heartlands of the North of England and parts of Scotland have led to suggestions that high rates of claiming for IVB and its successor Incapacity Benefit (IB) was also reflective of deindustrialization and an oversupply of labour (Stanley 2005; Beatty & Fothergill 2011). Nevertheless, the increase in numbers claiming IVB and IB was taken as evidence for the cultures of dependency narrative, rather than reflective of structural economic factors (Grover & Piggott 2007).

Though disabled people were not yet subject to conditionality, the Thatcher and Major Governments made some attempts to tackle the expansion of IVB. This included linking the rate at which the benefit was paid with prices, rather than with earnings in the 1980s (at that time a lower rate of inflation) to reduce expenditure (Burchardt 1999). In 1995, IVB was replaced by IB, introducing new eligibility criteria including whether the claimant 'could' carry out any work, irrespective of their age, qualifications, or likelihood of being appointed (Burchardt 1999).

Concerns around benefit generosity and the implications for generating 'cultures of dependency' also saw the emergence of a 'moral panic' over benefit fraud in the 1990s (Roulstone & Prideaux 2012). In early 1997, the Major Government introduced the Benefits Integrity Project, which was intended to investigate fraud within the benefits system (ibid). In addition to the reform of IVB, DLA was drawn into contention as a result of the increasing overlap between those on IVB/IB. However, this misunderstood the purpose of the benefit as an additional costs benefit, which could be claimed both in and out of work (Burchard 1999; see also section 2.6.2.2). Some overlap with IB was therefore inevitable (Roulstone & Prideaux 2012). The attempt to include DLA within the remit of the BIP resulted in a public outcry at the perceived targeting of disabled people. This was testament to the status of disabled people as a group viewed as 'deserving' of state support, as well as the legitimacy DLA was seen to hold at the time.

2.5.2.2 New Labour and the extension of conditionality: containing the expansion of disability policies

By 1997, public spending on disability benefits had escalated substantially. While the period from 1974 to 1982 saw spending remain steady at around £700 million per annum, by 1997 it had exceeded £2 billion. The election of the Labour Government in 1997 saw a renewed effort to tackle this expansion, with disabled people becoming subject to conditionality for the first time (Dwyer 2010; Roulstone & Prideaux 2012). This was embodied in the

introduction of the 'New Deal for Disabled People' (NDDP) as the cornerstone of their approach (Dwyer 2010; Roulstone & Prideaux 2012). The 'New Deals' played a central role in the Labour Government's commitment to tackling 'social exclusion' focusing on tackling the barriers that young people, disabled people, and lone parents faced in gaining and sustaining employment (Grover & Piggott 2005). Policies included the introduction of tax credits to make work more financially rewarding, as well as providing training and skills for the workplace (*ibid*). The reforms were therefore firmly focused on work as the route out of exclusion. The NDDP reflected two important trends that are discussed in Chapter 3: firstly, restricting eligibility through an increased reliance on medical testing, and secondly, the introduction of work-focused interviews requiring participation in activities designed to prepare individuals for the labour market (Stanley 2005).

The adoption of conditionality for disabled people in the UK has met with a range of criticisms. These have included concerns that focusing on 'employability' overlooks the very real barriers that disabled people face in entering employment (Page 2002). Writers from within the social model tradition (see section 1.3) have argued that the emphasis on labour market participation as the prerequisite to social rights has served to exclude disabled people from being able to participate in the labour market on an equal basis (Barnes & Mercer 2005). Discriminatory attitudes of employers surrounding disabled people's perceived capacity for work, as well as physical barriers in relation to access to buildings and workspaces, mean that disabled people do not compete on an equal basis (Barnes & Mercer 2005). Similarly, the organization of public transport may serve as a further barrier to disabled people's ability to engage in work. The buoyancy of local labour markets is a further factor. When work is scarce, such as during an economic downturn or in areas with high unemployment, disabled people are frequently placed at the back of the queue (Grover & Piggott 2007).

The centrality given to participation in paid work in conditionality policy also been viewed as disadvantageous to disabled people. Page (2002) has argued that conditionality has created a new form of employment-based citizenship,

the consequence of which has been to undermine the value of other forms of contribution. Similarly, Morris (2005) has argued that disabled people can and do make significant contributions to their local communities and to society as a whole (see section 5.3.3), and are increasingly taking on new roles, including that of employer (Barnes & Mercer 2005; Roulstone & Prideaux 2012; see also sections 2.6.2.2 and 7.4.1), though these positive roles are rarely recognized.

These concerns are echoed by Wright (2009), who has argued conditionality has been presented as a unique solution while failing to fully address issues such as in-work poverty. In Wright's view, such failings are exacerbated by a discourse that leaves little room for disagreement. As a result, disabled people are increasingly portrayed as a drain on society's resources rather than being recognized for the many and varied contributions they make to society (Barnes & Roulstone 2005). Barnes and Roulstone (2005) have called for a reframing of citizenship and the paid work/social security binary to recognize the range of ways disabled people contribute to society. This echoes Drake's (1999) calls for the development of a rights-based citizenship agenda in disability policy (see section 2.6).

Although the Labour Government (1997–2010) introduced new equalities legislation aimed at reducing discriminatory attitudes among employers (see section 2.6.2.1), it has been suggested that not enough was done to address barriers to work (Roulstone & Prideaux 2012). NDDP resources were targeted at individual supply side measures such as employment and job search skills (Roulstone & Prideaux 2012; Lindsay et al. 2007; Patrick 2011a; Weston 2012). Consistent with Drake's analysis of social security as a means to rehabilitate disabled people into society, Warren (2005) has argued that this placed the onus on disabled people to alter their behaviour in relation to employment, rather than on employers to change their attitudes towards disabled people. In addition, the quality of support available to disabled people looking to enter work provided in such schemes has also been called into question (Riddell & Banks 2005). Process such as 'creaming and parking' (Finn 2008), focusing resources on those who are already closest to the

labour market, while ignoring those who face greater challenges finding and retaining work, have also been disadvantageous to disabled people. This has been particularly common in programmes run by private sector organisations under contract to the state, which often operate under financial incentives from government for the number of ‘positive’ labour market interventions they make (Riddell & Banks 2005; Finn 2008).

The fairness and indeed efficacy of sanctioning disability benefits has also been critiqued, particularly given the lack of evidence to support their use (Lister & Bennett 2010; Weston 2012). Research has demonstrated that claimants are often unaware of the expectations placed on them or the reason for a sanction being imposed (Handler 2003; Griggs & Evans 2010). The threat of sanctions may therefore cause benefits users to disengage from the process rather than increase efforts to search for work. The evidence base for worklessness as an ‘intergenerational culture’, which underpins the ‘underclass model’ has also been contested (Shildrick et al. 2012). This has caused Patrick (2011b) to describe conditionality as ‘the wrong prescription’ for disabled people.

2.5.3 Care in the community and the marketization of care

While this section has focused on the expansion of social security, the immediate post war period also saw the expansion of the field of ‘social work’ with the creation of social work practice degrees and the increasing professionalization of the sector (Drake 1999). The workhouses and asylums of the Victorian era (see section 2.3) had evolved into long-stay institutions (Borsay 2005), where many disabled people were still effectively contained, and important decisions about their lives subject to the ‘expertise’ of social work professionals (Drake 1999). Successive governments had signalled moves towards deinstitutionalization, and changing social attitudes as well as the increasing visibility of disabled people acted as a stimulus to reform in the 1960s. So too had growing public and media awareness of the conditions and treatment of inmates in long-stay institutions (Roulstone & Prideaux 2012).

However, institutionalization continued to be the mainstay of local authority's approaches to social care for disabled people well into the 1980s (ibid). Where care in the community was mooted, this was underpinned by paternalistic assumptions about the family as the natural environment for care (Roulstone & Prideaux 2012). Disabled people therefore continued to be viewed as dependents in need of 'care', rather than as full citizens in their own right (Oliver 1983).

As with the discussion of social security, the economic crises of the 1970s heralded an important shift in both policy and practice. Conservative governments since 1979 had been firmly committed to the neo-liberal economic project (Standing 2011). However, it was not until Prime Minister Margaret Thatcher's third term that the principles of the market came to be applied to the organization of social care (Drake 1999; Pearson & Riddell 2006). This shift came about as a result of escalating costs in local authority social care budgets. A review conducted by Lord Griffiths in 1988 identified a lack of coordination between services such as health and the local authority, and a mismatch between services and resources (Pearson 2012). The proposed solution was to introduce a 'mixed economy' into the provision of care (ibid). Local authorities were no longer to be the major providers, but rather to act as 'purchasers' of care delivered through a market of voluntary and private sector providers (Roulstone & Prideaux 2012). The NHS and Community Care Act 1990 formally introduced 'care in the community' and adopted a number of Griffith's recommendations. These included that local authorities should assess individual's needs and develop a 'package' of support for them. However, they were to be *provided* through the private or voluntary sector (Pearson 2012).

The 1970s also saw the birth of the disabled people's movement, articulating the need for a change in societal attitudes through the social model of disability (see 1.3). As will be evident in the next section, the organization of care was a key campaign ground for the nascent movement. The advent of community care was viewed as a mixed blessing. While it signalled an end to routine institutionalization, Oliver and Barnes (2004) suggest that the reality

was little more than institutionalization by any other name. Criticisms have focused on the narrow framing of needs around domestic and personal care, which led to the exclusion of social, leisure, and family activities (Morris 2004; Pearson 2012). The act placed a *duty* on local authorities to provide services, rather than establishing a *right* for disabled people to receive support (Morris 2004). This meant that needs were assessed at a local level, and therefore the level of support could differ depending on where an individual lived (Morris 2004). Nevertheless, as discussion in section 2.6.2.2 below attests, the introduction of market mechanisms into the organization of community care also represented an important opportunity for the disabled people's movement to advance their calls for citizenship.

While the move to community care did nothing to challenge the postcode lottery of localized provision (Morris 2004), the late 1980s saw the emergence of support for personal assistance at a national level. In addition to DLA, a further source of support also came from the Independent Living Fund (ILF), which was created in 1988 (Drake 1999). This came about somewhat by accident following the abolition of means-tested SB and its replacement by Income Support (Burchardt 1999), which resulted in the loss of domestic payments made to disabled people requiring personal assistance (Pearson 2012). The ILF was established to compensate those affected by the change and was therefore only intended to be a short-term measure (ibid). However, it proved popular with disabled people who felt they were able to exercise greater choice and control over their care arrangements through ILF than from traditional social care provision (Roulstone & Prideaux 2012). The administration of ILF on a national level meant that individuals could use the funding in a range of ways to suit their own needs, and were able to exercise considerable choice and control over their care arrangements (Roulstone & Prideaux 2012; see also section 2.6.1.1). The fund could also be accessed in addition to support from the local authority, providing a valuable top up to existing provision.

In 1993, the scheme was formalized with existing recipients covered by one scheme, and new applicants covered by another (Pearson & Riddell 2006).

Eligibility to the new scheme was restricted to those with the highest support needs (ILiS 2012). This included disabled people who received the highest rate of DLA (see section 2.5.1), had no savings or capital worth more than £23,350, and received support from their local authority worth at least £340 per week. Over time, therefore, it has come to be used as an important supplement to the often minimal support provided to disabled people by their local authorities, enabling beneficiaries to live independently within their communities (Roulstone & Prideaux 2012). The ILF was closed by the Coalition Government in June 2015, with funding devolved to local authorities in England and Wales, although beneficiaries in Scotland continue to receive support through the new ILF Scotland (see section 3.5.3). The next section discusses the role of the disabled people's movement in advancing this agenda and the emergence of a citizenship agenda in disability policy.

2.6 Citizenship

The final dimension of Drake's (1999) typology relates to policies aimed at bringing about fundamental changes in society and the built environment in order to achieve equal citizenship for disabled people. As discussion throughout this chapter has highlighted, disability initially emerged as a category located outwith the bounds of citizenship. In the Victorian period, to claim the category of disability was to seek exemption from the obligation to participate in the labour market, and therefore to give up claims to citizenship (Stone 1984). Discussion in section 2.5 has demonstrated that labour market participation continues to be the primary means of obtaining citizenship. Whether or not they are viewed as 'deserving' of support, disabled people continued to inhabit a status outwith the realms of citizenship (Meekosha & Dowes 1997). However, by the late 1990s a number of reforms had taken place that can be viewed as the beginnings of a citizenship agenda in disability policy. Importantly, the growing strength of the disabled people's movement in the UK meant that disabled people themselves were playing an increasing role in shaping the direction of policy.

This section begins with a brief discussion of theoretical approaches to

disability and citizenship, focusing in particular on the contribution of the social model to these debates. It then moves to a consideration of policies emerging in the 1990s and early 2000s that can be viewed as representing the beginnings of a citizenship focused approach to disability. This includes the emergence of anti-discrimination legislation, and the introduction of Direct Payments (DPs). Discussion also briefly touches on the approach to disability pursued by the Labour Government of 1997–2010, and the explicit adoption of the social model of disability in the publication of the *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit 2005) policy document, which set out a cross-departmental approach to disability (Morris 2011).

2.6.1 Citizenship and disability: theoretical approaches

Historical conceptions of citizenship have focused on civil and political rights such as freedom of expression and the right to vote (Lister 2003, Dwyer 2010). However, in the post-war period TH Marshall (1992) articulated the emergence of social rights as a new order of citizenship. While the poor laws had viewed social assistance as necessitating exclusion from citizenship, social rights aimed to bring citizenship back in (Dwyer 2010). This was based on an understanding that some degree of social inequality was an inevitable part of capitalism, but resulted in differential access to citizenship (Roulstone & Prideaux 2012). Social rights such as social welfare and social security therefore acted to support and enable people excluded from citizenship achieve that status (Lister 2003).

The concept of social rights has been heavily contested from a range of perspectives. As discussed in section 2.5.2, the New Right have viewed much social policy as inherently dependency creating, because it undermines the free functioning of the market (Rummery 2002). Marshall's conception of social citizenship has also been criticized for focusing too heavily on the rights, while overlooking the attendant obligations (Roulstone & Prideaux 2012). In contrast, the New Right view citizenship as a contractual relationship based on

obligations which must be met before the granting rights (Soldatic & Meekosha 2013).

Marshallian citizenship has also faced criticism from feminist scholars (Meekosha & Dowse 1997; Rummary 2002; Lister 2003) who have argued that it was often presented as a gender-neutral concept. This resulted in the privileging of dominant perspectives of the 'ideal citizen' most usually characterized as an adult male (Meekosha & Dowes 1997). Feminist critiques of citizenship have focused on the differential roles played by men and women in society. While citizenship, particularly in relation to civil and political rights, is conducted largely in the public sphere, women's participation in social life is relegated to the private sphere (Rummary 2002).

The position of disabled people in relation to citizenship has often been ignored in wider debates (Meekosha & Dowes 1997). This is partly due to the dominance of assumptions that disabled people lack capacity to engage with both rights and obligations (Dwyer 2010). Authors writing from a social model perspective have also emphasized the role of social rights in creating dependency among disabled people (Oliver 1983). As has been apparent through this chapter, disabled people are viewed by social policy as passive dependents on services, rather than active agents in their lives (Meekosha & Dowes 1997). This view was perpetuated by the organization of social care in which decisions on need were made by 'expert' social workers rather than disabled people themselves. In contrast to the New Right, however, the disabled people's movement has sought to re-frame work as a citizenship right, rather than an obligation (Dwyer 2010). Employment should be reshaped to fit the needs of disabled people, rather than disabled people reshaped to fit the needs of employers (Drake 1999).

This debate is somewhat limited, however, because it fails to move discussion on from participation in the labour market as the *sine qua non* of citizenship (Roulstone & Prideaux 2012). Despite New Right criticism, the primary obligation of Marshall's citizen was to work (Roulstone & Prideaux 2012). However, this assumes that all individuals enter the labour market on an equal basis. Disabled people who are unable to participate in the labour market do

not have a right to access many of the benefits or services that might enable them to achieve equal citizenship status (Rummery 2002; Roulstone & Prideaux 2012). Restricting access to social rights until after labour market obligations have been met will therefore exclude disabled people who are unable to work without the support provided through social rights (Morris 2005). It is therefore not enough to simply adapt the workplace to disabled people (or indeed disabled people to the workplace). An inclusive citizenship also needs to recognize other forms of contribution beyond employment (Morris 2005).

Perhaps the most persuasive account of an inclusive model of disability citizenship comes from Morris (2005), who draws on both feminist and social model approaches to outline three key issues for disability citizenship: self-determination, participation, and contribution. Morris's conception of disability citizenship is influenced by communitarian approaches, which emphasize 'active citizenship' through volunteering and participation in community life. These ideas were also prominent in the New Labour reforms of the 1990s (Lister 2003). However, Morris argues, such accounts often failed to see disabled people as potential active citizens, viewing them instead as the passive objects of non-disabled people's active citizenship than as volunteers in their own right (Meekosha & Dowes 1997). Morris (2005) calls instead for a system of citizenship based on reciprocity, which balances the obligations of citizenship against the right to receive appropriate support to enable individuals to meet their obligations, whether through work or by contributing to the community in another way. Disability citizenship therefore requires the removal of barriers to participation in employment and all other forms of public life before the obligations can be imposed (Drake 1999).

2.6.1.1 Citizenship and independent living

The foregoing discussion highlights that disabled people face considerable barriers to realizing citizenship. Citizenship as a status therefore only becomes meaningful if disabled people have the support and resources to enable them to participate on an equal basis. Since the 1970s, disabled

people have campaigned for the right to independent living as a means to realizing this. The Independent Living (IL) Movement originated from small-scale grassroots activism in the US. Three students at the University of California, Berkley, who were unhappy with the support they were receiving, called for cash in lieu of services, which gave them direct control over their personal assistance (Pearson 2012). Their success sparked interest from other disabled people in the Berkley area, leading to the establishment of a local Centre for Independent Living (CIL), which provided support to disabled people using cash to hire their own personal assistants (PAs). The IL movement spread to the UK in the 1980s, but on a very ad hoc basis, where local CILs were established to work with a small number of sympathetic local authorities (Pearson 2012). It was not until the 1990s that cash for care approaches championed by the disabled people's movement became national policy (see section 2.6.2 below).

In contrast to the neo-liberal individualized notion of independence evident in the policies discussed in section 2.5.2, IL as defined by the movement related to the support required to enable disabled people to make choices about their own lives. As Briesenden (1986) articulates, independence is not meant to describe:

Someone who can do everything for themselves, but [...] someone who has taken control of their life and is choosing how that life is led [...] The most important factor is not the amount of physical tasks a person can perform, but the amount of control they have over their everyday routine. (p. 178)

Similarly, Morris (2004) has identified three main elements of IL: providing opportunities for choice and control; a challenge to the traditional conception of independence as individualism, and; an aspiration that any assistance required should be controlled by individuals. What differentiates this from the traditional model of social care provision in the UK is that rather than needs being determined by so called 'experts' and professionals, need is articulated

by disabled people themselves. It is therefore disabled people rather than professionals who are located as expert in their own lives (Morris 2004).

The following sections discuss the role of the disabled people's movement in campaigning for the right to IL

2.6.2 The era of disability citizenship: 1992–2010?

The foregoing discussion highlights some limitations to the inclusion of disabled people in traditional conceptions of citizenship. It has also sought to establish the basis for an inclusive citizenship status based on self-determination, participation, and contribution. The extent to which policies extend or restrict access to citizenship for disabled people is an important measure in Drake's (1999) typology. Sections 2.3 to 2.5 highlighted policies that sought to reshape disabled people to fit in with the expectations of society, and therefore undermined their citizenship. However, the growing influence of the disabled people's movement in the 1990s saw the emergence of policies that, had the potential to move disabled people closer to citizenship (Drake 1999).

2.6.2.1 The Disability Discrimination Acts 1995 and 2005: legislating for citizenship

As discussed in section 1.3 and throughout this chapter, the social model of disability is based on the understanding that society is organized in such a way as to exclude disabled people from equal participation (UPIAS 1974). However, despite the centrality given to labour market participation, it was not until the mid-1990s that it was acknowledged that disabled people's opportunities could be impacted by discriminatory employment practices. The Disability Discrimination Act 1995 (DDA) was therefore significant in formally recognizing discrimination against disabled people in employment and through the provision of goods and services (Morris 2011). The disabled people's

movement had been involved in lobbying for a private member's bill introduced in 1994 (Drake 1999). However, the final Act's provisions were significantly weaker and harder to enforce than those campaigned for (ibid).

Progress was halted for some time until a change of government saw a renewed focus on disability discrimination. In 1999 the New Labour Government established the Disability Rights Commission to advise on the amendment of the DDA, and to play a role in enforcing compliance. The Disability Discrimination Act (2005) introduced a duty to make reasonable adjustments to employment practices and the built environment in order to prevent discrimination against disabled people. In this sense, it was firmly rooted in social model thinking (Morris 2011). However, the definition of disability within the act remained the same as the 1995 Act, which stated that a person is disabled if they have a 'physical or mental impairment which has a substantial, adverse effect on a person's ability to carry out normal day-to-day activities' (Disability Discrimination Act (1995) p. 1). This rested on medical model assumptions about disability, placing the disability within the individual rather than arising from the organization of society. The burden of proof for meeting this definition also rested on the individual (Morris 2011). The language surrounding requirements to make 'reasonable adjustments' also made the 2005 act difficult to enforce in the courts (Roulstone & Prideaux 2012). This was made harder still when the DRC was merged with the Commission for Racial Equality and the Equal Opportunities Commission to form the Equality and Human Rights Commission (EHRC) in 2006 (ibid). Anti-discrimination legislation therefore represented an important turn towards a citizenship approach in disability policy. However, its impact has not been as far reaching as originally hoped.

2.6.2.2 Direct payments: the campaign for choice and control

The 1990s also saw significant advances being made in Independent Living. Influenced by the grassroots activism of the Berkeley students (see section 2.6.1.2), pressure began to grow in the UK for a system of 'cash for care'

(Pearson 2012). The ILF (see section 2.5.3) provided this option for those with the highest support needs, although it did not address the lack of choice and control available to disabled people in receipt of community care. Informal systems of indirect payments (made by the local authority and held by a charity but directed by disabled people in line with their needs) had been used in supportive local authorities (including in Scotland) since the 1980s (Pearson & Riddell 2006). However, the legality of these schemes had started to be called into question by the early 1990s (Pearson 2012). The pressure to contain public spending in this period was also increasing. Nevertheless, the introduction of a market in the provision of social care in the 1990s (see section 2.5.3) represented an important opportunity for the disabled people's movement to work with the then-Conservative Government to instigate new legislation for DPs (Pearson & Riddell 2006; Beresford 2014; Pearson & Ridley 2016). While the Conservatives were long-term opponents of legislation, research commissioned by the British Council for Disabled People in 1994 (Zarb & Nadash 1994) suggested that the introduction of Direct Payments (DP) could result in savings of around 40% on local authority home-care services could provide a vital focus for securing policy change. The promised savings provided an attractive lure to the then-Major Government (an administration keen to achieve spending cuts across welfare services) and acted as a spur to legislation.

The Community Care (Direct Payments) Act (1996) was an important step forward for independent living. However, it was limited in that it only enabled, rather than required, the provision DP to those who were eligible to receive community care (Pearson & Riddell 2004; Morris 2004). Local authorities had considerable discretion over how they delivered the policy, and social workers continued to retain power over who could access them (Ellis 2007). As a result, provision developed inconsistently, with access primarily restricted to those with physical or sensory impairments (Pearson 2000; Pearson & Riddell 2004). Take up of DP was also considerably higher in England than in Scotland, Wales, and Northern Ireland (*ibid*).

The idea that cash-based payments can be used to purchase and direct services within a mixed market has gained currency beyond the locus of social care. The Labour Government after 1997 continued the previous Government's approach to public sector reform through the introduction of 'new public management' (NPM) (Riddell 2006). Central to this was the redrawing of the relationship between citizens and the state (Rummery 2002). Service users were no longer viewed as passive recipients of care, but rather as active consumers (Beresford 2014). Influential in this regard is the work of Leadbetter (2004), who promoted the concept of 'personalization' across public services. Personalization is distinct from DP, but has a number of common elements. Leadbetter argued that public services could be reformed along a spectrum of personalization ranging from more customer-focused services, to service users actively involved in shaping and co-producing services. However, it is interesting to note that even at the most participative end of Leadbetter's spectrum, he envisages a role for professionals 'unlocking' the potential of service users, rather than service users being empowered in and of themselves. Personalization quickly became the government's preferred policy approach, in contrast to the years of campaigning for DPs by disabled activists. This was despite the absence of a robust evidence base to support its implementation (Beresford 2009). The progressive values on which 'personalization' is apparently based have also been called into question. Riddell (2006) has cautioned that the idea of 'choice' can have different connotations relating to either progressive ends articulated in IL, or regressive ones seeking to reduce the role of the state. Similarly, Rummery (2002) has argued that instead of empowering service users, increased consumer choice through marketization has served to empower providers and undermine the role of the state. The ability of 'care' services to produce a profit, as implied by a market-based model, is also a question worth raising (Morris 2011), particularly if the quest for profitability leads to deterioration in the quality of services.

The comparatively low-uptake of DP in Scotland was addressed following the creation of the Scottish Parliament, and the devolution of health and social care in 1999. New legislation enacted in 2002 imposed a duty on local

authorities in Scotland to provide a DP to all eligible social care users requesting them (Pearson & Riddell 2006; Pearson et al. 2014). This implied that the new Scottish Executive were broadly supportive of the aims of DP, or at least endorsed the NPM approach of their Labour colleagues in England (Riddell 2006). However, this was not replicated at the local government level, and take up of DP in Scotland continued to be low (Pearson & Riddell 2006). Research by Pearson (2000, 2006) indicated that local authorities' resistance to DP may have been driven by concerns over the marketization of care, in particular through the potential for undermining the role of the public sector. These concerns are not without merit, and have been articulated since the creation of the first CILs (see Williams 1983 for a stinging critique of IL as marketization).

Concerns were also raised that by shifting away from local authority provision, DP have contributed to the casualization of labour in the social care sector, and a reduction of terms and conditions (Pile 2014). Spandler (2004) however, has cautioned against dismissing DPs as back-door privatization. While she insists that it is important to acknowledge the role of marketization in the policy, she argues for the creation of a DP model that is able to deliver the principles of independent living without creating insecure employment. Similarly, Stainton and Boyce (2004) have emphasized the ability of DP to nurture strong and trusting relationships between the DP recipient and their PA. To this extent, especially where they have been supported by user-lead organizations such as local CILs, they have enabled some disabled people to exercise greater choice and control over their care arrangements (Stainton & Boyce 2004).

The shift in emphasis from local authority expertise to putting individuals in charge of their own care arrangements was not without challenge. Local authorities were reluctant to cede control of public funds and introduced rigorous monitoring processes to ensure accountability (Pearson 2000). As well as reducing the ability of disabled people to define their own needs by restricting how funding could be spent, this placed a considerable administrative burden on those in receipt of DPs. Local CILs were able to

provide assistance with payroll services and other administrative challenges, although where these were not available, the idea of taking on a DP may have been off putting. The reporting requirements may also have accounted for the lower uptake of DPs from those with learning and sensory impairments (Pearson 2000). Nevertheless, the opportunity to take on new roles as employers had the potential to challenge perceptions of disabled people in relation to work (Barnes & Roulstone 2005). Rather than being viewed as a net drain on resources, disabled people could be reimagined as supporting the local economy by providing employment opportunities (Barnes & Mercer 2010).

The years since the introduction of DP have seen personalisation personalization become the dominant policy approach across social care in England and Scotland (Pearson et al. 2014; Beresford 2014; Pearson & Ridley 2016; see also section 3.4.1). This has led to some confusion in terminology, with DP regularly being used synonymously with personalization or Personalised Budgets (PB) (Pearson et al. 2014). As will become evident in the next chapter, the emergence of SDS as a mechanism for choice and control in social care in Scotland has further muddied the waters (see section 3.4). It is therefore important to distinguish the way in which the terms will be discussed in this thesis. DP will therefore relate to payments made to disabled people by local authorities to enable them to hire PAs and thereby exercise choice and control over how their support arrangements are organized and delivered. Crucially, DP represents a rights-based approach, pioneered and championed by the Disabled Peoples' movement (Pearson et al. 2014). 'Personalization' relates to processes inspired by NPM techniques, including participation and co-production. While these processes may draw on the language of the disabled people's movement (Roulstone 2015), they have not been driven by disabled people, and tend to have professionals at the helm (Beresford 2014). SDS is often used synonymously with DP, although in the Scottish context it relates to a range of options that promote increased choice and control for service users, including DP (Pearson et al. 2014; see also section 3.4.1). As will become apparent in the next chapter, while SDS emerged in light of resistance to the marketization of care from Scottish local

authorities, it has more in common with personalization than DP being underpinned by notions such as co-production inspired by Leadbetter (2004) (Pearson & Ridley 2016).

2.6.2.3 Improving the life chances of disabled people?

The Labour Government of 1997–2010's tenure in office was characterized by a continuation of some of the neo-liberal reforms that had been initiated under the Conservatives. This included in particular the extension of conditionality to disabled people, and the introduction of personalization in community care. Nevertheless, this period also saw a shift towards an understanding of disability that was more reflective of social model thinking. This was embodied in the publication of *Improving the Life Chances of Disabled People* (or ILCDP) (Prime Minister's Strategy Unit 2005), a policy document outlining a strategic approach to disability. In contrast to the ad hoc development of policy (Berthoud 1998) that has been the pattern throughout this chapter, ILCDP was a cross-departmental initiative involving Health, Education, the Department for Work and Pensions (DWP), and the office of the Deputy Prime Minister. It also explicitly adopted a social model approach to defining disability, as well as committing to the movement's definition of IL. Disabled people and Disabled People's Organisations (DPOs) were involved in developing the proposals, and it was firmly endorsed by the disabled people's movement (Pearson 2006).

ILCDP proposed a number of changes that would impact on IL. These included the ability of service users to pool individualized budgets across different services in order to meet their needs. The influence of Leadbetter's (2004) thinking around personalization and participation (see section 2.5.2) is evident in this approach. However, the document also committed to the creation of a CIL in every local authority by 2010 in order to support access to DP, but also to promote IL more generally (Pearson 2006). As will be seen in the next chapter, ILCDP represented something of a high watermark for policy explicitly aiming to enhance the citizenship of disabled people. However, the

policy had limited impact in Scotland. Despite being signatories to *Improving the Life Chances of Disabled People*, little work took place to embed its thinking into Scottish policy and practice (Pearson 2006).

2.7 Summary

This chapter has drawn on Drake's (1999) typology to explore the evolution of disability policies from those that contained and segregated disabled people, to the emergence of policies seeking their involvement as equal citizens. Discussion has demonstrated that the way in which disability is defined and understood by different governments at different times has an important bearing on how policy is experienced by disabled people. The evolution of disability policy has not been a smooth, coherent, or strategic process, but rather has been characterized by a number of ad hoc responses to different needs that have emerged over time (Berthoud 1998). Some of these needs have been articulated by disabled people themselves, but more often than not, policy has been influenced by prevailing ideologies about the role of the state in the provision of welfare. It is nevertheless possible to identify three trends in the evolution of disability policy up to May 2010 that will be important to bear in mind in the following chapters. The first relates to the primacy given to participation in the labour market as the hallmark of the 'active' citizen. Concerns have been raised that social policy creates dependency on the state, thus undermining the importance of work and the free functioning of the market. Policies seeking to address this problem have seen the expansion of conditionality to disabled people.

The second trend highlighted in this chapter is connected to the first, and relates to disability as an administrative category (Stone 1984). Irrespective of efforts to tackle dependency and reduce the role of the state, the period immediately before the election of the Coalition Government in 2010 had seen a significant rise in the number of claims for disability benefits (Beatty et al. 2009; Roulstone & Prideaux 2012). The disability category, according to Stone (1984), is intended to resolve the dilemma between work and need.

However, as a political category it is inherently expansive and therefore prone to facing periods of crisis. Discussion in the next chapter considers reforms to disability benefits as characteristic of just such a crisis.

The final trend identified in this chapter relates to the adoption of the language of citizenship in policies relating to disabled people. On the surface this would appear to be evidence that the disabled people's movement has been highly successful in articulating their aims and bringing about a paradigm shift in the way that disability is defined and understood. DPs and ILCDP stand out as important examples of the aims of policy makers and disabled people coinciding at a particular point in time. However, it does not follow that this will always be the case. Discussion in the next chapter demonstrates the importance of recognizing language as a political tool. While the Coalition explicitly drew on the language of the disabled people's movement to justify their reforms, this was without the involvement of disabled people themselves. The adoption of the language of the social model does not therefore indicate the adoption of the philosophy behind it (Morris 2011). The next chapter will explore the ways in which these trends have been reflected in policy following the financial crisis of 2008, and the election of a Conservative and Liberal Democrat Coalition Government in May 2010.

Chapter 3 The Coalition government and welfare reform 2010–2015

3.1 Introduction

The election of a Conservative and Liberal Democrat Coalition government in May 2010 brought an end to thirteen years of Labour government. The Coalition came to power against the backdrop of the global financial crisis that began in 2008. The previous government's response to the ensuing recession had included a bail out of the banking sector, and the introduction of quantitative easing as well as short-term measures to boost demand such as a reduction in VAT (Taylor-Gooby & Stoker 2011). As a result, by 2010 the country was facing a public sector deficit of 16% (ibid). The Conservative Party within the coalition had campaigned on reducing this deficit, and once in power proposed spending cuts in the order of £112.6 billion (ibid). These cuts were targeted at spending on benefits, and significant public sector restructuring.

The 2008 crisis had affected economies across Europe, heralding the adoption of austerity measures to a greater or lesser extent throughout the region. However, the extent of austerity has varied considerably, with some countries (including the UK) making deeper cuts than some have argued their circumstances strictly dictated (Farnsworth & Irving 2012). This has been characterized as 'capitalising on the age of austerity' (Farnsworth & Irving 2012 p137) emphasizing that the singling out of social security and the public sector for spending cuts has been a political, rather than an economic, choice. Although all three main parties had made pledges to reduce the deficit, by focusing on these areas, as opposed to increasing the higher rate of taxation for example, the targeting of public sector spending disproportionately impacted upon lower income groups (Taylor-Gooby & Stoker 2011).

The Coalition's approach was supported through the cultivation of a public narrative emphasizing the inevitability and necessity of the cuts (Weston

2012; Wiggan 2012). This focused around two themes: the profligacy of the previous Labour government in failing to curb public spending (Driver 2011), and a return to the 'intergenerational cultures of worklessness' (Shildrick et al. 2012) narrative that had been prevalent in Conservative governments up to the early 1990s (see section 2.4). By concentrating on the insecurity created by the financial crisis, and placing blame for the reforms that followed on a 'workless' other, the coalition diverted attention from the failings of neo-liberalism that had brought about the financial crisis (Taylor-Gooby & Stoker 2011; Wiggan 2012). Unlike previous incarnations of this trend, discourses supporting welfare reforms have also been applied to individuals in receipt of disability benefits (Roulstone & Prideaux 2012). Increasingly, therefore, disabled people have arguably come to be viewed as 'undeserving' of state support.

This chapter outlines the ways in which the Coalition's approach to austerity has impacted on policies affecting disabled people. Drawing on the trends highlighted in the previous chapter, it begins by examining the reforms undertaken during this period as having been indicative of a 'crisis' in the work/need dilemma (Stone 1984; see also section 2.3) that has necessitated the redrawing of the disability category (Roulstone 2015). The second section moves on to discuss the expansion of conditionality in policies originating from the 'compensation' dimension of Drake's (1999) schema as set out in Chapter 2. These aimed to tackle 'dependency' within the social security system by 'activating' individuals into the labour market. Some of these changes had been initiated by the previous Labour Government, however the coalition's approach has represented an intensification of both these trends.

The previous chapter also highlights the emergence of policies that work to enhance the citizenship of disabled people, as well as a mis-match between policies that have adopted the language of the disabled people's movement, while falling well short of achieving equality. The penultimate section of this chapter scrutinizes reforms taking place during this period that were framed as promoting a citizenship agenda in order to assess their potential for enabling IL.

The final section of this chapter examines the social and political context faced by disabled people during this period, in the face of the scale and intensity of reforms embarked upon by the Coalition. The above discussion has highlighted that the approach taken to deficit reduction was a political choice motivated by a particular ideological perspective. As a result, the coalition faced political challenges to the implementation of their agenda, and though a large number of changes were proposed at the start of the period, not all of these came to fruition. Nevertheless, the pace of change, as well as the cultivation of a narrative that depicted those in receipt of benefits as 'scroungers' (Garthwaite 2011) led to a sense that disabled people were under attack (Cross 2013). The role of emergent activist groups and the devolved administration in Scotland in providing opposition to these changes is also briefly examined. However, this section illustrates that despite these pockets of resistance, narratives supporting the coalition's welfare reforms served to generate a 'climate of fear' for disabled people (Pearson & Trevisan 2015).

3.2 Redrawing the disability category

Discussion in Chapter 2 introduced the idea that disability can be understood as an administrative category which is used to resolve tensions over the boundary between those in need of state support, and those expected to participate in the labour market (Stone 1984). Where this boundary is drawn is a political decision, which makes the category inherently expansive, and therefore prone to crises (Roulstone 2015). This section examines the reforms to disability benefits under the Coalition as responses to just such a 'crisis' in the disability category (Roulstone 2015).

3.2.1 Employment Support Allowance and the biopsychosocial model of disability

Determining the boundary between work and need is a tension that exists across western welfare states (Stone 1984). As discussed in section 2.5.2.1, the rising numbers of individuals claiming IB in the 1990s and 2000s had been a growing concern. This dated in part to the re-categorizing of long-term unemployed people who experienced health problems in the 1980s and 1990s as 'incapacitated' for work (Roulstone & Prideaux 2012). However, by the late 2000s the number of newer claims for IB had also started to rise (Beatty et al. 2010). The Labour Government had been keen to increase supply of labour during this period in order to ensure the UK's ability to compete in a globalized market (Grover 2009). By the time the coalition came to power, the number of claims for IB had reached 2.6 million (Beatty & Fothergill 2011). Disabled people were also consistently less likely to be in employment than non-disabled people, facing a gap of around 26% since 2000 (Berthoud 2011). Following a review of IB in 2007, the Labour Government proposed the creation of a new benefit Employment Support Allowance (ESA) that would seek to support the return to work of those capable of doing so (Roulstone & Prideaux 2012). ESA was introduced for new claimants in 2009. However, the new benefit required all existing IB claimants to be reassessed for eligibility, a process which began after the general election in 2010 (Beatty & Fothergill 2011).

On coming to power, Conservative members of the Coalition were keen to use the new benefit to support their plans to bring about reductions in public spending on benefits (Driver 2011). The change from IB to ESA was projected to result in a marked reduction in the number of claims by as much as 970,000 (of whom 115,000 were from Scotland) (Beatty & Fothergill 2011). Analysis conducted in 2011 suggest that this was largely to be achieved through existing claimants being found 'fit for work' following reassessment (ibid). Figures from an early review of ESA in 2013 suggested that of the 603,000 IB claimants who had been reassessed, as many as 180,000 had been found fit for work (DWP 2013b). However, given the barriers to employment that many

disabled people face (see section 2.5.2.1) and the tough economic climate, it is by no means certain that many of those losing eligibility to ESA were able to find sustained employment. Instead, Beatty and Fothergill (2011) predicted that most would become 'lost' from the social security safety net. The introduction of ESA therefore represented a significant redrawing of the disability category.

Much of the reduction in claims for ESA compared to IB was expected to be due to the introduction of new assessment processes (Beatty & Fothergill 2011). Stone's (1984) conception of disability as an administrative category rests on the availability of 'objective' medical testing to determine eligibility for disability benefits (see 2.4). Increasing reliance on this mechanism has been an emerging feature of disability benefit reform in the UK since the 1990s (Stanley 2005). The eligibility test for ESA, known as the Work Capability Assessment (WCA), sorted claimants into three categories. The 'Support Group' for those considered to have impairments too severe for them to be expected to participate in employment; and the 'Work Related Activity Group' (WRAG). Claimants in the WRAG received ESA, but at a lower rate, and were expected to participate in activities designed to prepare them for work. Those found 'fit' were deemed ineligible, were moved to Jobseekers Allowance (JSA) (Beatty and Fothergill 2011), and faced a harsher regime of conditionality and sanctions (Dwyer & Wright 2014, see also section 3.3 below). In a change from the original design of ESA under Labour, the coalition introduced a one-year time limit for those in the WRAG (Beatty & Fothergill 2011). After this period, ESA became means-tested, meaning those with partners who were in even very low-paid work often became ineligible to continue claiming (Ibid).

ESA has also seen an increase in the regularity of assessments of fitness to work, with those in the WRAG subject to reassessment after three, six, or 12 months of their initial claim (Dwyer & Wright 2014). Emerging evidence has suggested that this intensification of assessments has had a significant negative impact on claimant's mental health, including suicides (Barr et al. 2016). The approach taken to establishing eligibility to ESA has therefore been the focus of considerable criticism, much of which has focused on the

relatively high proportion (50%) of claims that were initially rejected but later upheld at appeal (Shakespeare et al. 2016). Concerns were raised that this implied the existence of targets for the number of individuals found 'fit for work' (Franklin 2013). While this was consistently denied by the DWP, a number of independent reviews were conducted into the process (DWP 2013b). Disability groups opposing the changes, such as Disabled People Against the Cuts (DPAC; see section 3.5.2 below), focused opposition to the assessments on ATOS, the private French IT firm contracted by the government to carry out the WCA (Williams-Findlay 2011). However, the focus on the provider detracted attention from concerns about the efficacy of medical testing as a mechanism to determine fitness for work (Baumberg et al. 2015; Shakespeare et al. 2016), notably that the WCA did not actually assess capability for work-related activity, but rather an individual's functional capacity (Baumberg et al. 2015). Critics highlight that the existence of impairment is not the same as incapacity to work, which is influenced by social and other factors (ibid). For example, despite being described as an assessment for work capacity, the WCA does not take account of an individual's ability to do a particular job, their qualifications, or their likelihood of finding work they are qualified to perform (Shakespeare et al. 2016). As such, the WCA has tended to reflect medical, rather than social model understandings of disability (Roulstone 2015).

3.2.1.1 Biopsychosocial approaches to medical assessment

Other concerns over the limitations of the WCA have related to the theoretical basis on which the intensification of medical testing has been based. These have focused in particular on the biopsychosocial (BPS) model of disability (Waddell & Aylward 2010), which was influential in the Coalition's thinking around the WCA (Shakespeare et al. 2016). Ostensibly developed as a middle ground between the medical and social models of disability, the BPS focuses on the interaction between biological, social, and psychological factors in order to 'treat the whole person' (Waddell & Aylward 2010 p23). According to Waddell and Aylward (2010), major proponents of this approach, it represents a compromise between the individualizing medical model, with its emphasis on

professionalized interventions and cure, and the barrier-led approach of the social model. Combining biological and social factors with personal and psychological ones, they argue, makes it particularly relevant for the development of policy addressing long-term incapacity arising from common health problems.

Waddel and Aylward's (2010) BPS was developed in response to the growing rate of claims for IB. The challenge this posed, they argued, was that two-thirds of those claiming the benefit experienced common health problems such as lower back pain and stress. Because these are not defined as illness in an epidemiological sense, they are therefore difficult to objectively diagnose. Nevertheless, these conditions present a range of symptoms that may be experienced as debilitating by individuals. Standard medical approaches to sickness and disability embodied in clinical practice have tended to focus on rehabilitation and cure for such conditions in advance of returning to work. However, this resulted in significant periods out of the labour market while treatment was pursued, leading to the crisis in IB. Adopting their BPS would, in contrast, enable a rapid return to work in most cases, by changing the way in which clinical practitioners, individuals, and employers perceive these conditions (Waddel & Aylward 2010). In other words, it was not the condition that was preventing returns to work, but rather the way in which individuals and employers thought about what the conditions implied about capacity for work. If such conditions could be thought of more positively, returns to work could happen much faster, thus reducing the longevity of claims over the longer term (*ibid*).

It is possible to see this thinking in the framing of ESA, in particular in the regular re-assessment already discussed, as well as the work-related activity requirements which will be discussed in section 3.3 below. However, in spite of acknowledging the social model, and the positive rhetoric around seeing 'the whole person', the approach taken by the BPS continues to locate the deficit within the individual. The emphasis on psychological factors overlooks the environmental and social barriers that many disabled people face in returning to work (Shakespeare et al. 2016). These barriers require a more

fundamental change in the organization of the labour market than simply thinking more positively about impairment.

The absence of a robust evidence base to support the claims made in the BPS has also been a cause for concern (Shakespeare et al. 2016). The model was initially based on the impact of the experience of psychological illness (Engel 1977). However, Waddel and Aylward (2010) applied it instead to the experience of lower back pain, arguably a very different condition (Shakespeare et al. 2016). In so doing, the BPS has shifted from being a descriptive account of a particular treatment approach to an explanatory model to be applied to all experiences of illness (ibid). Waddel and Aylward's (2010) BPS has therefore taken an impairment and context-specific discussion about sickness absence, and applied it to all people claiming long-term sickness benefits (Shakespeare et al. 2016). As per Stone's (1984) analysis, medical assessments (based in this case on biopsychosocial indicators) have enabled the Coalition to reduce access to the disability category by redefining what is understood by disability (Roulstone 2015).

3.2.2 From Disability Living Allowance to Personal Independence Payments

The decision to reform DLA and replace it with a new benefit, the Personal Independence Payment (PIP), in 2011 can be viewed as a further example of the Coalition's redefining of the disability category in response to a perceived 'crisis' (Roulstone 2015). On coming to power the Coalition argued that too many people were claiming DLA, that it was not reviewed often enough, and that the lifetime award had made it too easy to claim indefinitely, thereby exacerbating dependency (Roulstone 2015). The proposals to reform DLA came as something of a surprise, and had not been mooted in their manifesto. However, while popular opinion of the benefit saved DLA in the 1990s (Roulstone & Prideaux 2012; see also section 2.5.2.1), by 2010 the creeping conditionality applied to disability benefits under the previous Labour Government, accompanied by the return of the narrative of dependency, had made it once again a target reform (Roulstone 2015). DLA was replaced by

PIP for new claimants from October 2013. The new benefit mirrored DLA with a distinction drawn between the 'care' and 'mobility' components. However, the care component was only available at two levels, paid at the middle and upper rates of DLA (Campbell et al. 2012). This effectively saw the abolition of the lower rate of DLA. As discussed in section 2.5.1, the lower rate had been introduced in response to findings that the former AA had failed to meet the needs of individuals with the 'least severe' impairments (Roulstone & Prideaux 2012, p. 144). As a result, providing support at three levels was an important foundation of DLA. It was anticipated that the abolition of the lower rate would be particularly disadvantageous to those with learning disabilities and fluctuating conditions (Campbell et al. 2012). The legislation enacting PIP also included a requirement to cut the amount of funding for the new benefit by 20% (DWP 2011). This was taken by many as evidence that the reforms were largely motivated by concerns over public spending (Campbell et al. 2012), giving further support to the crisis in the disability category thesis (Roulstone 2015).

As with ESA, the introduction of PIP was supported by an increased reliance on medicalized assessments based on biopsychosocial indicators (Roulstone 2015). By increasing the role for medical assessments, claimants with lifelong or degenerative conditions who had been entitled to indefinite awards under DLA would face re-assessments every three to four years (DWP 2012). In addition, while the assessment for DLA focused on social and environmental contexts, the PIP assessment has been criticized for being based on a restrictively medical understanding of disability and impairment (Scope 2011). Changes to the criteria used to determine eligibility for the mobility component have been particularly contentious in this regard. Under the new criteria claimants have to demonstrate that they can "stand and then move no more than 20 metres safely, to an acceptable standard, repeatedly and in an acceptable time period" (Young 2013). The criteria under DLA was 50 metres. Again, this was seen to be particularly disadvantageous to people with fluctuating conditions, who could possibly walk this distance on one day, but not on another (Muscular Dystrophy UK 2016). The higher rate mobility component was used by many disabled people to fund access to their own

vehicle, for example, through the Motability scheme (Cross 2013). This enabled disabled people to lease an appropriately adapted vehicle, a lifeline in areas with limited or inaccessible public transport (Muscular Dystrophy UK 2016).

In a further parallel with ESA, the creation of PIP triggered a reassessment of all existing DLA claimants. This was conducted in many areas (including in Scotland) by Atos Healthcare (National Archives 2012). This process was plagued by delays, with reassessments unlikely to conclude until 2018 (Scottish Government 2014b). The delays were brought about as a result of difficulties with the administration of applications, partly due to the complexity of the form (Grey 2014). This posed challenges to both administrators handling applications as well as individuals claiming the new PIP (ibid).

DLA as an 'extra costs' benefit had long been viewed as holding certain legitimacy in the public consciousness, and did not face the same stigma as out-of-work benefits such as IB (Roulstone & Prideaux 2012). However, the close similarities between PIP and ESA have seen the new benefit, and disabled people by association, drawn more explicitly into debates around dependency. Indeed, the coalition's consultation on the PIP White Paper explicitly raised concerns about a link between DLA and increasing levels of worklessness (Campbell et al. 2012; Roulstone 2015). This was a clear misrepresentation of the benefit, which unlike IB, was always available both in and out of work. This misapprehension was also replicated in press and media narratives around the reform (Roulstone 2015). The new PIP has therefore seen disabled people becoming redefined increasingly as the undeserving poor (ibid).

This discussion of ESA and PIP has demonstrated that policies pursued during the period 2010–15 represented a concerted attempt to redraw the disability category and reduce eligibility to disability benefits (Roulstone 2015). An increased reliance on medical testing based on the BPS model of disability has been central to achieving this aim (Shakespeare et al. 2016). The narratives supporting these changes have emphasized the need to tackle

‘dependency’ within the welfare system, echoing the preoccupation with ‘underclass theory’ by governments in the 1980s and 1990s. The following section demonstrates that this has also seen the expansion of policies seeking to tackle dependency through increased conditionality.

3.3 Expanding conditionality

Conditionality, as is evident from the discussion in section 2.5, has been an emerging trend in the administration of benefits since the 1990s, and an important response to the perceived growth of an ‘underclass’ living in passive dependence on overly generous welfare payments (Murray 1990). The application of conditionality to disabled people had begun under the previous Labour government through the NDDP (see section 2.5.2.2). However, the Coalition government’s tenure in office has been characterized as having seen conditionality become ubiquitous in the social security system (Dwyer & Wright 2014).

3.3.1 Conditionality under the coalition

The amalgamation of six key benefits and tax credits into the Coalition’s flagship Universal Credit (UC) has embodied their approach to conditionality. This saw the consolidation of Income Support, JSA, ESA (for those in the WRAG), Housing Benefit, Child Tax Credits, and Working Tax Credit into a single monthly benefit (Dwyer & Wright 2014). The aim of the policy was to simplify the benefits system, making it easier to understand and to provide incentives for work (DWP 2010). Crucially, however, it also removed the distinction between in- and out-of-work benefits, meaning that, for the first time, conditionality could be applied to those in low-paid work, as well as those seeking work (Dwyer & Wright 2014). While DLA gained greater legitimacy for being available both in and out of work (Roulstone & Prideaux 2012), the coalition’s policy has seen low paid or insecure labour become increasingly associated with benefit dependency (Lister & Bennett 2011). This is somewhat

ironic given the way in which their economic policy has seen the expansion of this form of employment (Standing 2011).

The expansion of conditionality under UC necessarily saw an increase in the severity of the sanctions that could be applied in order to enforce compliance. Though the full implementation of UC was delayed due to technical problems related to the IT system intended to support the simplified benefit, the conditional elements of the new regime were nevertheless introduced in 2011 (Dwyer & Wright 2014). These required claimants in receipt of any of the benefits included under UC to sign a 'claimant commitment', which is a contractual agreement that sets out the specific steps to be taken in order to prepare for work, as well as the sanctions faced if individuals failed to meet them (Dwyer & Wright 2014). Sanctions ranged from stopping the payment of benefits until the claimant 'complied' with the conditions imposed, to effectively banning individuals from receiving benefits for up to three years (ibid).

As one of the benefits that would eventually make up UC, the Coalition's approach to ESA saw a significant expansion of work-related conditionality to disabled people (Patrick 2011a). Recipients of ESA in the WRAG were subject to the claimant commitment and expected to engage with advisors located at Jobcentre Plus (JCP) at 'work-focused interviews' or risk sanctions of one, two, or four week's suspension of their benefits (Patrick 2011a). The number of individuals in the WRAG who experienced sanctions grew steadily following the implementation of the new regime (Scottish Government 2015a). In Scotland alone the number of sanctions increased from 300 in 2011 (when the new regime commenced) to 2,566 by 2014 (ibid). Critics have argued that this was evidence that the level of conditionality had been intentionally set higher than most disabled people could reasonably expect to meet, in order to further reduce the rate of claims (Shakespeare et al. 2016). By 2015, ESA claimants were almost as likely to face sanctions as non-disabled individuals claiming unemployment benefits (Webster 2015). Over time, sick and disabled people receiving support through the WRAG who were found to have some capacity for work were increasingly being treated like any other jobseeker. The announcement in June 2015 that payments for those in the WRAG were to be

equalized with JSA (Osborne 2015), though outwith the period of enquiry for this study, adds weight to this assertion. This was a significant re-imagining of the purpose of the WRAG, which was originally intended to provide additional support to enable disabled individuals to move closer to the labour market.

The application of conditionality and sanctions was intended to act as a stick to spur individuals into employment. The previous government had recognized that some disabled people faced particular labour market disadvantage, and therefore provided assistance to help them overcome this (Lindsay et al. 2007). The support available to those in the WRAG to enable them to move closer to the labour market was originally intended to come from the Pathways to Work (PtW) scheme created by the Labour Government under the NDDP (see section 2.5.2.2). Though limited in its understanding of disabling barriers (as discussed, this depended on disabled people adapting themselves to the labour market, rather than reshaping the labour market in order to accommodate disabled people), PtW was intended to act as a 'carrot' to incentivize individuals to prepare themselves for the workplace. In 2011 the Coalition merged PtW with the existing schemes for young people and lone parents to create a unified 'Work Programme' (WP) (Roulstone & Prideaux 2012). Participation in the WP was mandatory for ESA recipients in the WRAG who were expected to be reassessed and found 'fit' within three, six, or twelve months of their award being granted (DWP 2010/16). Failure to participate in the WP when mandated could lead to sanctions (Dwyer & Wright 2014). The 'carrot' of support to re-engage with the labour market was therefore increasingly used as a stick to compel participation in work-related activity. All other ESA recipients, including those in the SG, could choose to participate voluntarily. However, as will be seen in Chapter 5, given fears over increased conditionality requirements, very few viewed this as a realistic option.

In line with the Coalition's commitment to reducing the role of the state, the WP was provided by private sector organizations working under contract to the DWP (Weston 2012). The 'black box' model of contracting adopted for this process meant that companies bidding for contracts were not required to provide details of how they intended to deliver their stated outcomes (ibid).

Though the previous PtW had also had significant private sector involvement, the lack of transparency in the contracting process placed the WP even further outside of state control (Weston 2012). Additional financial incentives were included in the procurement process to encourage contractors to focus resources on harder-to-reach claimant groups, including disabled people (ibid). However, early on in the scheme, research (Rees et al. 2013) identified the operation of widespread ‘creaming and parking’ in the WP, suggesting that these incentives had not been effective at targeting support to those furthest away from the labour market.

3.3.2 Behavioural responses to long-term sickness benefit claiming:

containment through surveillance and conflicting conceptions of agency

Conditionality as a response to ‘worklessness’ is based on a particular conception of agency and human motivation. Discussion in section 2.5.2 highlights the emergence of ‘underclass theory’ as a response to a perception that individuals were choosing a life on benefits as an easier alternative to work as a route out of poverty. Individuals claim benefits, the narrative goes, because they are easy to access, as well as generous, and therefore create disincentives to work (Wright 2012). Conditionality serves to ‘correct’ this negative agency in order to bring about changes in individual behaviour by encouraging or compelling participation in paid work. These ideas emerged in response to perceived limitations of social democratic explanations of poverty prevalent in the post-war period, which emphasized structural factors contributing to poverty, such as the economy or globalization (Wright 2012). Social policy responses from the Social Democratic perspective therefore envisaged a welfare safety net in order to ‘manage’ the impacts of capitalism, such as cyclical unemployment (Pierson 1998). However, such accounts tended to overlook the role of agency, depicting those experiencing poverty or unemployment as passive victims, rather than active agents within their lives (Lister 2004).

In recent years, social-democrats, particularly those taking a critical realist stance, have sought to strike a balance between structure and agency in approaches to policy (Hoggett 2001). Giddens' (1984) structuration theory views individuals as active agents, capable of making choices, who are also shaped by structural forces such as culture. While this addresses the deficit of agency in the social democratic approach, Giddens has been criticized for presenting an unrealistically positive account of agency that overlooks individual capacity for negative behaviour (Hoggett 2001). This has resulted in the ceding of important ground that has been claimed by narratives focusing on negative agency, making arguments in favour of conditionality hard to contest (Wright 2012).

3.3.2.1 Conditionality as surveillance: containing negative agency?

The expansion of conditional benefits systems has seen the emergence of new debates around the processes required to enforce compliance and promote acceptable forms of agency, to which the concept of surveillance is increasingly being applied (Henman & Marston 2008; Maki 2011; Dee 2013). Henman & Marston (2008) coin the term 'welfare surveillance' to describe the way in which conditionality is used by the state to exert power or control over citizens in order to bring about changes in behaviour. Emanating from a perceived belief that people claiming benefits will be doing so fraudulently, surveillance is employed to monitor whether recipients are genuinely deserving of assistance (Maki 2011, Dee 2013). The role of social security in seeking to rehabilitate and integrate disabled people into society (Drake 1999) has already been touched upon (see section 2.5). Conditionality as surveillance therefore represents a mechanism for the state to achieve this.

Less widely applied in the literature around conditionality is the concept of 'self-surveillance'. Building on the work of Foucault (1991), self-surveillance involves individuals modifying their own behaviour in order to fit the expectations of society (or the state) (Vaz & Bruno 2003). Importantly, self-surveillance is a conscious process that is carried out knowingly, even if this

goes against the way an individual would wish to act (ibid). The literature tends to suggest that this is experienced benignly and accepted by most individuals who adopt self-surveillance techniques. However, Hoggett (2001) has argued that this can also be experienced acutely as a form of 'psychological invasion'.

While surveillance is concerned with the state as an external power, self-surveillance is both an internal and external process. Power is mediated by external expectations from the state, the media, and communities, and also internally reinforced through comparison between ourselves and the expected 'norm' (Henderson et al., 2010). As I have argued elsewhere (Manji 2016), in this regard, self-surveillance could be conceptualized as a subtle or 'hidden' form of conditionality, causing individuals to adapt their behaviour according to social norms about how benefits claimants *should* behave. Rather than simply seeking to rehabilitate and integrate disabled people into society, conditionality as self-surveillance seeks to bring about more fundamental behaviour change, with echoes of the Victorian asylum. Indeed, Vaz and Bruno (2003) discuss self-surveillance as emanating from Foucault's (1991) discussion of Bentham's Panopticon, where inmates in the asylum adopt self-surveillance as response to their awareness of being permanently under scrutiny. Surveillance and self-surveillance therefore have strong parallels with the containment theme discussed in section 2.3.

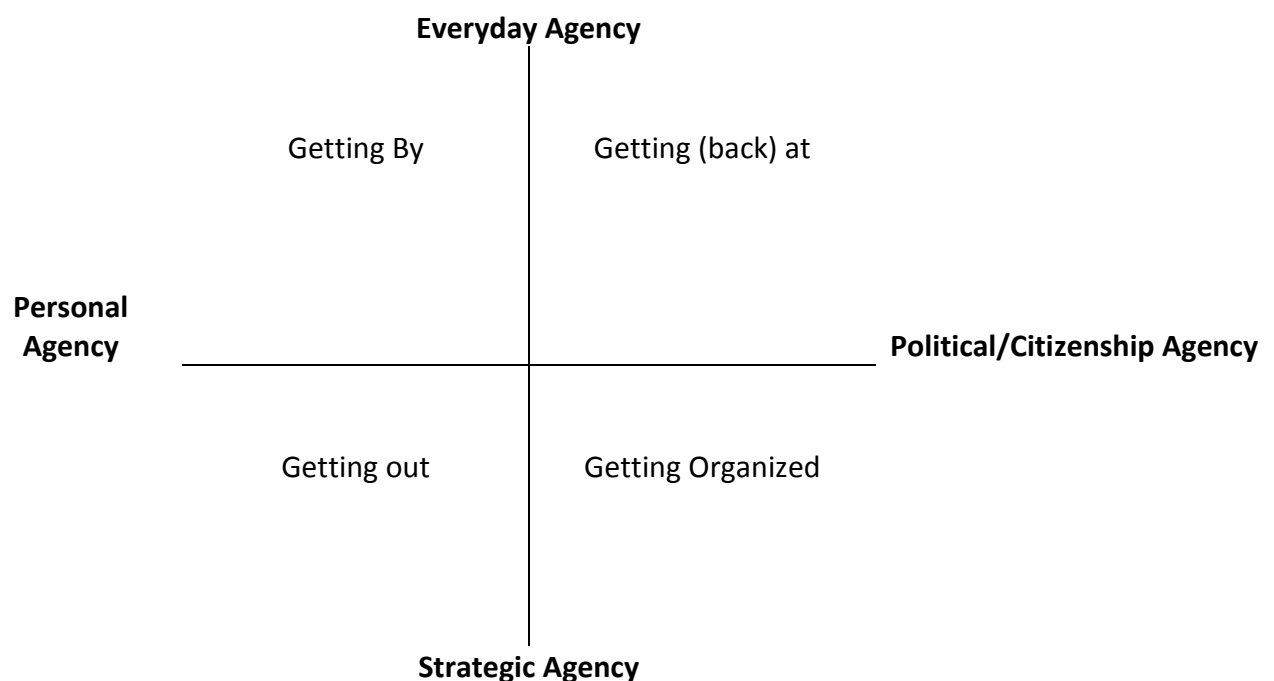
3.3.2.2 Alternative conceptions of agency: getting by, getting out, getting back at, and getting organized

The conception of agency envisaged by the New Right has tended to emphasize self-interest, particularly on the part of benefit claimants (Wright 2012). However, restricting analysis to a conception of 'bad agency' that must be corrected in order to promote acceptable behaviours overlooks the subtlety and complexity that all human agents exhibit in their interactions (Wright 2012). Human beings are motivated by a range of different factors, including but not restricted to, self-interest (Hoggett 2001; Wright 2012). Individuals are

not unitary beings, but may express different forms of agency at different times. Importantly this introduces the possibility of multiple selves (Hoggett 2001). Drawing an example from the above discussion, self-surveillance could be experienced and consented to by one self, while being simultaneously resisted by another. Viewed in this way, the conception of agency on which conditionality policy is based appears somewhat two-dimensional (Hoggett 2001).

Lister (2004) has sought to capture the complexity of human agency in a taxonomy of agencies expressed by people experiencing poverty (Figure 3.1). The different dimensions represent continua and can be expressed by the same individual in different ways and at different times.

Figure 3.1: Lister's taxonomy of agency



(Adapted from Lister 2004)

Perhaps the most extensively researched form of agency in Lister's schema is that relating to 'getting by'. Kempson et al. (1994), Daly and Leonard (2002), Hosain et al. (2011), and Daly and Kelly (2015) variously point to the coping strategies adopted by people experiencing poverty, including shopping differently, budgeting carefully, and reducing spending on social interactions. These studies all highlight the amount of work that goes into the day-to-day process of 'managing' on a low income, and stand as useful counters to narratives portraying people in poverty as lazy and feckless. Similarly, Flint (2008) discusses the ways in which these narratives had been internalized by people experiencing poverty through regular self-critique at feeling that they were not working hard enough to make ends meet. He also describes the operation of guilt as a form of self-surveillance, which caused participants in that study to feel that they must constantly keep busy.

Discussions of budgetary strategies have revealed an interesting distinction made by individuals and households between income from employment, and that from benefits (Kempson et al. 1994). This distinction echoes Zelizer's (1989) concept of 'special monies'. Unlike 'market monies', 'special monies' relate to the different social meanings accounted to particular forms of income and expenditure, for example, 'wife's monies'. This gendered differential is also evident in Kempson et al.'s (1994) findings, where men paid bills, while women covered 'housekeeping'. That individuals differentiate benefits from other forms of income and use them in particular ways to reflect this stands in contrast to the view of benefits as being claimed purely for the purpose of work avoidance and income maximization.

Other expressions of agency discussed by Lister (2004) include efforts to 'get (back) at' the system. In this she discusses forms of everyday resistance to poverty and its causes. She cites benefit fraud as a possible example of this. Though she insists that this is not as widespread as some accounts would lead one to believe, the active decision to defraud can be seen as an expression of agency aimed at challenging an unfair system. Similarly, rejecting 'othering' or stigmatizing narratives can act as a form of discursive resistance (see section 3.5.1 for a discussion of this). This is illustrated by

Pemberton et al. (2016, p. 22) who found significant awareness of structural barriers to employment among their participants who actively contested stigmatizing narratives. However, the pervasiveness of these discourses was also highlighted by what they termed 'contradictory consciousness' (p. 22) where participants simultaneously rejected negative portrayals applied to themselves, while stigmatizing others. Participating in the informal economy or even petty crime are further examples of 'getting (back) at'. Many of these are strategies also aimed at 'getting out' of poverty. Kempson et al. (1994, p. 275) identified a hierarchy of approaches to managing poverty, ranging from 'finding (better paid) full-time work' to petty crime. Interestingly, begging was something that was viewed as beyond the realms of acceptability.

These accounts all credit individuals experiencing poverty with considerable agency, and stand as an important counter to ideas of passivity. However, in recognizing that individuals are able to exercise considerable agency, there is a danger in focusing too heavily on individual coping mechanisms while ignoring the many structural impediments that still exist to exiting poverty (Dagdeviren et al. 2016). The concept of 'resilience' is a useful case in point (ibid). Resilience has become a widely used term when discussing poverty and social exclusion and the ways in which people 'manage', particularly through short-term reductions in income, e.g. through redundancy (Dagdevireien et al. 2016). However, these approaches seldom consider issues, like power and privilege, which can serve to make some individuals more resilient than others. Those on higher incomes, for example, may be more likely to have savings or capital that enable them to absorb short-term shocks such as redundancy. This would make them appear more 'resilient' than someone in insecure, low-wage employment with no savings. However, this ignores the influence of structural factors such as the adoption of an economic model that has led to a growth in insecure labour (Dagdevireien et al. 2016). Focusing on the agency involved in resilience, to the exclusion of structural forces, therefore only reveals part of the picture (Dagdevireien et al. 2016). In discussing the other forms of agency in her taxonomy, Lister (2004) is careful to note the limitations to their exercise. This is particularly so with

‘getting organized’, where efforts to coalesce around a stigmatized identity such as ‘poor’ or ‘on benefits’ can act as a deterrent to involvement.

This section has discussed the intensification of conditionality and sanctions applied to disabled people over the period from May 2010 to May 2015. It has also explored different conceptions of agency applied to people who use benefits. While conditionality policy adopts mechanisms of surveillance and self-surveillance to adopt assumed ‘bad agency’, this section has highlighted that human agency can be exhibited in a plurality of different responses that can be exercised by individuals at different times and in different circumstances.

3.4 Promoting the language of citizenship through welfare reform?

An interesting feature of the reforms discussed above has been that, while initiating a return to discursive trends around the ‘deserving and undeserving poor’ (Stone 1984), the Coalition also drew heavily on the language of the disabled people’s movement in order to justify their approach (Roulstone 2015). Discussion in Chapter 2 demonstrates that the way in which disability is defined and understood by policy makers has an important bearing on how policies are experienced by disabled people (Drake 1999). While much of the history of disability policy has been underpinned by medical model understandings, the 1990s and early 2000s saw the emergence of an agenda that explicitly worked to promote the citizenship of disabled people (see section 2.6.2). This was exemplified in the adoption of the social model of disability and the disabled people’s movement’s definition of IL in the ILCDP (Prime Minister’s Strategy Unit 2005) policy document. Discussion in this chapter, in contrast, demonstrates that the reform of ESA and DLA have both been heavily underpinned by medical model-thinking about disability. On the surface, then, these policies would appear to be unlikely to enhance the citizenship of disabled people. However, the framing of PIP to emphasize

‘independence’ clearly echoes the aims of the disabled people’s movement. An early briefing on the creation of PIP from the DWP stated:

The Coalition Government is committed to supporting disabled people to lead independent lives and exercise choice and control... [DLA] is no longer in step with the needs of disabled people, ... it is not personalised and it is not sustainable. (DWP 2012, p. 2)

The first part of this quotation explicitly mirrors the definition of IL set out by the disabled people’s movement (see section 2.6.1.1). However, by emphasizing the need for a ‘personalized’ approach, it also indicates a very different ideological perspective, drawing on ideas around the marketization of services. As discussed in section 2.6.2.2, while there has been synergy between the aims of IL and personalization, they represent two very different philosophical approaches. The campaign for IL has sought to achieve greater choice and control for disabled people over the support they receive in their day-to-day lives (Pearson et al. 2014). By contrast, the personalization agenda has been driven by the desire to reduce the role and size and role of the state (Morris 2011).

Differing understandings of the term ‘independence’ between the disabled people’s movement and those promoting a neo-liberal economic agenda have been central to this (Roulstone 2015). While the movement sought to establish a definition of IL that emphasized individuals having the choice and control to decide on the appropriate support to live independently, it was not successful in engaging this into the public consciousness (Morris 2011). As a result, the neo-liberal conception of independence as non-dependence on the state has been allowed to dominate (ibid). Discourses on welfare reform have explicitly contrasted the idea of ‘independence’ with the negatively framed ‘dependence’. Seen in this way, the movement’s notion of adequate state support *for* IL has come to represent independence *from* state support. In drawing on the language of the movement, the Coalition sought to legitimize

the move from DLA to PIP as being grounded in a citizenship approach, while seeking to promote a very different agenda (ibid).

3.4.1 Self-directed Support in Scotland: an alternative to neo-liberal marketization?

Changes in the organization of social care in Scotland have provided a possible opportunity for the advancement of the citizenship. Concerns over the marketization of care have seen a lower uptake of DP in Scotland. The citizenship agenda for disabled people in Scotland has therefore not been as advanced in Scotland as it has been in England. In announcing the move to Self-directed Support (SDS) in 2009, the Scottish government signalled a new approach, which was intended to increase the amount of choice and control individuals were able to exercise (Pearson et al. 2014). SDS, like personalization and DP, is part of an assortment of approaches to the commissioning and provision of community care. While it is often used synonymously with DP, SDS in the Scottish context refers to a range of options that disabled people can 'choose' from in order to receive their support (Pearson et al. 2014). The four options available under SDS are: having a DP; the local authority holding funding but allowing the care recipient to decide how that should be spent, e.g. by hiring a PA; traditional services chosen and provided by the local authority; or a mixture of all three (Scottish Government 2014c).

SDS has also involved a shift in language around the purpose of community care. While traditional services have focused on particular tasks such as toileting, washing, dressing, etc., SDS is designed to focus on the 'outcomes' individuals wish to achieve as a result of the support they receive (Pearson et al. 2014). These could include being able to socialize more with friends, or taking up new hobbies. This is a significant culture change, for both local authorities and disabled people. Traditional service provision has typically resulted in a gap between the aspirations of disabled people and their lived realities (Witcher 2014). This could mean that, without appropriate support,

some disabled people would struggle to achieve the outcomes they seek (ibid).

While SDS explicitly drew on the language of the disabled people's movement, in emphasizing choice and control, the theoretical underpinnings have nevertheless been contentious. Discussion in section 2.6.2.2 distinguished between DP, which were championed by the disabled people's movement as an important mechanism for enabling IL, and 'personalization', with its associations with neo-liberal marketization. However, in Scotland DP have been viewed as part of the marketization approach (Riddell 2006; Pearson et al. 2014). The debate around SDS in Scotland has therefore sought to circumvent the negative associations with DP by emphasizing ideas such as co-production (Pearson et al. 2014). This concept has its roots in communitarian approaches to citizenship. However, its application in the context of public sector reform was pioneered by Leadbetter (2004) and is therefore closely associated with the 'personalization' agenda in social care promoted by successive Labour, Coalition, and Conservative governments in England (Pearson et al. 2014; see also section 2.6.2.2). In seeking to distance policy from the marketization of care, SDS has nevertheless explicitly adopted the language of personalization. As was evident from the previous discussion of PIP, language can be used to imply allegiance to one agenda, while seeking to serve another. Despite its positive language associations, SDS may therefore prove to have more in common with public sector reform and the marketization of care than the needs and wishes of disabled people. The involvement of individuals and organizations of disabled people will therefore be critical to assessing whether SDS has the potential to enhance citizenship.

These challenges notwithstanding, the introduction of SDS represented a watershed moment in the organization of social care in Scotland.

By providing service users with a range of options over how they organized their social care, SDS had the potential to widen the range of service users who were able to benefit from personalized approaches (Pearson et al. 2014). The reach of DP had historically been limited not just due to the political tensions in Scotland, but also as a result of assumptions around an

individual's capacity to exercise choice and control over their care (Pearson 2004). By enabling individuals to instruct the local authority fund holder on how they wished their allocated budget to be spent, Option 2 allowed the exercise of greater choice and control without some of the challenges that come with managing a DP (see section 2.6.2.2). Similarly, the ability to mix traditional services with more personalized approaches was to enable service users to have greater flexibility over their care arrangements. Flexibility in and of itself does not lead to greater choice and control for service users, however, and the wider context that disabled people exist within must also be taken into account (Witcher 2014). The experience of poverty, as well as discriminatory attitudes, may lead to a 'reality gap' between the opportunities presented by policy and the ability of disabled people to aspire to greater choice and control (ibid). Despite the potential of SDS to bring about change, early evidence has suggested that the traditional care culture has been hard to shift. In 2015, the majority of those in receipt of local authority community care in Scotland continued to receive support from Option 3 (traditional services chosen by the local authority (Pearson & Ridley 2016)). This calls into question the amount of choice and control service users have been able to exercise under the new system, and raises question over whether individuals were being given sufficient information and support to explore the other options available to them.

The implementation of SDS at the height of the Coalition's austerity measures may have reduced its potential to bring about the changes it promised (Pearson & Ridley 2016). Local government in Scotland has faced a disproportionate share of the cuts to the Scottish Budget (Spowart 2011), and these have been unequally distributed to social services (Pearson & Ridley 2016). This has inevitably inhibited the potential of SDS to bring about the culture change required, and has diverted attention away from outcomes in favour of issues around resource allocation and budgetary management. Evidence from the SDS test sites charged with piloting the different SDS approaches has suggested that preoccupation with budgets served to restrict creativity over how outcomes might be achieved (Pearson & Ridley 2016), despite findings that where outcomes were considered before finance, it

frequently resulted in savings compared to the allocated budget (Pearson & Ridley 2016). Other research has highlighted that comparatively small-scale and inexpensive interventions can still make a substantial impact on independent living outcomes, and can reduce reliance on social care over the longer term (Witcher 2014). Nevertheless, at least one local authority had been found to be using the implementation of SDS as a façade behind which to reassess existing DP recipients with a view to reducing spending in social care (Pearson et al. 2014). This has further limited the potential of SDS to promote the citizenship of disabled people.

A further challenge to the ability of SDS to achieve its potential is in the growing burden being placed on service users to meet the costs of their care. Since 2003, social care activities related to personal care (washing, dressing, toileting, etc.) in Scotland have been provided free of charge to those over the age of 65 (Bell et al. 2007). However, adults in receipt of social care aged under 65 are often expected to pay a contribution towards the cost of providing their care. As part of their preparations for SDS, a number of councils in Scotland have reviewed their charging policies, introducing care charges to new client groups as part of the assessment process. Approaches to charging vary across local authorities, but approaches are generally calculated on the basis of income. Councils tend to disregard benefits such as ESA and JSA from their calculations, but not DLA, which is often counted as income for the care charge on the grounds that the care component is intended to cover the costs of care. Where a disabled person in receipt of social care is also in employment, the means test used to estimate the rate of charge the individual pays is usually takes account of a proportion of their weekly income above a certain limit. The proportion of income on which the means test is applied varies considerably across local authorities in Scotland, from 0% of income all the way up to 100% (Learning Disability Alliance 2013). This means that some social care users who are in work could be subjected to charges on the basis of 100% of their earned income. Two councils in Scotland, Edinburgh City Council and Fife Council, have abolished care charges for all adult social care users, although the rest of Scottish councils continue to impose charges for community care.

3.5 Welfare reform: generating a climate of fear

The foregoing discussion has examined the reforms undertaken by the Coalition Government as representative of a 'crisis' in the disability category (Stone 1984; Roulstone 2016). Central to this is an understanding of the category as a political concept. The decision to contract (or indeed to expand) is a political one, which is also subject to political constraints. On coming to power in 2010, the Coalition government proposed a raft of changes to disability and other benefits. Many of these were subsequently dropped due to public lobbying, or financial constraint, or delayed due to administrative challenges. An interesting feature of the reforms in the Scottish context has been the role played by the devolved administration in seeking to chart a different course from that of Westminster by mitigating the impact of some of the changes. The emergence of new groups of activists making use of social media to mobilize opposition to the welfare reform agenda also had an important if limited impact (Williams-Findlay 2011). The scope and pace of the reforms proposed in the first two years of the Coalition's time in office nevertheless served to generate the sense that disabled people in particular were under attack by the new government (Cross 2013). Expected changes at the commencement of fieldwork for this study included:

- Closure of the ILF (mitigated in Scotland)
- Universal Credit: real-time information system (delayed)
- Universal Credit: changes to marginal tax rates between benefits and earnings (delayed)
- Abolition of Income Support Severe Disability Premium
- Abolition of the Disability Element of Working Tax Credit
- Removal of mobility component of PIP from disabled people living in residential accommodation (abandoned)
- Sanctions for non-reporting of changes to circumstances for claimants of PIP (abandoned)

- 'Passported' eligibility e.g. to 'blue badge' scheme (mitigated in Scotland)
- Housing Benefit Under Occupancy Criteria (mitigated in Scotland)
- Devolution of Council Tax Benefit and 10% cut in funding (mitigated in Scotland)

In addition, changes to the mechanisms used to calculate the real terms value of benefits in relation to prices introduced by Coalition Chancellor George Osborne saw a reduction in the generosity of benefits. This has largely been managed through the move from the RPI to CPI measure of inflation in 2010, and the 1% cap on inflationary increases to certain benefits from 2012. Although disability benefits were largely protected from the 1% freeze, the change from RPI to CPI in 2010 has still seen the value of these benefits fall in relation to prices over that period. One of the justifications for the changes had been that the decline in the value of wages over time had meant that benefits had become more financially rewarding than remaining in paid work (Osborne 2012). This created a financial incentive to remain on benefits rather than to seek paid employment. However, the initial RPI to CIP change also impacted on in-work benefits such as DLA.

While the changes listed above and throughout this chapter have been considered individually, many disabled people would have received a combination of different in- and out-of-work benefits, including those not related to disability. As a result, the reforms proposed would have a cumulative impact, with losses experienced from several sources of benefit income at once. Disabled people at the start of this period therefore faced a 'perfect storm' of cuts and changes to eligibility (Wood 2012, p. 87). Lobbying organizations called for a cumulative impact assessment of the reforms to assess the effect on minority groups, including disabled people and women (Lister & Bennet 2010). However, the Coaliton consistently refused to publish this information. The decision in 2010 to cut funding to the EHRC, the public body charged with enforcing compliance with anti-discrimination legislation, by 60% also contributed to the sense that equality and citizenship for minority

groups was not a significant part of the coalition's agenda. At the same time, the cultivation of a narrative that focused blame for the cuts on the actions of individual benefit claimants, portraying them as 'scroungers' (Garthwaite 2011, Briant et al. 2012) served to legitimize these reforms for much of the public. By 2013, this had contributed to the creation for disabled people of a climate of fear (Pearson & Trevisan 2015). This section therefore serves to illustrate the social and political context facing disabled people in Scotland at the commencement of fieldwork for this study.

3.5.1 The age of the 'scrounger': stigma, resentment, and vindictiveness in discourses of welfare reform

The period between 2010 and 2015 also saw a hardening of attitudes towards disabled people, and those in receipt of benefits more generally. Section 3.3.2.1 discussed the emergence of surveillance and self-surveillance as a means of enforcing compliance with conditionality. Related to this is the concept of 'sousveillance' (Dennis 2008). In contrast to surveillance, which is imposed from above, sousveillance exhibits as a form of power emanating from the bottom up (ibid). This can have a positive and emancipatory application, but can also be manipulative, inciting communities to surveil each other and correct deviant behaviour through condemnation or vigilantism. In a similar vein, in discussing the policy effects of Murray's (1990) 'underclass theory', Young (2003) highlights the ways in which resentment against members of a community who are perceived to be receiving more favourable treatment, such as those in receipt of benefits, can spill over into vindictiveness against them. Such resentment can also be fostered in order to build public support for social policies that seek to control behaviour. Hoggett et al. (2013) point to the cultivation of 'anti-welfare populism' by governments and the mass media as examples of this. To expand on the discussion of surveillance above then, self-surveillance as behavioural control can therefore be exercised internally by an individual, horizontally within a community, and vertically through the operation of government and media narratives that foster feelings of unfairness.

There is growing evidence of such processes at work through the reforms discussed in this chapter, contributing to the sense of fear that was generated at the time. Indeed, this is clearly evident in the Coalition's rhetorical approach to welfare reform during this period, where it is possible to identify three distinct discursive strands (Pemberton et al. 2016). The first is that individuals make antisocial choices in their lives, which are characteristic of the 'underclass'. Secondly, and underpinning the first, is the belief that worklessness is a lifestyle choice, rather than a result of structural factors such as the recession and the growth in insecure labour. Finally, the Coalition emphasized a moral narrative whereby benefits are not a universal safety net, but rather something gifted by those who have, to those who have not (Pemberton et al. 2016). The potential for this to create resentment within communities is self-evident. Similarly, Garthwaite (2011) has highlighted the role played by the Coalition in fostering a narrative that depicts those who use benefits as 'shirkers and scroungers', while analysis of media reporting of welfare reforms has identified a hardening of attitudes towards disabled people in public discourse (Briant et al. 2012). Much of the tabloid coverage perpetuated coalition rhetoric (ibid), however, there was some critical coverage in particular from some of the more centrist broadsheets. Nevertheless, this meant that welfare reform was seldom far from the headlines, which contributed to the climate of fear experienced by those in receipt of benefits during this period. The reportage was further supported by the emergence of what has been described as 'poverty porn' (Brooker 2014) through the proliferation of television programmes such as *Benefits Street*. Again, while sometimes sympathetic, overall these programmes served to popularize the notion that individuals claiming benefits were openly defrauding the system. Benefit claiming had become increasingly stigmatized as a result, with a growing differentiation between those who contribute to the system, and those who take out (Baumberg et al. 2012). As with self-surveillance, benefit stigma can be experienced at a number of levels, including personally, socially, and institutionally (ibid).

These discourses have been popularized across society, although Baumberg (2016) (echoing Young 2003) has demonstrated that people living in areas with higher levels of benefits claiming are more likely to espouse these views. Likewise, Chase and Walker (2012) highlight that people who have been labelled with a shaming or stigmatized identity are more likely to participate in 'co-shaming' and othering behaviour against those they perceive as being less deserving than themselves. While Flint (2008) has argued that family history and personal narratives can also play a role in shaping this, Hoggett et al. (2013) have demonstrated how such processes can lead to the growth of resentment within communities. This resentment and co-shaming behaviour has been observed among those in receipt of long-term sickness benefits, such as ESA, since 2010 (Garthwaite 2015).

Resentment can run the risk of becoming vindictiveness (Young 2003) when negative feelings of mistrust are directed at individuals rather than a faceless other. Quarmby (2011) has argued that the financial crisis of 2008 and subsequent reforms, as well as the media narratives around this, have amounted to the scapegoating of disabled people. Indeed, in exploring the motivations for hate crimes, she points to perceptions of disability having become synonymous with 'scrounging' as an important factor. This can make acknowledging a stigmatizing identity, even to family members, difficult for people who receive benefits, and may lead to social isolation (Garthwaite 2015).

As with mechanisms of self-surveillance, narratives around 'scrounging' have also been found to have been internalized by benefit claimants (Patrick 2015). This can have a profound impact on individual's sense of self, with some evidence suggesting that these processes can be experienced as 'self-loathing' (Pemberton 2016). This can also have a significant impact on social relationships. The period of reforms since 2010 has therefore seen a significant hardening of attitudes towards people claiming benefits in general, as well as those on disability benefits in particular.

3.5.2 The role of online activism in challenging welfare reforms

It would be easy, given this discussion, to view disabled people in this period as passive victims of the reforms that took place. However, the period also saw the emergence of new activist groups of disabled people campaigning to challenge policy change (Pearson & Trevisan 2015). As Chapter 2 demonstrates, activists within the disabled people's movement in the UK have played an important role in bringing about policy changes including the creation of DP. The new activist groups have seen more modest successes in their activities (Pearson & Trevisan 2015).

Making use of the opportunities presented through social media to bring together geographically dispersed activists, these groups have nevertheless mobilized some opposition to the Coalition's proposed reforms (Pearson & Trevisan 2015). The group known as 'Disabled People Against the Cuts' succeeded in generating considerable negative mainstream media publicity for the WCA provider ATOS during the London Paralympic Games in 2012 (Pearson & Trevisan 2015). This may have played some role in ATOS exiting their contract for the WCA a year early (Sidique 2014). However, as highlighted in section 3.2.1, despite the change in provider, policy remained largely unchallenged. Nevertheless, technological advancements in social media have opened new opportunities for disabled people's collective action, generating some successes in resistance to the Coalition's reforms. The emergence of activist literature critiquing the reforms, including the 'Sparticus Report' (Campbell et al. 2012) which compiled responses to the Coalition's consultation on PIP is a further example of this. These groups have, by their nature, tended to be disparate and separate from the mainstream of British politics, and their impact has therefore been somewhat limited.

3.5.3 Scottish devolution: mitigating the impact of Westminster reforms

This thesis focuses on the impacts of reforms on disabled people in Scotland, where devolution has provided a slightly different context for the reforms taking place. In the lead up to the 2014 Referendum on Scottish

Independence, the SNP led Scottish Government were keen to draw on counter-narratives generated by disabled people's activist groups as well as the wider anti-cuts movement in order to demonstrate the potential for a more progressive outlook under an independent Scotland. This approach achieved success in two important areas: the mitigation of the under-occupancy criteria for Housing benefit (colloquially known as the Bedroom Tax) (Beatty & Fothergill 2015), and the devolution of ILF (Scottish Government 2014d). However, at the time that fieldwork for this study commenced, neither of these divergences from UK policy had been announced, meaning participants faced considerable uncertainty over how they might be affected by these changes.

Proposed changes to the housing benefit (HB) for people residing in local-authority or social-rented sector (housing associations) housing came about as a result its amalgamation into UC (Tarr & Finn 2011). Prior to 2013, HB was calculated on the basis of rent. However, from April 2013 the amount of HB paid to cover the cost of rent could be reduced if households were deemed to be 'under occupying' by living in a property with more bedrooms than they were found to need. The proportionate reduction amounted to 14% for one bedroom and 25% for two or more bedrooms (Shelter 2013). Claimants were expected to make up any difference in the rent themselves. Similar rules had already been put in place for private rented housing tenants (DWP 2013a).

The change prompted considerable criticism, and was thought to be particularly disadvantageous to disabled people who might require an additional room for equipment or to enable a PA to stay the night (Inclusion Scotland 2012). The UK Government made funding available for local authorities to make discretionary payments to affected households as an interim measure for 2013/14 (DWP 2013a). Cross-party support (with the exception of the Scottish Conservatives) within the Scottish Parliament saw discretionary funds topped up to enable Local Authorities to mitigate the policy. However, these funds continued to be administered on a discretionary, and therefore case-by-case, basis. In 2014 new powers to the Scottish Parliament meant that the Scottish Parliament were effectively able to fully mitigate the impact of the change in Scotland for all those affected by

changes to under occupancy criteria (Scottish Government 2014e; Beatty & Fothergill 2015).

A further policy area in which the Scottish Government have been able to pursue a different approach has been in relation to plans for the future of the ILF. Unlike the mitigation of under occupancy criteria, the impetus for this change came from the Coalition Government's decision to close the ILF and devolve funding to local authorities in England, and to the Scottish Government (Belgrave 2013). As discussed in section 2.5.3, the ILF was initially intended to be a stop-gap measure, but proved extremely popular among disabled people. By 2010 the fund provided support to 19,000 users across the UK, with 97 pence in every pound going to the end user, making it a highly efficient programme (ILiS 2012). The move to abolish the ILF stands to further undermine the Coalition's rhetorical appropriation of the citizenship agenda. The closure of the fund was strongly contested by disability rights activists, and led to a Judicial Review into the legality of the closure (Pearson et al. 2014). Despite an earlier ruling that the closure had been unlawful, the government appealed and the High Court ruled in December 2014 that the closure had been legal (BBC News 2014).

Following the devolution of the ILF in March 2014, the Scottish Government announced a further £5.5 million to enable the new ILF Scotland (ILFS) to open to new applicants (Scottish Government 2014d). This move had the potential to result in a very different context for independent living in Scotland than south of the border (Pearson et al. 2014). ILF funding in England was devolved to local authorities, but without ring-fencing, making it harder for the funds to be protected in the interests of promoting independent living, which effectively marked an end to the scheme there (Pearson et al. 2014).

3.6 Summary

This chapter has explored the Coalition government's approach to the reform of disability benefits in the light of three important trends. The first viewed

changes to IB and DLA as reflective of an attempt to address a crisis in the disability category, by redrawing eligibility for these benefits. This was achieved through the adoption of medical assessments underpinned by the BPS model of disability. This is linked to a second trend, which saw the further expansion of conditionality to disabled people during this period. This was based on a particular conception of agency, and the perceived need to correct behaviour of claimants through surveillance and sanctions. While medical testing and conditionality had first emerged in UK policy in the 1990s, the period 2010–15 saw a considerable expansion and intensification of these trends. The third section of this chapter identified the emergence of a new trend in the adoption (or co-option) of the language of the disabled people's movement in order to justify reforms (Roulstone 2015). This has been most evident in the replacing of DLA with PIP. In Scotland, by contrast, while the introduction of SDS represented considerable potential for a citizenship approach, debates around terminology and the timing of its implementation in an era of acute austerity, has seen it adopt similar frames to those employed in the personalisation agenda in England.

The final section of this chapter provided an overview of the social and political environment in which the reforms took place. In particular, it emphasized the emergence of a 'climate of fear' for disabled people, and the increased stigmatization of benefit claiming. This has led, in some cases, to an increase in the experience of hate crime, as negative discourses have fostered resentment and vindictiveness (Young 2003) within communities. Disabled people have responded to this through the emergence of new activist groups, which have harnessed the potential of social media to protest against the proposed reforms. The on-going constitutional tensions within the UK have also created policy windows enabling the emergence of divergent approaches in Scotland. Nevertheless, the sheer scale of the reforms combined with a narrative that has served to denigrate and individualize has meant that these pockets of resistance have been somewhat limited.

The three trends discussed in this chapter form the basis of the research questions that are outlined in the next chapter. Chapter 4 also discusses the

selection of methods and epistemological underpinnings of this study, before outlining their application to the collection and analysis of data.

Chapter 4 Methods

4.1 Introduction

This chapter outlines the research methods employed in this study. It begins by restating the three research questions in light of discussion of the literature in Chapters 2 and 3. It then addresses the methodological and epistemological underpinnings of this research. The key ethical considerations addressed in conducting this research are then elucidated. The chapter moves on to discuss the process of conducting fieldwork, recruiting participants, and conducting of interviews. Finally, the approach taken to analysing data is described.

4.2 Research questions

Discussion in Chapters 2 and 3 has highlighted three trends in the Coalition Government's approach to disability benefit reform. The first related to policies which aim to tackle perceived problems with 'welfare dependency' by making the receipt of benefits conditional on certain behaviours and activities, while punishing non-compliance through the use of sanctions (section 2.5.2). These are based on particular assumptions about individual agency (section 3.3.2). The second trend related to a well-established response to a perceived 'crisis' in the disability category (Stone 1984; Roulstone 2015) by reducing demands on social security through a redrawing of the disability category (section 3.2). In practical terms this involved changing eligibility to certain benefits and the introduction of medical assessments based on biopsychosocial indicators (Shakespeare et al. 2016). Both of these trends have been supported by the creation of a public moral discourse that has increasingly stigmatized those in receipt of benefits as 'scroungers' (Garthwaite 2011; Briant et al. 2012). The final trend related to the language framing the reforms, and the adoption (or co-option, see Morris 2011) of terms traditionally associated with the disabled people's movement such as 'independent living'. This is in spite of the stigmatizing narratives popularized through media coverage. Unlike the first two trends, which have a well-established history, this last has emerged as a

new approach to redesigning disability policy (Rousltone 2015). Drake's (1999) analysis (see section 2.2) highlighted that the way in which disability is understood by the government of the day has an important bearing on how policies are experienced by disabled people. The adoption of the language of the disability movement may therefore indicate a move towards policies designed to enhance the citizenship of disabled people. Consideration of these trends raises the following questions:

- 4) *Policies promoting a conditional approach to the receipt of benefits are based on certain assumptions about recipient's agency. To what extent are these assumptions reflective of individual disabled people's attitudes to benefits and the labour market? In what ways have disabled people been affected by the intensification of conditionality?*
- 5) *The reform of ESA/IB and DLA/PIP has been characterized as a redrawing of the disability category in response to a perceived crisis. In what ways has this reform impacted on the experience of claiming and using disability benefits? In what ways have disabled people been affected by popular and media narratives supporting the reforms?*
- 6) *Policies adopted both at Westminster and at Holyrood between 2010 and 2015 drew heavily on the language of the disabled people's movement, emphasizing concepts like independence. To what extent have these policies enhanced disabled people's citizenship status during this period?*

4.3 Methodology and research design

Discussion in section 3.3.2 highlights the importance of recognizing the ability of individuals to exhibit a plurality of different forms of agency. However, it also serves as a reminder that this continues to be shaped and constrained by structural factors that may be outwith the individual's control (Hoggett 2001).

The extent to which social phenomena can be explained by either structure or agency has been an important philosophical divide in the social sciences (Gorski 2013). A researcher's own position in relation to these questions has an important bearing on the way in which they approach social enquiry (Gilbert 2001). This section briefly outlines my own position on these matters with reference to some of the key epistemological debates within Disability Studies. It begins by outlining the emergence of the social model of disability and the emancipatory research paradigm as a reaction to the positivist tradition, before highlighting some of the limitations of this approach. I argue that while the social model has provided an important counter to the objectifying research methods of the positivist tradition, its focus on structure to the exclusion of agency may serve to undermine individual disabled people's capacity as actors within their own lives. I conclude this section with a brief exploration of my own position as a researcher and the influence this has on the way I have approached the research presented in this thesis.

4.3.1 Epistemology: from social model to critical disability studies

Section 1.3 outlined the contribution made by the social model of disability as means of defining and understanding disability. In distinguishing between *disability* and *impairment* it recognizes that discriminatory attitudes, and physical barriers in society, serve to disadvantage disabled people. However, it also described some of the limitations to this approach. The social model emerged in response to the treatment of disabled people in the research process (Watson 2012). Residents at the Le Court Leonard Cheshire home in the 1970s invited researchers in to the home in order to research their circumstances, hoping their findings would add weight to calls to enable them to gain more independence and control over their lives. However, the researchers were concerned to take a balanced and objective view and therefore failed to condemn the conditions in the home. This was viewed as a betrayal of trust by the residents, and led directly to the founding of UPIAS articulating the social model of disability (Watson 2012 – see also section

1.3). The social model of disability therefore makes an important contribution not only to the understanding of disability, but also to research practice

In the 1990s, disabled researchers writing from a disability studies perspective sought to build on these foundations to develop a means of researching disability that was in line with the principles of the social model (Oliver 1992; Oliver 1997). This was codified in the emancipatory research paradigm (Stone & Priestley 1996), which was developed through interaction between disabled academics and activists in the disabled people's movement (Watson 2012). This approach took an explicitly political stance in opposition to research typified by the medical model (see section 1.3), which viewed disability as the product of personal tragedy, and placed researchers and professionals in the role of expert. The purpose of research is as critical to this construction as the role of the researcher. The medical model results in research that aims to generate information on disability rather than changing the conditions in which disabled people live (Oliver 1992). In contrast, the principles of emancipatory research seek to empower disabled people to overcome the oppression they face (Stone & Priestley 1996). By eschewing claims of objectivity, researchers recognise their own limitations and disabled people are located as the experts in their own lives (Oliver 1997).

It is clear from this discussion that the emancipatory research paradigm emerged as a rejection of methods that took an explicitly 'positivist' approach to researching disability (Oliver 1992). That is, epistemological approaches that saw the world in terms of objective scientific truths (O'Gorman & Macintosh 2015). In doing so disability studies has drawn from other disciplines that sought to empower and liberate other oppressed groups. Feminist academics have highlighted the objectification of women's voices by researchers (Ramazanoglu 2003), arguing that the quest for 'objectivity' in positivism has served to universalize the male experience, and subjugate experiences that differed from this (Morris 1992). In contrast, feminist research recognizes that the researcher is not an objective observer, but rather an integral part of the research process (Ramazanoglu 2003).

Discussions of objectivity are central to the emancipatory research paradigm in as much as they relate to the balance of power between researcher and subject (Stone & Priestley 1996). Feminist theory has highlighted that the objectification of women in the research process is primarily to do with women's lives being interpreted by the people they are oppressed by (Morris 1992). Similarly, early disability studies advocates sought to change the social relations of the research process in response to the power of the so-called 'expert' over the disabled subject underpinning medical model research practices (Oliver 1992). Emancipatory and feminist research methods therefore both aim to bring about more equal and balanced power relations in the research process. However, disability studies scholars have also highlighted limitations to the feminist interpretivist position, arguing that in contrast to emancipatory research, interpretivism still places the researcher in the role of 'expert' and therefore fails to fully change the social relations of the research process (Oliver 1992). The emancipatory research paradigm is therefore presented as a unique and separate epistemology.

The emancipatory research paradigm has not gone without criticism both within and outwith disability studies. In particular, the role and identity of the researcher in relation to the research has been the topic of some debate. Adherents to the emancipatory paradigm have argued that the only way that the power relations between researcher and research can be equalized is by research being conducted by people with shared experience of oppression (Branfield 1998). According to this view, research into disability should only be conducted by disabled people (*ibid*). However, this perspective has been challenged by those who would argue that simply identifying with oppression does not lead to emancipatory research (Morris 1992). Differences in class, education, and life experience can all affect power relations between researchers and their subjects (Barnes 1992). The researcher therefore has an obligation approach research reflexively, acknowledging and addressing differential power relations in the research relationship (Lee 1993).

The ability and indeed desirability of claims to objectivity have continued to be a topic of some debate within disability studies, with some calling for

impartiality to be recognized as an important hallmark of quality research. However, the notion that research and researchers are value free is equally debatable. The increasing marketization of higher-education funding means that research is far from being free from external control (Barnes 1996). Claims of independence from the academic community are therefore selective and unequally distributed. The 'myth of the independent researcher' serves only to underline the gulf between the researcher and researched (Barnes 1996, p. 107). Indeed, it has been argued that the failure to take a stance is tantamount to condoning the oppression that disabled people face (Oliver 1997).

The requirement within the emancipatory research paradigm to state an explicit and political accountability to the disability movement (Stone & Priestley 1996) has also faced criticism for resulting in a binary 'for us or against us' approach. These critiques represent something of an epistemological shift within disability studies. Writers taking a more critical perspective have called instead for the discipline to embrace a plurality of opinions, and a richness of debate that will enable it to become a more mature and sophisticated discipline (Shakespeare 1996). This has the potential to reframe the notion of accountability in disability research. While being accountable to research subjects should underpin any ethical approach to research, the requirement to account to a wider movement remains somewhat more problematic (*ibid*). A critical disability studies perspective could call instead for academics to express a 'commitment' to the movement (Shakespeare 1996). This would enable a recognition of their limitations as researchers and indeed the limitations of the research process: that academics can never truly equalize the relationships between researcher and subject, the researcher will inevitably retain the role of expert. However, this does not prevent them from understanding of the oppression that disabled people face, and expressing a commitment to work to change that (Shakespeare 1996).

The emergence of critical disability studies (Watson 2012) also reflects a shift away from the materialist or structuralist approach of the social model in

favour of a more nuanced view (Shildrick 2012; Goodley 2013). This has provided important and useful insights on the structure/agency nexus. Section 1.3 highlighted that a significant shortcoming of the social model is that emphasizing the structural barriers to inclusion (disability) has led the embodied realities of impairment and pain to be overlooked (Morris 1992; Watson 2012; Goodley 2013). The focus on structure to the exclusion of agency further runs the risk of overlooking disabled people's own capacity to bring about change (Watson 2012). As a result, the emancipatory paradigm tends to portray disabled people as victims, which merely serves to perpetuate their oppression (ibid). Critical disability studies scholars have highlighted that, by failing to engage with the experience of impairment, the movement has vacated an important space in the lived experience of disabled people (Watson 2012). This has enabled the emergence of narratives from medical sociology, which do not engage with disability studies, and that serve to pathologize disability as an individual failing. The practical implications of this are evident in the increasing influence of the BPS on policy (Shakespeare et al. 2016) as highlighted in section 3.2.1. This also serves to disempower disabled people by failing to give voice to the full range of their lived experience (Morris 1992, Watson 2012). The critical disability studies perspective has therefore sought to enable researchers to move beyond debates around the relative position of disability and impairment (Watson 2012). By exploring both agency and structure, as well as the influence of each on the other, it is possible develop a pluralistic understanding of disability that incorporates the totality of the lived experience (Watson 2012).

4.3.2 Positioning myself as a disabled researcher

Given these debates, it is important to situate myself reflexively in relation to the research I have conducted (Morris 1992). I am dyslexic, and as such I identify as a disabled person. I am disabled by a society that measures the acquisition of knowledge through the application of 'correct' spelling and grammar, or the ability to recall 'facts' under exam conditions, rather than through the enjoyment of ideas and participation in debate. I also experience

impairment effects (Thomas 1999): the frustration caused by the vagaries of my short-term memory, and the fatigue I experience if I have to concentrate for long periods of time. I am also a woman, a mother, and I self-identify as 'Black'¹. These identities all signify a shared identity with those who experience oppression, and are an important part of my motivation for this work. I am a member of the Disabled People's movement in Scotland, and have come *to academia from* the movement, rather than the other way around.

Nevertheless, I have certain privileges which confer power in a research relationship. I come from a middle-class background, and have benefitted enormously from a state education system and publicly funded university system. My background also generates certain assumptions about me. Although 'English' is not an identity I ascribe to, I speak with a Home Counties accent that sends certain messages about my background and education. I also operate in an academic setting that sets standards about the way in which research is conducted and its purpose (Shakespeare 1996), however much I may have struggled with these as I made the transition from activist to academic. My impairment is also an unseen one, and is therefore not necessarily obvious unless I choose to disclose it. I do not receive disability benefits and therefore my range of experience as a disabled person is quite different from that of the participants in this research.

For these reasons, I express my commitment to the disabled people's movement rather than accountability to it (Shakespeare 1996). I believe that research can inspire, and it can give voice to those whose voices are not often heard. However, I recognize the limitations of the transformative potential of a doctoral research project. In adopting a critical disability studies perspective (Watson 2012), I have sought to give voice to disabled people throughout the research process, highlighting structural barriers to inclusion, and treating them as experts in their own lives. At the same time, I have tried

¹ Capital 'B', signifying a political identification with 'Black' as an identity encompassing all people of African, Asian, Caribbean and Arab heritage, rather than lower case 'b', i.e. black as a description.

to maintain a critical and reflexive approach to recognizing human agency by ensuring that an understanding of the disabling barriers faced in society does not overshadow the legitimacy of personal experience of impairment.

4.3.1. Research design

This research project has sought to explore the experiences of changes to a particular set of policies at a particular point in time. This required research design and the selection of methods that dispose themselves naturally to exploring and giving voice to lived experiences. As with feminist theory (Ramazanoglu 2003), disability studies have had a long association with qualitative methods. Indeed, Barnes (1992, p. 115) described these as 'fundamental' to emancipatory research. This is not to argue that it is impossible to apply a quantitative or mixed-methods approach to researching disability (Bury 1996). However, this project has primarily been concerned with meanings, something which qualitative methods lend themselves well to exploring (Mason 2002). A qualitative research design was therefore felt to be the most appropriate method to allow full interrogation of the research questions outlined at section 4.1. These methods enabled an exploration of both individual agency and the structural barriers that shape and constrain these (Watson 2012). Qualitative methods are also well suited to research that touches on sensitive topics (Lee 1993; Elam & Fenton 2003), by enabling the researcher to build trust with the research participant, and explore experiences in their own words. Given the discussion of the climate of fear that existed at the commencement of fieldwork, this was an important consideration (see section 3.5). Research for this study was conducted using in-depth, semi-structured, one-to-one interviews with individual disabled people. As Jones (1985a) highlights, depth interviewing allows researchers to ask questions about the things most important to research subjects, and to situate these within a rich context of daily life. The remaining sections of this chapter outline the way in which these methods were employed through the research process.

4.4 Ethics

Disability and the use of benefits are both sensitive subjects, and this was particularly so at the commencement of fieldwork for this study (section 3.5.1). Research ethics were therefore an important consideration in this research. These issues are touched upon throughout this chapter; however, this section provides a brief overview of some of the main ethical considerations and the approach taken to addressing them. Qualitative research is conducted in the real world with real people, and it is therefore impossible to militate against all possible ethical challenges that may arise (Bryman 2004). An open and reflexive approach enabled the discussion and consideration of such issues as they occurred.

The sensitive nature of the research topic, given historical understandings of disability (section 2.3), and the growing stigmatization of benefit claiming (section 3.5.1), was an important consideration at the outset. Sensitivity may be particularly acute when discussing topics where participants do not meet the expectations of society or ascribe to deviant identities (Elam & Fenton 2003). A number of strategies exist within qualitative methods for dealing with sensitive topics through the interview process, which helped to inform my approach. In particular, the use of warming-up questions and time to enable participants to become comfortable in the interview situation before broaching sensitive topics was particularly useful (Elam & Fenton 2003). Interviews were conducted in the main in participants' homes, enabling them to be in familiar and comfortable surroundings. This also meant that they took on the role of 'host' in the interview, observing the social formalities of making cups of tea and welcoming me into their homes. This allowed them time to become comfortable with the interaction, and I was careful not to rush into the research, but allowed the participant to take the lead.

Discussions relating to personal finances, use of benefits, or impairment had the potential to either offend or upset, and I was keen to minimize this risk. The framing and ordering of questions was important, and in this regard I employed general warm-up questions before moving on to more sensitive

topics (see Appendix I), and allowed participants to take as much time as they needed in the interview process. I also developed links with organizations (see section 4.5.1 below) who would be able to signpost information and advice to participants should they need this. In the event, none of the participants became upset during the course of their interview. Chapters 5–7 demonstrate that many of them were frustrated with the situation that they found themselves in, or upset about the way that they felt they had been treated, but no individual seemed to find discussing this in the interview to be problematic. Elam and Fenton (2003) suggest that participants may be more willing to open up about sensitive topics if the research is viewed as having a positive impact. While it was important to manage expectations about what a study such as this could achieve, participants did appear to be keen to take part because they hoped that sharing their experiences in the research might help to make a difference.

This study received ethical approval from the University of Glasgow College of Social Sciences Research Ethics Committee (see Appendix II). Consideration was also given to the ESRC's Principles of Research Ethics (2015). Ethical approval for research with disabled people can often face challenges due to conceptions of disabled people as inherently 'vulnerable'. This has been the subject of considerable debate. While policies that designate disabled people as 'vulnerable' often exist ostensibly to protect them (Sherwood-Johnson 2013), these can also be used to disempower or inhibit disabled people's participation (Burghardt 2013). The concept of 'vulnerability' may also be used to undermine the severity of crimes against disabled people (Roulstone & Sadique 2014). In Scotland, Adult Support and Protection policy aims to address this problem, by distinguishing between disabled people *per se*, and people who are deemed to be 'at risk' (Sherwood-Johnson 2013). Nevertheless, this has resulted in policy where the conditions for vulnerability are poorly defined (*ibid*). The framing of Scottish policy has also been critiqued for giving considerable discretion to professionals to determine what 'at risk' means (*ibid*). Indeed, the disabled people's movement expressed concern as to the provisions of the Adult Support and Protection Bill in 2005 which codified this approach (Elder-Woodward 2005). In this sense, then, the

Scottish framework is influenced by medical model ways of thinking about disability. This is difficult to challenge, as questioning this construct is often viewed as unethical in itself (Burghardt 2013).

As a corrective to this, authors writing within the Ethics of Care literature have sought to highlight the universality of vulnerability, and the centrality of this to the human condition (Burghardt 2013; Sherwood-Johnson 2013). From this perspective, vulnerability is not conceptualized as an individual failing, but rather as something that is experienced by all humans in different contexts and at different times in our lives. Nevertheless, university ethics committees have tended to adopt a more individualized approach to vulnerability. Indeed, the University of Glasgow College of Social Sciences specifically list people with learning disabilities as 'vulnerable' (University of Glasgow 2015). Ethical approval for this study was initially declined on the basis that some participants may have had impairments that may have prevented them from giving written consent. While I had been open about this, and careful to outline the steps I would take to discuss and obtain informed consent through a digital voice recorder, this was not initially deemed sufficient. On clarification that these procedures would be the exception, rather than the main means, of obtaining consent the project was eventually granted ethical approval.

Standard practices were adopted in relation to the storage and management of the data. Data was anonymised soon after collection, with any files containing identifying information such as recordings stored digitally on a single-user password protected computer stored at my home. Any printed transcripts or documentation arising from the research were stored in a locked filing cabinet. I also took the decision to share full transcripts with all participants following their interviews to enable them to check and verify the information. This was assisted in some cases by the organizations I recruited through who supported some participants to review their transcripts ensuring that they understood and were happy with the content. One participant requested that changes were made relating to a particular issue they had experienced, expressing concern that they had given information that might reflect badly on them.

Preserving the anonymity of participants was particularly important in this study and the provisions made for this were stressed in recruitment activities, and discussed with each participant at the start of each interview. The emergence of new online activist groups responding to welfare reforms (Williams-Findlay 2014; Reilly & Trevisan 2015; see also section 3.5.2) provided an opportunity to recruit participants who were not traditionally involved in the disabled people's movement. This had the potential to bring new perspectives into the research (Bowker & Tuffin 2004), but equally opened up new ethical considerations. This is an emerging field, and much of the literature focuses on the ethics of naturalistic observation of online communities (King 1996; Bowker & Tuffin 2004; Zimmer 2010; Reilly & Trevisan 2014), which was not the method employed in this study. However, some of the discussions of ethical approaches to online interactions in research are nonetheless pertinent. This was particularly so for the need to balance the expectation of privacy against the public nature of online information (Zimmer 2010). All participants were interviewed in person rather than online, and therefore ethical considerations are restricted to recruitment activity rather than the interview process. Nevertheless, online discussions as part of recruitment activity took place in a public forum, which could potentially be traced. These interactions were freely entered into and it was made clear that I was recruiting for the purposes of research. People were also encouraged to contact me offline via direct messaging, although I subsequently discovered that my own privacy settings on Twitter prevented them from doing so. As a further safeguard, participants' identities have been protected by the use of pseudonyms and the decision not to directly quote from material that could be found through a search engine (Reilly & Trevisan 2014). Participants were given the opportunity to choose their own pseudonyms, and where this option was not taken, pseudonyms were selected by myself. Care was also taken in the transcribing and reporting of data to ensure that place names and other identifying information was removed.

Ensuring that all participants gave informed consent was a further ethical consideration, as discussed above. Those taking part in the study were issued with an information sheet (see Appendix III) outlining the aims and objectives of the research and highlighting the ways in which their data would be stored. Further copies of this were given out and discussed at the start of each interview, along with time to ask questions or seek clarification over the aims of the study. It was made clear that interviewees could withdraw at any stage without question and that they did not have to answer any questions they felt uncomfortable with. Written consent was obtained from each participant (see Appendix IV) and forms were stored in a locked filing cabinet at the University of Glasgow.

Participants all received a £10 high street gift voucher as thanks for taking part in the study. Taking part in qualitative research can be time-consuming for participants and researchers therefore often feel that it is important that this is openly acknowledged (Dickert & Grady 1999; Wendler et al. 2002). This was a small research project with minimal funding and it was therefore impossible to adopt a compensatory approach as advocated by Dickert and Grady (1999). However, I felt it important that participants received some token recognition for giving up their time. Participants were also likely to be experiencing financial constraint as a result of the changes they were experiencing and a token gesture was felt to be even more important (Neale & Hannah 2012). The vouchers were not mentioned in any of the recruitment documentation in order to avoid the implication of undue incentive to take part (McNeil 1997). One participant was interviewed and subsequently withdrew from the study, but still received a voucher in thanks for the time he had given to take part (Wendler et al. 2002).

Participants generally responded positively to receiving the vouchers, and were pleased to have received them. The majority viewed them as an additional bonus to having taken part, and planned to use them in order to treat themselves. One participant took offence at being given the voucher. I explained that they were covered by my research funding and that they were being given to all research participants and he reluctantly accepted it.

4.5 Fieldwork

Fieldwork for this study was carried out between November 2013 and June 2014, with the majority of interviews taking place before April 2014. Twenty-three participants were recruited through snowball sampling (Mason 2002). The initial intention was to adopt a purposive sampling framework to include characteristics such as gender, age, benefits claimed, geographical location, and impairment type (Ritchie et al 2003a). This would have enabled closer comparison of the experiences of different characteristics, for example whether those with mental health problems had been affected by the changes differently from those with physical impairments. However, the method of recruiting through third parties and gate keepers (see 4.5.2) meant that in the end this became more of an opportunistic sampling method, recruiting those who volunteered to take part, rather than only those meeting all of the criteria (Ritchie et al 2003a). Nevertheless, a basic criteria remained that participants should broadly speaking be:

- Individuals of working age (18-65).
- Experience a physical or mental impairment that limited their ability to carry out day-to-day tasks, or experience of a long-term health condition.
- Should be in receipt of at least one of the following benefits in the past three years, and have claimed that benefit for at least two years:
 - Incapacity Benefit / Employment Support Allowance
 - Disability Living Allowance / Personal Independence Payment
 - Independent Living Fund
 - Severe Disability Premium
 - Disability element of Working Tax Credit
 - Local authority community care/Direct Payment or Self-Directed Support

This method enabled a more flexible approach to sampling, than through strict adherence to a purposive sampling framework, and allowed me to largely involve those who expressed an interest in taking part in the study. However,

it has resulted in a less diverse sample than was originally intended, reducing the potential for comparisons. The detail of the eventual sample demographics, and the implications of this for findings presented here are discussed below.

4.5.1 Overview of research participants

The aim in recruiting participants for qualitative research is not to achieve statistical representativeness, but rather to ensure that the sample is 'symbolic' of the population from which it is drawn in order to enable generalizations to be made from the findings (Lewis & Ritchie 2003). This involves as far as possible capturing the diversity of that population (ibid). This section and section 4.5.2 reflect briefly on the extent to which this was achieved in the sample for this study, as well as exploring some of the limitations encountered. An overview of the final sample is provided in Table 4.1 below.

Table 4.1 – Participant Characteristics

Name	Gender	Age	Main Impairment	Employment status	Main benefits/ payments received	SIMD quintile*	Local Authority Area
Adrian	M	50	Mental ill health	Out of work	ESA (SG) and DLA	3	Perth and Kinross
Ailsa	F	Withheld	Learning disability	In training	DLA, JSA, HB, CTB	Address withheld	Edinburgh
Anthony	M	46	Physical impairment	Medically retired	ESA (SG), DLA	5	East Renfrewshire
Bill	M	51	Physical impairment	Working	DLA, ILF	3	Edinburgh
Catriona	F	29	Physical impairment	Full-time student	DLA	Address withheld	Glasgow
Dennis	M	35	Physical impairment	Working	DLA, DP	3	Glasgow
Donald	M	64	Physical impairment	Retired	DLA, CTB, Pension Credit	4	Stirling
Fiona	F	28	Physical impairment and mental ill health	Working and part-time student	DLA (had claimed ESA WRAG in the past).	Data unavailable	North Lanarkshire
George	M	50	Learning disability	Out of work	ESA (WRAG), HB	4	Edinburgh
Harry	M	60	Physical impairment	Retired	ESA (SG), DLA	5	Stirling
Hayley	F	32	Learning disability and physical impairment	Out of work	ESA (SG), DLA, HB, CTB	2	Edinburgh

Jayne	F	61	Physical impairment	Working	DLA	4	Argyle and Bute
Lewis	M	46	Physical impairment and mental ill health	Out of work	ESA (likely SG), DLA	1	Glasgow
Liam	M	50	Physical impairment and mental ill health	Out of work	ESA (WRAG), HB, CTB	2	Stirling
Michael	M	41	Learning disability and physical impairment	Out of work	DLA, HB, SDA	2	Edinburgh
Pat	M	67	Physical impairment	Retired	DLA, ILF, DP	1	East Dunbartonshire
Peter	M	50	Sensory and physical impairment	Out of work	ESA (SG), DLA, HB, CTB	4	Glasgow
Ross	M	60	Physical impairment	Retired	DLA, DP	Address withheld	Glasgow
Sheila	F	62	Physical impairment and mental ill health	Retired	DLA, ILF, DP	2	East Renfrewshire
Sophie	F	47	Physical impairment	Working part-time	DLA, IS, SDA, CTB, HB, DP	3	Edinburgh
Susan	F	62	Physical impairment	Retired	DLA, DP	5	Glasgow

Thomas	Gender Queer	33	Physical impairment and mental ill health	Part-time student	DLA	5	Edinburgh
Vanessa	F	32	Physical impairment	Working	DLA, ILF, DP	3	Glasgow

* Based on SIMD (Scottish Government 2012). No data available for postcodes newer than 2012.

Key: Benefits/Payments received

CTB – Council Tax Benefit

DP – Community Care Direct Payment or SDS Option 1.

DLA – Disability Living Allowance

ESA (SG) – Employment Support Allowance in the support group

ESA (WRAG) – Employment Support Allowance in the Work Related Activity Group

HB – Housing Benefit

ILF – Independent Living Fund

IS – Income Support (to be abolished under Universal Credit)

SDA – Severe Disablement Allowance, additional payment under IS (to be abolished under Universal Credit)

Participants were aged between 28 and 67 at the time of interview, and included nine women, twelve men, and one person who identified as gender queer. In the first couple of months of recruitment activity the study received particular interest from men aged between 40 and 65. This might have been because this was a demographic that were involved in activist groups or had a history of participation in the disability movement (see discussion of recruitment in section 4.5.2) and were therefore more likely to want to take part in the study. This also meant that these individuals were more likely to be well informed about the changes taking place, while also having better access to support networks to enable them to manage the changes. Once this became apparent, particular effort was made to recruit women and younger disabled people in order to ensure that the sample was broadly reflective of the population of disabled people in Scotland (Lewis & Ritchie 2003). The final sample was skewed slightly in favour of men. This may also be reflective of the gendered nature of 'managing' on benefits which may have meant that many women were too involved with processes involved in 'getting by' on benefits to take part in research (Kempson et al. 1994; Lister 2003; see also discussion in section 3.3.2.2). Nevertheless this meant that the final sample was not completely gender balanced, which may have implications for some of the findings. The inclusion of more women may have enabled some of the gendered experience of the reforms (Lister & Bennett 2010) to be more strongly represented in this study. The final sample was evenly split between those with an activist background and those who had never been involved in disability activism.

The Scottish Index of Multiple Deprivation (SIMD) provides a measure of relative deprivation based on the postcode area that an individual lives in (Scottish Government 2012). This is not an individual measure of deprivation, but rather an area-based one. Table 4.1 gives information on the SIMD quintile based on each participant's postcode. This is based on SIMD data for 2012, the date closest to the commencement of interviews for this study. Those in quintile 1 live within the 20% most deprived postcode areas in Scotland, while those in quintile 5 live in the 20% least deprived postcode areas in Scotland. Participants in this study were distributed across the SIMD quintiles, though there were slightly more living in the 20% least deprived postcodes (N=4), than in the 20% most deprived (N=2). Three participants

did not disclose their addresses and interviews were carried out away from their homes so this data was not available for them. One participant lived in a very new build property and therefore her postcode did not feature in the 2012 data for SIMD. As discussed in section 1.4 the most deprived areas in Scotland had the highest rates of reported disability according to the 2011 census (Scottish Government 2014a). Individuals in these areas may therefore be expected to be most likely to be impacted by the reforms. As a result their lower representation within this study may mean some of the experience of those in the highest areas of deprivation in Scotland were not included in this study. However, it should be emphasised that while SIMD gives an indication of the level of deprivation within that postcode, it is not an individual measure, and therefore not reflective of the relative deprivation experienced by participants themselves. As a result individuals could be experiencing deprivation, while living in an area with relatively low deprivation, and vice versa. The most significant difference between participants' experience of the reforms and their experience of financial hardship was related to their employment history, rather than their relative experience of deprivation. This is discussed in more detail in 5.2.2 below.

Participants came from a range of different social backgrounds, but all self-identified as white. Ethnic minorities make up only 4% of the Scottish population (Scottish Government 2015b), although disabled people from ethnic minority communities are known to face additional barriers, including higher rates of poverty and a differential experience of discrimination (Scottish Parliament 2016). These barriers to inclusion may have made it harder for individuals from ethnic minority groups to take part in this study. This was unfortunate, as their inclusion may have highlighted something different in the experience of welfare reform.

Recruitment was restricted to the central belt of Scotland. This is partly because this is the area of Scotland with the greatest population density, but also from a practical perspective ensured that participants were all within driving distance from my home in Stirling. Discussion of the evolution of social care in Chapters 2 and 3 has highlighted that disabled people face a 'postcode lottery' of provision with different local authorities varying considerably in the support available. It was therefore important to attempt to capture some of this diversity in the sample. Eight different

local authorities were represented within the sample, though the majority of participants came from either Glasgow or Edinburgh (again, the largest cities within the central belt). The majority of participants also resided in urban settings, with only two participants living in semi-rural areas.

Interviewees were asked to describe their impairment (see section 1.3 for a discussion of how this term is defined and used in this study) in their own words. Participants with experience of physical impairment made up the majority of the sample. However, a number also experienced mental ill health, in particular depression, in addition to their primary physical impairment. The experiences of those with mental health problems only, those with sensory impairment and those with learning disabilities are not well represented in this study. Individuals with experience of these impairments, especially, those with learning disabilities may face particular challenges in negotiating the increasingly complex system that was being introduced. Their underrepresentation in this study has meant that it has not been possible to fully draw out some of these experiences. Again, this is reflective of the mode of conducting research through interviewing, which will have excluded some people with sensory or communication impairments. Steps were taken in the recruitment to ensure that the interviewing process was as accessible as possible. I worked with a number of impairment-specific organizations who would have been able to provide materials in alternative formats, or interpreters should this have been required. Participants were also informed that they could have a PA or advocate present if they wished, and several did so. One participant was concerned that I might have difficulty understanding him on the tape without having non-verbal cues to fall back on. It was agreed that I would share my transcript with him early on, highlighting any areas that I had difficulty interpreting. In the event, my queries were minimal. Despite efforts to recruit from a range of different impairment types table 4.1 highlights that the experience of physical impairment remained dominant within the sample. A greater diversity of primary impairments may have enabled more detailed comparison between the experiences of those with physical and other forms of impairment which may have been affected differentially through the reforms.

Those taking part in this study made use of a range of different benefits to support them in their daily lives and often received more than one, reflecting the ad hoc

development of disability policies discussed in Chapter 2. The main benefits used were ESA/IB, DLA, and ILF. Just over half (N=12) received a community care package from their local authority, including DP or SDS. The majority of participants claiming ESA were in the support group (N=8), and only three were in the WRAG and therefore subject to conditionality. Seven of the eight on ESA had transferred from the former IB, while only one had started claiming ESA directly. Three participants had claimed IB prior to retirement, and had not been affected by the move to ESA. One participant had received ESA in the past, but had since found employment. None of the participants in receipt of ESA in the WRAG had received a sanction. Given the prominence of conditionality and sanctions in the literature on reform (see sections 2.5.2 and 3.3), not to mention the centrality of this matter to the research questions, this would have been an interesting and important perspective to have been able to include in the research. I discussed this with the organizations that were assisting me with recruiting, and attempted to find more participants meeting this description, but no one came forward. This may have been because people experiencing sanctions were under greater pressure and therefore had less time to take part in research. It is also likely that individuals who had experience of being sanctioned may have been more nervous about participating in case their involvement had negative consequences for them (see section 6.4 for a discussion of this). Nevertheless it is important to acknowledge that this is a notable limitation to this work. Seven participants received Housing Benefit and six participants received Council Tax Benefit, though only one participant had been negatively affected by changes to Housing Benefit (see 5.2.1). Again, changes to Council Tax Benefit and Housing Benefit during this period would have impacted on disabled people, and the inclusion of more individuals in receipt of these benefits may have revealed more about the experience of these changes for disabled people. It may also have enabled the exploration of the extent to which these benefits were able to provide some financial cushion against losses elsewhere.

Interviewees also had a range of different employment backgrounds and experiences. Again, the balance between in work, out of work, and retired may be reflective of the sampling and interview strategy. Interviews all took place during the daytime, and while they were arranged at times that were most convenient for the participants, those who were in work all had flexible working arrangements that

enabled them to meet me during the day. While I would have been happy to meet outside working hours, someone working in insecure, temporary, or casual employment would have found it much harder to take part, and may have been deterred from coming forward as a result.

4.5.2 Recruitment strategy

Recruitment of participants was initially conducted via Scottish-based disabled people's organizations² (DPOs), building on pre-existing relationships I had with members of the disabled people's movement in Scotland. Using gatekeepers to access communities of interest can help to establish trust between researchers and prospective participants (Emmel et al. 2007). This is particularly important when working on sensitive topics, and given the climate of fear that surrounded welfare reform at the time that this study commenced (see section 3.5). Several of the organizations involved knew me prior to commencing the research project and were therefore able to feel secure in my motives as a researcher. Recruiting in this way also signalled to prospective participants that I had appropriate credentials to conduct the research fairly and ethically.

Furthermore, working with DPOs ensured that participants were drawn from organizations led by disabled people themselves. Unlike charities for disabled people, DPOs are political organizations, which are part of the wider disabled people's movement. Their involvement lends legitimacy to the research by grounding it in the perspectives of members of the political movement (Stone & Priestley 1996; Oliver 1992). A drawback to working with gatekeepers can be that they may exert undue pressure on participants to take part in research, or to present a particular organizational perspective (Miller & Bell 2012). This is particularly so where

² DPOs are organizations led by and for disabled people. They are usually staffed by disabled people and crucially have disabled people in charge of strategic leadership. This contrasts with charities working for disabled people. These typically emerged out of philanthropic responses to disability (see Chapter 2). Today many charities have disabled people represented on their trustee boards. The measure of a DPO is therefore the extent to which disabled people are involved in shaping the organization at every level.

organizations hold positions of power or influence over their members. The democratic, user-led nature of the organizations involved in this study helped to militate against coercion.

DPOs by their nature are political organizations and it is acknowledged that at the time that fieldwork took place the disabled people's movement in the UK was engaged in a campaign to overturn the changes being examined in this study. Participants recruited in this way therefore had particular reasons for taking part in the research. This is not to argue that what they shared with me was any less truthful or legitimate an account of their personal experiences. Those who were not members of DPOs were just as likely to be affected by the changes taking place. Nevertheless, individuals recruited from DPOs were likely to have a particular perspective on them. This was balanced in the research by the inclusion of interviewees recruited through charities for disabled people, and others who had no involvement with the political activity of the disabled people's movement. The final sample was evenly split between these two groups.

Organizations were contacted initially by email informing them about the project and asking that they circulate a small advert via the organization's membership mailing lists (see Appendix V). Some organizations also identified individual members who they thought might be willing to take part and put me in touch with them directly. Some way into the recruitment process I discovered that the email address I provided on the advert was incorrect. I therefore re-contacted the organizations advising them of the error and requesting that the correct details be sent out. It is possible that some volunteers may have been missed as a result of this error because they did not receive the updated contact details, or were put off by my lack of response to their first contact. Organizations who assisted with recruitment included:

- Inclusion Scotland (DPO)
- Independent Living in Scotland Project (DPO)
- People First (DPO)
- Self-Directed Support Scotland (DPO)

- National Union of Students Scotland Disabled Students Committee
- STUC Disabled Members Committee
- Scottish Independent Advocacy Alliance (DPO)
- Glasgow Centre for Inclusive Living (DPO)
- Glasgow Disability Alliance (DPO)
- Lothian Centre for Independent Living (DPO)
- Health and Social Care Alliance (The Alliance) Scotland
- RNIB Scotland
- Enable Scotland

Working with gatekeepers brings obvious benefits for researchers, but there is a concern that it may be less beneficial for the organizations involved (Patrick 2012). In recognition of this imbalance I offered my assistance to the organizations in return for their help with finding people to take part in the study. Only one organization took me up on this offer, and asked me to attend a consultation event with their members to minute discussion that took place at the event. I was also invited to deliver a presentation on my research to two other organizations. Four research participants were recruited as a result of this direct engagement.

A further drawback to working with gatekeeping organizations is that those not associated with the organization are necessarily excluded from the study (Patrick 2012). The use of social media as a recruiting tool was adopted in an attempt to overcome this limitation. Social media has formed an important focus for activism around welfare reform as discussed in sections 3.5.2 and 4.4, and was therefore viewed as a possible means of recruiting those involved in the disability movement in new and more informal ways. However, in the event, participants contacted through this medium formed only a very small part of the sample.

Social media activity focused on Twitter and Facebook as sites used regularly by emerging anti-cuts activist groups (Pearson & Trevisan 2015). Only one participant responded to a general request via Twitter. Nevertheless, Twitter did prove to be a useful way of making contact with gatekeepers, and a number of organizations responded to my Tweets by requesting more information about the study. Facebook

proved to be similarly challenging. I joined online activist groups and posted information about the study in these groups, but only one participant was recruited this way. The difficulties encountered in recruiting online may be reflective of the sensitivity and stigma around claiming of disability benefits (see section 3.5). Equally, my social media privacy settings (discussed in section 4.4) may have prevented individuals from contacting me directly.

Personal contacts and friendships with disabled people who used the benefits considered in this study also assisted the sampling strategy. Recruitment of participants was a snowballing process that continued throughout the fieldwork stage. All participants were asked at the end of their interviews if they knew of anyone who might be interested in taking part. While there was genuine interest in the project and a willingness to take part, continual work was needed to achieve the sample. Welfare reform was a topical issue at the time that fieldwork took place, so it is perhaps unsurprising that people were keen to share their views and experiences, despite concerns discussed above. However, it was interesting that, with the exception of two organizations that recruited four and three participants respectively on my behalf, no single approach resulted in more than one or two participants coming forward. This led to a diverse range of perspectives and views being captured in this research.

The ideal number of participants is a matter of some debate among qualitative researchers (Baker & Edwards 2012). Unlike quantitative research, probability sampling is not an appropriate means of establishing a sample size as the goals of enquiry are quite different (Ritchie et al. 2003a; and see discussion in section 4.3). As a result, qualitative samples tend to be smaller than quantitative ones. This is partly a case of practicality in the high-yield data derived in particular from interviewing (ibid). Nevertheless, it is also important that sample sizes are not so small as to prevent meaningful comparison between different cases (Mason 2002). The concept of 'saturation' is much rehearsed in these debates (Baker & Edwards 2012): that recruitment should cease once data collection has reached diminishing returns and little new evidence is forthcoming (Ritchie et al. 2003a). The decision on when to terminate recruitment in this study was largely informed by this idea. Recruitment stopped once I felt that the issues discussed by participants were

familiar enough to give me a sufficient picture of the main experiences relating to my three research questions, within the time constraints that I faced.

4.5.3 Interviewing

Once participants had agreed to take part in the study they were interviewed at a time and place of their own choosing. The majority preferred to meet in their own homes, although a small number (n=5) took place at the organization they were recruited through. Interviews lasted between forty minutes and two and a half hours, with an average length of around one hour.

Interviews were conducted using one-to-one, semi-structured, depth interview techniques. Discussion centred around a topic guide providing broad questions and prompts (see Appendix I). This was treated as a live document and was adapted and changed as the research developed in order to explore emergent themes. Questions in the topic guide were framed as general areas of enquiry rather than as direct questions to participants. This prevented them from becoming repetitive over time, and enabled me to adapt the question to the particular research participant (Morton-Williams 1985). I also referred less to the topic guide as I became more familiar with it.

Discussion began with a general introductory question, and participants were asked to tell me something about themselves, before moving to more specific issues concerning the support they received in their everyday life, and any changes they had experienced in their support arrangements. Questions were kept intentionally open ended to enable interviewees to interpret them in their own way, and to highlight things that were most meaningful to them (Jones 1985a). Participants were also given time and space to consider their answers, and to develop tangents, before being guided back to the topic.

Interviews were recorded using a digital voice recorder and I also took notes to assist with prompts, and to aid reflections and analysis at a later stage. One participant requested that the interview not be recorded and instead I took a detailed

note of our conversation. I also took time immediately after the interview to supplement these notes with my own reflections on the process and what she had said. I kept a detailed fieldwork diary throughout this phase of research, which I completed as soon as possible after leaving the participant to ensure that my reactions and responses were kept fresh. This acted as an *aide memoire* during the analysis phase and helped to develop themes for coding (see below), but was not treated as data as such (Mason 2002).

I worked hard to build a rapport with participants, and to earn their trust throughout the interaction. The decision on how much of myself to give to the research relationship is was a difficult one, and has been much discussed in the literature on qualitative research. Feminist researchers have criticized the structured interview process for maintaining distance between the participant and researcher (Fontana & Frey 2005). Instead, they have encouraged researchers to become part of the research relationship, and to make creative use of bias in the interview process (Ramazogulou 2003). At the same time, it is necessary for the researcher to be cautious about how much of their own opinions they share as this may discourage interviewees from sharing conflicting views; or equally may encourage them to say what the researcher wants to hear (Jones 1985a). In the context of researching disability, the extent to which to espouse a political affiliation with the social model and the disabled people's movement is also an important consideration. On the one hand this may reassure some, but equally, too strict an adherence to the political ideals of the social model may alienate participants who do not share the same perspective. I tried to develop a friendly and non-judgemental tone in interviews to encourage participants to share their views, and responded with empathy, but did not share my opinions unless they were directly sought.

Whilst identifying as a disabled researcher I also took the decision not to disclose this to participants unless specifically asked. Disclosing a shared identity when discussing a sensitive topic is a tricky step to take, as this can be equally beneficial or damaging in a depth interview (Lee 1993). Though my identity as a disabled person is an important part of my political orientation and my motivation for this research, as discussed above, I did not use disability benefits and therefore had a very different experience as a disabled person to the participants involved in this

study. I was also conscious of power differentials in some of the interviews (Barnes 1992). This was not something that I had any control over (Fontana & Frey 2005), but it was important to me not to come over as patronizing by disclosing my identity as a disabled person. Disabled people do not have a single unifying experience, but a plurality of experiences (Shakespeare 1996). While a shared identity may build rapport and elicit greater trust in the relationship between a researcher and a participant, a stranger might equally provide the safety of being located outside a particular community (Lee 1993). This is a balancing act for any researcher, and I decided that the role of empathetic stranger was the most comfortable approach to take.

4.6 Analysis

The process of analysing and interpreting qualitative data is a complex and highly personal process (Jones 1985b). While strategies abound in the literature (Jones 1985b; Morton-Williams 1985; Richards & Richards 1994; Ritchie & Spencer 1994; Bryman 2004), each researcher will develop their own style and approach. This section will outline the approach taken to analysis of data collected in this project.

The role of the researcher in conducting qualitative analysis is a controversial one and has been a matter of some debate within disability studies, particularly where disabled people have not been directly involved in conducting the analysis (Barnes 1992; Shakespeare 1996; see also section 4.3.1). Tensions can arise between activists and researcher, especially when their aims in the research end up differing (Fontanna & Frey 2005). Inevitably, the researcher ends up imposing something of their own worldview on the data, however hard they attempt to avoid this (Jones 1985b, Shakespeare 1996). A participatory or collaborative approach to research design, data collection, and analysis can help to overcome these challenges, ensuring that the participants are involved at every stage of the research project (Reason & Bradbury 2001). However, challenges of time, geography, and resource made that difficult for this particular project. The aim was to capture experiences from people living across the central belt of Scotland, taking into account a breadth of different characteristics including impairment, employment status, and benefits

used. This resulted in a somewhat heterogeneous group of participants. Participatory methods demand significant time commitment on behalf of those involved in generating the research, and given the often challenging circumstances many of the participants faced, this was not a demand I felt able to make of them. It was important, therefore, in deciding not to involve participants in the analysis stage that my approach to the analysis of data should give consideration to approaches that ensured that the voice of participants was retained as much as possible.

4.6.1 Analysis Phase 1: familiarization, developing themes, and coding the data

The process of qualitative data analysis been traditionally viewed as un-transparent, leading to assumptions that the method lacks rigour (Spencer et al. 2003). However, in recent years there has been a proliferation of guides to conducting qualitative analysis (Bryman & Burges 1994; Mason 2002; Ritchie & Lewis 2003). Spencer et al. (2003) identify a threefold process of analysis, involving 'data management', the development of 'descriptive accounts', and then finally, the development of 'explanatory accounts'. Similarly, Mason (2003, p. 148) has encouraged qualitative analysts to read their data 'literally, interpretatively, and reflexively'. Importantly, qualitative analysis should be viewed as an iterative and indeed continuous process that may commence with the initial data collection, before progressing through the coding and organizing of data, through to writing and presenting findings (Spencer et al. 2003). This was no less so for this study. The approach taken to analysis, as outlined below, drew on elements of the 'framework approach for applied policy research' (Ritchie and Spencer 1994; Spencer et al. 2003).

While an early phase of analysis involved reflecting on interviews and emerging themes through field notes, analysis for this project formally commenced following the collection of data. This was largely due to time pressures and other demands which meant that it was not possible to transcribe all interviews immediately after they had taken place, rather than an explicit decision to treat analysis as a separate phase. The first phase of analysis involved familiarizing myself with the totality of the data I had collected (Spencer et al. 2003). Transcribing interviews myself, rather than contracting this out, was a distinct advantage in this regard. I made regular

notes reflecting on how participants had described their experiences on tape as I transcribed. I also noted down themes that occurred in the data on a separate document using bullet points to develop a rough hierarchy (see Appendix VI). Initially these were largely descriptive of the generality of participant's experiences. Topics covered experiences of particular benefits or 'anxiety over expected reform'. Though I took the decision not to include my fieldwork diaries as formal data (Mason 2002), making reference to these as I transcribed helped to trigger recollections about the interviews and assisting my emersion in the data. Again, transcribing some time after the interviews had been conducted had the advantage of allowing me to reflect on them at some distance, and this reflection enabled me to pull out overarching themes.

Once the transcripts had been completed and verified by participants, I carefully read through them all, helping me to draw out further thoughts and themes. Again, these were largely descriptive, although emergent themes such as 'disability hate crime' and 'relationships with PAs' that would later form the basis for more explanatory accounts (Spencer et al. 2003) began to appear. Finally, a two-page narrative account was developed for each participant, giving an overview of the key issues that had been discussed in that interview. The application of themes to raw data is necessary to imposing order on the rich and varied material that is generated through qualitative researching (Spencer et al. 2003). However, a downside of this approach can be that data become fragmented and divorced from their original context (Richards & Richards 1994). These narrative accounts therefore helped me to keep each participant's 'story' in mind as coding and fragmentation of the data took place.

Once fully immersed in the data I drew together my notes and emergent themes document into a more structured coding matrix (Appendix VII). Themes were grouped under similar headings and connections made between different concepts and ideas. These included the descriptive *a priori* themes discussed above, but also reflected ideas that had emerged through the research process (Ritchie & Spencer 1994). For example, the experience of financial constraint was an *a priori* theme, although the treatment of different forms of income as 'special money' was a pattern that emerged through familiarity with the data.

The application of codes to the data was conducted using NVivo software for qualitative data analysis. Codes were applied to all transcripts in a systematic way ensuring that all of the data was fully interrogated and explored for meaning (Spencer et al. 2003). As with all methods of analysis, using computers to interrogate qualitative data comes with both advantages and drawbacks. Technology can restrict creativity as the researcher is constrained by the limits of the software's functionality (Richards & Richards 1994). This can also undermine analysis if coding is started before the researcher is properly familiar with the data (ibid). On the other hand, computer software can assist researchers in getting a sense of how widely experienced a particular phenomenon is, though the depth of feeling about a particular issue is also important to capture (Spencer et al. 2003). Crucially, the use of software significantly reduces the administrative burden of fragmenting and organizing large amounts of textual data (Richards & Richards 1994). NVivo is widely used by social science researchers and many institutions offer training in how to use it. I attended two NVivo training courses before starting work on coding. I also made use of online tutorials to familiarize myself with the software and its uses. These tutorials focused on functionality: how to input and organize data, create codes, and carry out simple queries. Courses did not cover creative ways of thinking about data and developing ideas, and this was something I felt was an important gap in the training made available to doctoral researchers.

4.6.2 Analysis Phase 2: developing descriptive and explanatory accounts and presenting findings

Once coding had been completed the next phase of analysis involved carefully reading through the assembled 'chunks' of data under each thematic heading in NVivo, before developing descriptive accounts of the main issues occurring under each theme. While Ritchie and Spencer (1994) recommend the development of charts to aid this process, I found that descriptive writing which grouped some of the main themes together under broad headings such as 'applying for benefits', 'experiencing financial constraint', and 'independent living' better enabled me to understand and explore the data under each theme. In addition to summarizing

participant's experiences under these main headings, I began to collate quotes that supported these ideas, as well as to highlight divergent cases. These descriptive accounts formed the basis of draft findings chapters.

Subsequent drafts sought to synthesize ideas and relate these more closely to existing theory in order to develop more explanatory accounts (Spencer et al. 2003). However, this was very much an iterative process, involving drafting and redrafting material and reclassifying themes. A challenge that I encountered in the transition from descriptive to interpretative exploration of the data (Mason 2002) was the need to balance concise and analytical accounts of trends with being able to capture the depth and complexity of participants' experiences (Ritchie et al. 2003b). Ritchie et al. (2003b) argue that the use of quotations should help to exhibit the diversity of cases that exist within the data. However, the use of verbatim quotations tends to privilege the voices of those who are most articulate. Interviews are discursive interplays between researcher and participant, and important issues may arise over the course of several pages of discussion, which cannot be easily summarized in a short quotation. However, this can result in the voices of less eloquent participants becoming hidden, reducing the diversity of cases that can be presented. Returning to the narrative accounts that were developed at the start of the analysis enabled me to develop illustrative case studies which provided additional background and context to the discussion of issues that were particularly deeply felt by some participants. This approach also ensured that the voices and experiences of all participants were given equal weight whether through direct quotation or narrative case study.

A further challenge that was encountered in the analysis of data related to my closeness to the data. I had built a strong rapport with many of the participants, and as I have discussed had invested considerable time in familiarizing myself with the data. While an intimate knowledge of the data is important ingredient of qualitative analysis (Ritchie & Spencer 1994), overfamiliarity can lead to the analyst becoming 'bogged down' (Spencer et al. 2003), which can reduce the potential for analytical insight. This project therefore benefitted from an enforced break of six months following the birth of my first child. This enabled me to return to my findings with fresh eyes, and a refocused analytical lens, which I hope has helped to deepen the analysis presented in the next three chapters.

On my return from maternity leave, a final stage of analysis involved re-engaging with existing literature in order to develop concepts and ideas that emerged through the data, and to make connections with unexplored fields. An interesting example of this related to the concept of 'hidden conditionality' that is discussed in section 6.3. Exploring this as a form of 'surveillance' enabled connections to be made with different forms of surveillance, including 'self-surveillance'. This in turn led to connections with literature connecting the concept of agency in conditionality policy with Young's (2003) concept of 'vindictiveness'. This allowed me to bring together my analysis of the diverse experiences of stigma and shaming with bullying and harassment as different expressions of the phenomena of vindictiveness in the context of benefit stigma.

Taking a break from analysis also assisted with a further challenge which I had faced throughout this project, which was the fast pace of change in this area. The project had commenced only two years into the Coalition's term of office, during which time they had made a number of policy announcements. As discussed in section 3.5, this had contributed to a sense that disabled people were facing a period of considerable change and uncertainty. However, by the 2015 General Election, it was clear that many of the reforms that had been proposed at the start of the period would not come into effect. The six-month break between October 2015 and April 2016 allowed me to view the reforms I was examining as having taken place during a discrete period of time, and I was able to refine the scope of my enquiry and thereby to exclude issues that had initially appeared relevant, but which had not come to pass.

4.7 Summary

This chapter has provided an overview of the research methods employed in this study. It began by outlining three research questions that emerged from the review of literature presented in Chapters 2 and 3. It then explored some of the key epistemological debates within disability studies, before situating myself in relation to these. Section 4.4 highlighted some of the ethical challenges faced in conducting the research, as well as the way in which I sought to reflect on and resolve these. The

remaining sections provided a detailed overview of the methods of recruiting and interviewing participants as well as the approach taken to analysis of the resultant data.

The next three chapters are organized by research question, and outline findings in relation to each of these. Chapter 5 examines the way in which participants in this study exhibited different forms of agency in relation to using benefits and their orientation to the labour market. The impacts of the coalition's conditionality policies are also explored. Chapter 6 considers participants' experiences of negotiating the redrawn disability category, and in particular the increased focus on medical testing that has enabled this. The creation of a moral narrative around who is and is not deserving of state support has been a key feature of the Coalition's welfare reform agenda. Chapter 6 therefore also explores some of the impacts of this discursive trend. Finally, Chapter 7 presents findings that relate to the impacts of policies which have been framed in the language of the disabled people's movement in order to interrogate the extent to which they have enhanced disabled peoples citizenship status. Chapter 8 concludes by discussing the way in which these findings have made a unique contribution to knowledge as well as outlining recommendations for future policy.

Chapter 5 Disability, agency and conditionality

5.1 Introduction

Policies promoting a conditional approach to the receipt of benefits are based on certain assumptions about recipient's agency. To what extent are these assumptions reflective of individual disabled people's attitudes to benefits and the labour market? In what ways have disabled people been affected by the intensification of conditionality?

Discussion in section 3.3.2 highlights that theories underpinning the reform of benefits since the 1970s have been based on a particular conception of agency. While social-democratic approaches in the post-war period tended to focus on structural explanations for the experience of poverty and unemployment (Wright 2012), theories emanating from the New Right have focused instead on individual behavioural explanations (Dwyer 2010). Discussion in Chapter 3 contrasted this with debates that have emphasized a more pluralistic understanding of individual agency (Hoggett 2001, Lister 2004). This chapter explores the exercise of different forms of agency by participants involved in this study, in light of these debates. In doing so, it draws on Lister's (2004) taxonomy of agency: 'getting by', 'getting (back) at', 'getting out' and 'getting organized' (see Figure 3.1, section 3.3.2.2). The chapter begins by exploring the ways in which participants used and 'managed' the benefits they received. It finds that they were able to exhibit considerable agency in this regard, expending their payments in order to meet their own particular needs. However, the climate of austerity was causing some participants to constrain their expenditure in order to prepare for anticipated reductions in their benefit incomes.

The second section of this chapter explores the expression of agency in 'getting out' of the benefits system and into paid work. Participants had a range of labour market experiences, with the vast majority having worked at some point in their lives. They also expressed overwhelmingly positive views around working, as well as contributing to society through volunteering. This section also explores participant's experiences of conditionality policy and the support received through the Work Programme.

The third section of this chapter explores the expression of agency in relation to 'getting active' in response to welfare reform. A small number of participants had been involved in the disabled people's movement prior to the reforms taking place, while others had become involved in activism as a result of the changes they were facing. However, a significant proportion felt that activism was unlikely to bring about changes they hoped to see. This theme is expanded in the final section of this chapter, which considers the exercise of agency involved in 'getting (back) at' the benefit system. Lister's (2004) account of this highlights forms of agency expressed through engaging in the informal economy or misusing or miss-claiming benefits. This was not generally evident among those involved in this study. Instead, participants demonstrated an acute sense of powerlessness in the face of the reforms they were facing.

The chapter concludes by emphasizing the range of different forms of agency expressed by people in receipt of disability benefits. These findings add weight to work by Hogget (2001) and Wright (2012) that argue that the narrow framing of conditionality policy around correcting negative agency provides a very two-dimensional perspective, which runs the risk of undermining many and varied ways in which people act. Nevertheless, participants' experiences of powerlessness in the face of the scale of change taking place also serves as an important reminder of the continuing importance of structure in shaping and influencing the exercise of individual agency.

As mentioned in section 4.6.2, the discussion below and in the next two chapters is supported by reference to direct quotations from interview transcripts. Case study boxes are also included to provide a fuller narrative account of a participant's experience in relation to certain key findings.

5.2 'Getting by': using disability benefits creatively to meet needs

Agency exhibited as 'getting by' is perhaps the most widely recognized in relation to the experiences of individuals living in poverty (see section 3.3.2.2). This section

reports findings which reflect the ways in which participants expressed agency in the ways in which they managed their benefit incomes. It begins by exploring how payments such as DLA were used in order to meet the individuals' particular needs and requirements. The flexibility to use benefits in this way was highly valued by participants, although the growing uncertainty over the Coalition's welfare reform agenda was making this harder to achieve. Those involved in this study were increasingly adapting their spending patterns in order to adjust to or prepare for anticipated financial losses as a result of the proposed reforms.

5.2.1. Benefits as 'special money': using DLA creatively to meet additional costs

In examining the ways in which individuals made use of the benefits they received, an interesting distinction emerged between those who used their benefits purely as income (ten), and those who kept them separate from income to pay for particular things relating to disability or impairment (ten). Three participants did not explicitly distinguish between benefits and other sources of income, although when probed were able to point to particular things that they would use their benefits to pay for. This differential treatment echoes Zelizer's (1989, p. 342) concept of 'special monies' discussed in section 3.3.2.2, and was particularly evident in the way in which some of those in receipt of DLA safeguarded this income in order to meet additional costs they faced. The distinction between income and 'special' use was largely reflective of the divide between participants who were working or who had other sources of income (e.g. pensions), and those who were out of work. The majority of those who used benefits to cover everyday living costs were not working at the time of interview, and were claiming ESA as an income replacement benefit (Burchardt 1999). Those who were in work or were in receipt of occupational pensions, therefore, found it easier to make and maintain a distinction between benefits and general income.

DLA was most commonly used to cover additional costs of transport, with two-thirds of participants citing this as the main use for their DLA. Inaccessible public transport in certain areas made it hard for people to get around, so having access to funds to cover the additional costs of private transport was vital to enable them to live

independently. The majority of participants (17 out of 21) used the Motability scheme, which enabled those in receipt of the High Rate of DLA to lease a car for a period of three years, and to pay for appropriate adaptations to the vehicle (see section 3.2.2). However, making use of the scheme required sacrifice of the mobility component of DLA, which was deducted at source in order to cover the costs of the lease and the adaptations. This made it easier for participants to make a distinction between using their benefit for additional costs versus everyday living costs. However, it also reduced the flexibility that they felt the benefit enabled them to exercise over how they used the funds:

A lot of people think that because you've got a mobility allowance you've got money to get around. In actual fact if you bought a car with your mobility allowance, you've spent it. You've still got to run the car, you've still got to put petrol in it. (Vanessa, 32)

...

I don't use the mobility scheme or anything, I always steered away from that kind of thing, because it ties up your whole mobility allowance, it always suited me better to have my own car. (Susan, 62)

Like Susan in the quote above, three participants had decided to pay for their own vehicles and adaptations to preserve that flexibility, while a further participant had started using Motability, but later missed the flexibility she had previously enjoyed over how to use her DLA. Three participants were unable to drive so used the mobility component of their DLA to pay for taxis.

Covering the costs of personal assistance or other forms of care and support was another significant use for DLA. Seventeen out of 21 participants who used DLA received the care component. Twelve also received support from their local authority in the form of a social care package. Five participants had been affected by community care charges (see sections 3.4.1 and 7.4.2.2 for a discussion of this) and were using their DLA to cover these fees. This served to further reduce the flexibility they had over how they used their funds. Nevertheless, participants were able to use

uncommitted DLA funds in a range of other ways to cover additional costs. One participant used his DLA care component to pay for a PA to accompany him on holiday each year:

I used to go completely on my own, and hire an agency over there. But I just got to the stage where I just preferred to take one of my support workers with me.
(Bill, 51)

The flexibility to use his funds in this way was greatly valued by Bill because it meant that he did not have to spend his holiday training someone new, but could instead enjoy a proper break. Other uses for uncommitted DLA funds were wide and varied, reflecting the diversity of additional costs that many disabled people face:

I can't hang out clothes without a great deal of difficulty, because I can't reach my arms up that high, so I use a tumble drier. So, you could say that you know, some of that DLA cost goes to fund my tumble drier. (Jayne, 61)

The different uses for the funding were often quite personal, enabling the individual to determine their own needs and how best to meet them. Three participants had fluctuating conditions, which caused them to experience sudden bouts of fatigue. They used their DLA to cover the additional costs of premium foods or takeaways to ensure that they ate properly when they were too tired to cook from scratch. Another participant used her DLA to cover the cost of visits to a private physiotherapist because the treatment she needed was not available on the NHS. Three participants were using their DLA to pay towards the cost of a new wheelchair, which is a significant financial investment but one vital to ensuring their independence.

While the flexibility afforded by DLA was highly valued by participants, the context of austerity and disability benefit reforms was starting to have an impact on the extent to which participants were able to maintain the separation of DLA from other income. This was particularly the case where participants had limited financial resources to

begin with. As a result, DLA was increasingly being used as a supplement to everyday living costs:

My DLA's used for what it's supposed to be, part of it is I use a lot of taxis [...] but then a lot of my DLA is used up because of the size of house I have, bills and heating. (Lewis, 46)

Lewis was living alone in a four-bed adapted property and had had his housing benefit cut by around £100 per month because he was found to be under-occupying his property³ (see section 3.5.3). Lewis was out of work and his only income was from DLA and ESA at around £591.80 per month. Unsurprisingly, the cut to his housing benefit was taking up a significant proportion of his income. Lewis had tried to move but had struggled to find suitable accommodation elsewhere. As a result, he was using his DLA to subsidize his 'bedroom tax' payments and every-day living costs.

The challenge of meeting everyday living costs was particularly hard for those who were not in work and in receipt of ESA. These participants were struggling financially, and were regularly using their DLA to cover the costs of basic household necessities:

We usually put my money and [my wife's] money together and we split it. Then we pay all the bills, then we've got [wife's] DLA [and] some of that goes on bills. (Michael, 41)

The experiences highlighted here contrast with dominant narratives about the passivity of benefit claimants (section 2.5.2). Participants in this study believed that they were using their benefits as intended, and often made a personal distinction between earned income and benefits income treating the latter as 'special monies'.

³ The interview had taken place in early 2014 prior to the Scottish Parliament's decision to mitigate this change across Scotland. Mitigation at the time of interview was therefore at the discretion of the local authority and at that time, Lewis been unsuccessful in applying for relief.

Given the wider discourses around benefit fraud (see section 3.5.1) it was perhaps unsurprising that participants should want to emphasize this. However, it was also evident that they were using benefits flexibly to meet genuine needs, exhibiting considerable positive agency in the process. Nevertheless, they were also finding it increasingly difficult to cover all of the additional costs they faced in their daily lives. This theme is expanded on in the next sub-section, where the context of austerity and welfare reform had seen participants increasingly struggle to 'get by' on the benefits they received.

5.2.2 All in it together? Living with the expectation of financial hardship

At the time that interviews for this study were conducted, the UK economy was still recovering from the financial crisis, and facing unprecedented cuts to public services (see section 3.1). Unsurprisingly, given this context, coping with the financial impacts of the reforms emerged as a significant theme. Fifteen out of 23 participants made explicit reference to having experienced some form of financial constraint in the period of reform, or expressed concern over their future financial security. Nearly all had developed some form of coping mechanism to enable them to manage with reduced financial resources, or to anticipate future financial constraints.

Four participants talked about having experienced a decline in the value of their benefits following the change in the inflationary mechanism for uprating benefits (see section 3.5). Two were out of work at the time of their interviews, so the reduction in benefit value was affecting on their entire income. One participant, Jayne (61), was working in the public sector where pay freezes had also seen a decline in the value of her earned income over time:

We haven't actually had a pay rise [...for] was it four years or was it five years? So, [...] having that extra money [from DLA] did make a big difference. (Jayne, 61)

Prior to 2010, the stability in the value of her DLA had acted as a financial cushion for her and her family. However, she was conscious that this, too, was beginning to erode.

A further cause of financial constraint highlighted by participants was the sense that the cost of living was beginning to increase, with household essentials such as utilities and food rising faster than the overall rate of inflation⁴. This echoes research by Plunket et al. (2014), who also found that living standards, as measured by net household income, had fallen by around 5% between 2008 and 2012. Around two-thirds of participants made reference to feeling a squeeze in their living standards, expressing concerns that the money they had was not reaching as far as it had previously done. This was often particularly acute for participants who had previously been in work, but who were now reliant on benefits for a significant proportion of their incomes.

Seven participants had impairments that were affected by moderate changes in temperature. This group was likely to be particularly conscious of changes in utility costs because of the need to keep their homes heated to a constant temperature all year round. Jayne had taken steps to try to make her home more energy efficient in an attempt to make savings:

*You would have thought with all the other measures
we've employed that you should see some reduction.
But it's not happening at all. You know, simply because
of the amount that it's gone up year on year. (Jayne 61)*

⁴ Inflation is measured on the basis of average annual increase in the cost of a basket of goods. However, individual items may rise faster or slower than others, artificially inflating or depressing the overall inflation rate. Since the financial crisis, household essentials have risen faster than other items in the basket, but the average has been pulled down by slower rises in other items such as luxuries. See: <http://www.bankofengland.co.uk/education/Pages/resources/films/whatisinflation.aspx> [accessed on 21.05.15]

Similarly, Lewis had decided he could only afford to heat two rooms in his home. He was aware that this might prove to be a false economy due to the possibility of getting damp in unheated rooms, but felt that he had no other choice.

Four participants had faced difficulties in managing the rising costs of food. Michael volunteered at the local food bank, but also described having relied on food parcels from the same food bank to help him and his wife Hayley to get by. The food bank only permitted three visits in one six-month period, and Michael was aware that they were only entitled to one more visit in that period. They had economized as much as possible on their weekly outgoings, and tried to shop around to look for bargains but found this difficult in their local area:

They [the local store] keep changing what [food] they get in, it's just confusing. You just get used to one [brand] and then they change to another. Then they've put the price of milk up [...] the price of food keeps going up. (Michael 41)

Another participant, Liam (50), had started growing vegetables in his back garden to help him deal with the rising cost of food items.

Other participants talked indirectly about increases in the cost of living, for example having to manage their resources more carefully, or cutting out things that they perceived as unaffordable luxuries. Having to go without an annual holiday abroad was the most frequently mentioned of these economies, with half of the participants who had experienced increases in the cost of living citing this as a household economy they had made. Most of those who mentioned this had previously been in employment and so had been used to being able to afford a holiday abroad. However, one couple cited this who had not had a long history of stable employment. While a holiday abroad may appear to be an obvious and easy expense to forgo, the impact for participants was significant, and appeared to be an important indicator to them of the decline in their living standards.

Awareness of forthcoming and future changes to the benefits system and the imposition of austerity measures by the Coalition Government meant that around a quarter of participants were taking steps to anticipate future financial losses. Most of those actively preparing for change were employed and so had additional sources of income that they were able to fall back on if required. However, two were doing so despite not being in work at the time of interview. One was in full-time education and believed that she had good future job prospects that would provide her with a level of security; the other had recently retired, so again had an additional form of income from his occupational pension.

The vast majority of participants did not have other forms of income to fall back on, making it harder for them to take steps to anticipate losses. One participant also highlighted that financial security from employment can often be precarious for disabled people:

*I'm in a fortunate position to have a reasonable wage.
[But] I suppose for me, the thing that annoys me is
when it costs **me** more than it would cost someone
[else] with my wage. [...] I'm earning a decent wage but
we don't have a lot of spare income. (Vanessa, 32)*

Given the additional expenditures that disabled people face in daily life, unanticipated financial shocks can be harder to absorb, even for those earning a reasonable income.

A further coping mechanism highlighted by participants involved receiving support (either financial or emotional) from friends and family. Around half of the participants mentioned receiving some form of support from friends or family, or having people they could turn to in the event of financial difficulties. While a small proportion felt uneasy about needing to rely on family, particularly for financial aid, most were glad to have this sort of support to fall back on. For those in relationships, the additional support they received from their partner was also a critical coping mechanism (see section 7.4.1.3 for a wider discussion of the role of informal familial care). However, for one participant, Adrian, this was viewed a source of anxiety and even of guilt

when his changed circumstances had meant he had to rely increasingly on his wife's income to support them both:

You get to the point where you're actually thinking you're not contributing in any way to this relationship, other than the occasional meal, and being home for support, so having the benefit coming in is my income, and it's my way of contributing to the relationship. It's not a lot, but if it got taken away, that whole self-respect bit would be further undermined. (Adrian, 50)

Adrian's shame at no longer contributing to the household through earnings was reinforced by the change in their gender roles, with his wife having become the main breadwinner. This serves to highlight that household spending patterns among those experiencing financial constraint were often heavily influenced by gender norms (Kempson et al. 1994). Interestingly, the income Adrian received from benefits had served to bolster his self-respect, and enabled him to feel that he was still contributing to the home.

In contrast to the overall picture of constraint, one participant, Sophie, felt that she was reasonably well-off on benefits. She had recently been assessed as eligible for the higher-rate care component of DLA, which had had a positive impact on her financial security. This had also enabled her to get the support she needed to take on part-time work, further boosting her income. Sophie's experience was unusual, however, and the majority of participants had either experienced financial constraint, or were worried about financial constraints occurring in the future. Nevertheless, there remained an awareness among participants that some of them were in a stronger position to cope with future changes than others. This came from an acknowledgement that they were not alone in being affected by the changes taking place through their exposure to wider media (see section 3.5.2), as well as through their interactions with campaigns against reform (see section 5.4) and other disabled people. Roughly a quarter of participants felt that they were in a relatively fortunate position in comparison to many others:

I'm probably fortunate I mean I've got a house and most things, and somebody to help me. But there are people out there that don't [...] it must be extremely stressful, and some of them have very little to live on.
(Harry, 60)

That is not to say that they were unconcerned or unaffected by the reforms. All of the participants in this category expressed similar worries about their future financial security. However, they were aware that they were in a somewhat privileged position by comparison to many others, and were motivated to speak about their own experiences in the hope of being able to help others.

The findings presented in this section have demonstrated the exercise of considerable agency in the ways in which participants used their benefits to meet their needs. Similarly, while a number had already experienced financial constraint as a result of changes to benefits or wider economic forces, or were anticipating financial losses in the future, many had been able to develop strategies or draw on other resources to enable them to cope with and manage this. Again, this stands in contrast to dominant narratives emphasizing the passivity of benefit 'dependants'. The very act of surviving, coping, and getting by requires considerable agency (Lister 2004). Nevertheless, the context of austerity was proving difficult for some, and the majority were concerned that the Coalition's reform agenda could see things becoming worse. The next section examines strategies involved in 'getting out' of benefits and into paid work. In particular, it interrogates the extent to which increasing conditionality intended to 'activate' individuals into the labour market was supporting participants to achieve this aim.

5.3 'Getting out': conditionality, the work programme, and attitudes to paid work

'Getting out' of poverty is largely exhibited in relation to finding paid work or increasing hours of paid work in order to boost incomes. This section explores participants' attitudes and orientation towards paid work (Lister 2004). The debate

about benefit claiming contributing to worklessness is somewhat less meaningful when applied to disability benefits such as DLA, which is available both in and out of work. However, as discussion in section 3.2.2 has highlighted, the Coalition's rhetoric around reform nevertheless attempted to draw DLA into their broader narrative around benefit dependency. In contrast to dominant narratives depicting those in receipt of benefits as unwilling to work, participants in this study demonstrated strong positive associations with employment. However, many of them faced particular barriers that limited or prevented their engagement in the paid labour market. Nevertheless, many of them contributed to their communities in a range of other ways including through volunteering. The section goes on to examine the extent to which reforms aimed at 'activating' individuals into the labour market, through the imposition of conditionality and sanctions, were successful in supporting participants into paid work. Despite the rhetoric, the majority of participants were not affected by conditionality, and none had faced sanctions.

5.3.1 Attitudes to paid work: challenging the discourse of 'worklessness' as a lifestyle choice

Of the 23 participants in this study, seven were in work at the time of their interviews, of whom two were working part-time, and five working full-time. Three were studying, one full time, and two part-time, while another participant was taking part in a training scheme with a view to moving into paid work. Seven participants had previously worked but had chosen to retire, or had taken early retirement due to ill health, and were claiming a pension. A further seven were of working age but unable to work because of their impairment or their experience of societal barriers to work. Of these, only Michael (41) had never undertaken any form of paid work, while a further three had only had short periods in the labour market.

In the course of each interview, participants were asked for their views on work and employment. All participants recognized the benefits that work could bring to them both socially and financially. This was summed up by Anthony, who had worked since leaving school until being medically retired due to the deterioration of his condition eight years previously:

[It's] the social contact, earning your own money, your own independence, your own income, you know, the self-satisfaction of doing something worthwhile or [doing] something that you find rewarding, [...] the people you meet, the socialization through work.
(Anthony, 46)

Some participants explicitly contrasted working with choosing not to work, and claiming benefits instead. This narrative was particularly acute for Fiona, who had spent a period of time on ESA between completing her Masters and starting her PhD. She had found this to be a very difficult experience, which she was keen to avoid in future. However, she also felt that working had positive features other than simply not being reliant on benefits:

I know that I probably if I really had to I would [give up] work, but I want to work because I've got a good brain! My legs don't work but my brain does. And I want to be able to keep working as long as I possibly can, and have nice things and I know that I'm not going to be working till I'm 65 but I'll just need to see how it goes.
(Fiona, 28)

The majority of the remaining participants felt that they were unable to work at the time of their interviews. In most cases this was either due to the effects of their impairments, or the disabling barriers they faced in society (see section 5.3.2 below), or a combination of the two. Nevertheless, participants who were not working still demonstrated a strong positive orientation towards work:

I want to go back to work. It isn't a case of I have chosen, I mean effectively I've taken about an 80% drop in my salary, to sit at home and do nothing. I mean that isn't a lifestyle choice, whatever [they say]. I got ill, I lost everything. (Adrian, 50)

For Adrian, working had been an important source of self-esteem, and being unable to work was extremely frustrating to him. This highlights the importance of work not just as a source of income, but also as a bolster to individuals' sense of self. This echoes findings by Flint (2008), who discusses the way in which individuals in receipt of benefits associated work with status and self-esteem. None of the participants who were out of work expressed views that suggested that this was an easy option for them. In most cases, they had given up working because they acquired an impairment, or an existing condition had worsened, which meant that they were unable to continue working. Two participants, Liam and Donald, had been involved in skilled manual work, one as a central heating engineer, and the other as a plasterer/roughcaster. Both had wanted to return to work, but had been unable to because of the physical demands of their jobs. Liam (50) in particular felt that these demands had contributed to his impairment:

I: And do they know what caused it [back problems]?

LIAM: Probably the work.

I: The work that you did?

LIAM: Aye, hanging over roofs in the pouring rain [...] snow, everything. Lifting, whatever – 50/60 kilos at a time, when you're only supposed to lift 25.

Both Liam and Donald felt that they were too old to retrain for different occupations. Four participants who were not in work were optimistic about being able to return to employment at some point in the future if their conditions improved. However, the vast majority were pessimistic about their future prospects, feeling that their conditions were unlikely to improve sufficiently to enable them to return to work. This was especially so for those who had retired from work due to ill health. All of the retirees felt that they had contributed to the system throughout their working lives, and had earned their pensions. However, they also spoke positively of their time in employment and felt that it had brought them a sense of self-esteem and enabled them to contribute to society. The participants who hoped to return to work also

discussed experiencing additional barriers that would make finding a job harder for them.

Given the emphasis placed on work in the Coalition's discourses as well as media coverage of reforms, it was perhaps unsurprising that some of the participants echoed these narratives in their discussion. However, this was the case for only a small proportion (n=6) of participants, who felt that there was a difference between themselves as legitimate benefit claimants, and those who were out to scam the system. Liam expressed this view perhaps most candidly, echoing some of the rhetoric used in media discourses around benefit claiming (see section 3.5):

There's one down the road there. Next door's never worked. The one after him that's never worked. [...] So, in this street, before I stopped working, there were only two that never worked. [...] Everybody's always worked apart from two, and now they get everything. (Liam, 50)

Fiona expressed similar views, but slightly more cautiously:

I know it's terrible, but there's certain people you can tell a mile off that they just do not want to work. Whereas I was kind of in the opposite position. I was frustrated that I couldn't work. (Fiona, 28)

She also expressed concern about the way that people who she felt were genuinely too ill to work were being treated. She felt that the actions of the small few who didn't want to work were being used to punish people who were unable to work:

I feel really blessed that I can work because I've got something that I can offer. But I do feel genuinely sad for people who are unable to get out and they're constantly being asked 'are you still ill?' That just makes me feel so sad because I could easily be in that position. (Fiona, 28)

However, these views, though present, were expressed only by a small minority of participants. The majority of participants either made no mention of the 'other' or felt that benefit claimants like themselves were out of work for legitimate reasons such as ill health, labour market disadvantage arising from discrimination, or other barriers to work. Nevertheless, it was also apparent that these discourses were beginning to have an impact on how participants viewed themselves when they were unable to work:

You felt out of place. Everyone was away at work and you weren't, and that was very difficult. And as much as even now, it doesn't bother me anywhere near as much as it did, but sometimes I get a reflection that I'm not seen as part of society anymore, because I don't work, and so I'm not a contributor. But I do try to contribute in other ways. (Harry, 60)

The impact that these narratives were having on participants' daily lives is discussed in Chapter 6.

Discussion in this section has highlighted that in contrast to depictions of those on benefits as feckless and lazy, the participants in this study demonstrated a strong work ethic. However, as will become apparent in the next section, they faced considerable barriers to finding and retaining work.

5.3.2 Labour market disadvantage and barriers to paid work

The barriers faced by disabled people in finding and retaining employment have been discussed throughout this thesis (Drake 1999, Papworth Trust 2011, Berthoud 2011 and see also section 1.4). As a result, disabled people do not enter employment on an equal footing with non-disabled people. This was no less apparent in the experiences of participants in this study:

The societal, the physical, the attitudinal, the cultural and economic barriers that prevent disabled people from working. You know, with the unemployment rate being so bad, there's so many hundred people chasing each job. Who do you think the employer's going to pick? The person with a disability? I don't think so. They're going to be seen as a cost or a burden. They're not going to pick them. (Anthony, 46)

All participants were aware that finding work could be harder for disabled people, and well over half had direct experience of barriers to working. The most commonly cited issues included physical barriers, such as inaccessible buildings and public transport links, as well as attitudinal barriers based on assumptions about the individual's capacity to take on a job. One participant said that he would be unwilling to disclose his impairment in a job application because of this:

Because I then become a cost to them. You know? 'We might need to change this building, we might need to do this, we might need to do that, ooft, can't have that. We'll take [a non-disabled person] instead.' (Lewis, 46, former civil servant)

Participants with higher support needs also highlighted the additional cost of receiving personal assistance at work. Community care tends to be provided in the home rather than in the workplace. Some participants made use of government schemes such as Access to Work which provide support for adaptations and personal assistance. However, they were also concerned that this was likely to become a future target for government expenditure savings.

Another important challenge related to the organization of working practices. Seven participants felt that they were limited in the types of work or number of hours they were able to take on, believing that traditional working practices were ill suited to recognizing this. Pat understood this as a central problem in the way that work is constructed in this country:

I would like to see a much more open labour market. Rather than, or as well as, the disabled person being forced to be 'fit' for the labour market; the labour market should become 'fit' for disabled people. (Pat, 67, retired social worker)

Pat's phrasing echoes Barnes and Roulstone's (2005) critique of active labour market policies that aim to reshape individuals for the benefit of employers, rather than reshape employers to the needs of disabled people. Participants with fluctuating conditions for whom flexibility in employment was particularly important felt this most strongly. Four participants had been able to find flexible forms of work that enabled them to remain in employment. However, three felt that they were prevented from this, because working practices were not suited to their needs. Of the four who were working in flexible employment, one, Sophie, had experienced pressure from discourses around benefit claiming and the imminent move to UC (see section 3.3.1) to increase her hours of work. She felt that this was simply not possible while managing the additional fatigue that this would involve. She also felt that this policy was contradictory when she faced a financial penalty from marginal taxation rates if she did increase her hours of work. Because she had only recently started working, Sophie had no history of National Insurance payment, and so was still receiving the historical Income Support. This was to be merged into UC with a reduction in marginal tax rates, although unlike the conditional elements of UC, the change to marginal tax rates was still to take place at the time of interview. Two other participants who were engaged in full-time work talked about the difficulties they had faced in managing impairment effects such as fatigue or chronic pain while working full time. The understanding of their employers and the ability to work flexibly had been critical to both participants being able to remain in their roles.

Barnes and Mercer (2005) have highlighted that lower levels of educational attainment among disabled people due to discriminatory educational practices such as segregation may also act as a barrier to employment. The majority of participants in this study did not match this picture. Fifteen participants had either been employed in professional roles or possessed degree level or higher qualifications. Of those,

twelve had had long periods of stable interaction with the labour market before either retiring or having to give up work due to ill health. Three were still in the process of completing their higher-education qualifications, and were hopeful of being able to gain at least part-time employment on completion of their studies. However, of the remaining nine participants, four had experienced barriers resulting from lower levels of literacy or poor educational attainment, or had faced stigma as a result of having attended segregated education. These participants also tended to be the ones with less stable or fewer long-term interactions with the labour market, suggesting that educational attainment may well have been a barrier to their ability to find and retain work.

5.3.3 Valuing contributions outside of paid work

I think [work is] a positive thing, but it's not the only thing. There's value in volunteering and other people can contribute in other ways. (Anthony, 46)

Discussion in section 2.6.1 highlighted the need in debates around work develop an inclusive conception of citizenship which takes account of a broader range of contributions outside of paid work (Morris 2004). The involvement of participants in this study in voluntary and other activities underlines the importance of this. Twenty-one out of 23 regularly volunteered for an organization or community group, and many for more than one organization. The types of volunteering activities undertaken varied considerably. Some participated in groups that operated only in their local area, while others were involved in national organizations. Some were impairment or service specific groups, while others brought together disabled people from across different impairment types. This may well be partly reflective of the sampling strategy employed in this study (see section 4.5.1) where around half of participants were recruited through organizations of and for disabled people, and therefore were likely to be active as volunteers within these. Nevertheless, this was still a significant finding and provides an important counter to some of the prevalent assumptions around disabled people's capacity for active citizenship (see discussion in section 2.6.1)

Table 5.1 gives a flavour of the range of different things participants were involved in.

Table 5.1: Voluntary activities engaged in by participants

Activity	Number of participants
Trustee of a charity	7
Advocacy or peer training	7
Member of a user group or peer support network	4
Actor in a satirical theatre group	2
Volunteer with local area access panel	2
Volunteer in a food bank	1
Volunteer at the Special Olympics	1

The participants spoke warmly about the opportunities that volunteering had provided them to contribute to their communities, to meet new people, to learn new skills, as well as to remain active. The following are some of the ways in which they described what volunteering had meant for them:

Volunteering is a positive thing to do, it's positive for the local community, where you do it, it's positive for the person doing it, you know, it's mutually beneficial.
(Anthony, 46)

...

It gets me out of the house, I meet people, and I'm helping somebody, that's the way I look at it. (Donald, 64)

...

I really, I did enjoy it, I enjoyed the challenge I was getting [...], which was you know, getting me out of the house, and things like that. (Peter, 50)

Participants' took part in voluntary activities irrespective of whether they were also in work or not. However, for those who were not in employment, this played a particularly important role enabling them to give something back to their communities. While being unable to participate in paid work was found to have negatively affected participant's self-esteem, volunteering provided an important counter to this. This supports findings by Pemberton et al. (2016) who found that individuals were prone to highlight voluntary activities and work histories as evidence of self-worth in the face of stigmatizing narratives around worklessness.

The informality and flexibility possible through engaging in voluntary activities was also highly valued. This was viewed in contrast to the rigidity of the organization of paid work that several felt had excluded them from being able to enter paid employment. Participants talked about being able to update and manage websites from the comfort of their own homes, or feeling free to miss meetings if they were not feeling well enough to attend, in a way that would not generally be acceptable in the workplace. One participant, Sophie, had been able to move into paid part-time employment as a result of voluntary work she had taken on. She had started helping out as an usher at a local theatre, and had been offered paid work in the same role for a few hours each week. This had enabled her to retain the flexibility that was so important to her, while also being able to earn a small income.

The experience of volunteering was not universally positive, however, and the climate of fear (see section 3.5) generated by the wider reform agenda was impacting on the ability of some participants to make the contributions they would like to. Adrian, one of the few participants who was not engaged in volunteering, felt that he was unable to because it might be seen as evidence of capacity to work. He believed that the benefit system, and the assessment for ESA in particular made no distinction between being able to volunteer for a few hours a week and being able to take on full or part time employment:

You're either ill, and therefore you have to stay at home and be miserable and feel guilty about it. Or, you're well enough to do a full-time job without any support. There is no middle ground. (Adrian, 50)

Similarly, Anthony was wary about discussing his volunteering activities because he was concerned that it would be used to compel him to return to full-time work:

I think it could be used against me and I think it's quite sad that people aren't able to talk about or even, other people are even quite reluctant to do stuff, in case they think it goes against them. (Anthony, 46)

This is a theme that will be returned to in Chapter 6.

The priority given to participation in paid work over other forms of contribution in dominant narratives reinforces the distinction between the active citizen and the passive benefit recipient (Morris 2005), but also overlooks the many ways that disabled people can and do contribute to their communities. Too often in this construct, disabled people who are unable to work are viewed as unwilling or unable to contribute to society. The experiences of participants in this study suggest that a model of citizenship which includes disabled people as full members should recognize the difference between the demands of volunteering and participating in paid work, while also recognizing the contribution made by volunteering to the local community and wider society.

The next section will look in greater detail at the impact that policies designed to encourage or compel participation in paid work had had on participants in this study.

5.3.4 The intensification of conditionality: supporting and enabling returns to work?

Policies which make the receipt of benefits conditional on participation in certain activities have become a dominant feature of UK welfare reforms since the 1990s. The creation of ESA in 2009 represented a significant expansion of this approach to disabled people (see discussion in section 3.3). This section will look at participants' experiences of these policies. It will begin with an exploration of the new work related activity requirements of the ESA before considering participants experiences of the

Work Programme. While the expansion and intensification of conditionality has been one of the most widely publicized elements of the reforms, the majority of participants in this study were not affected by the change in policy. This may be reflective of the climate of fear (see sections 3.5 and 6.3) that had been generated at the time that recruitment for this study took place, which may have deterred those affected by conditionality from coming forward. Similarly, the severity of sanctions involved in non-compliance may have meant that those affected by conditionality were too busy ‘getting by’ to have time to participate in social research. Nevertheless, the comparatively small number of participants affected by conditionality in this study is still noteworthy.

The primary mechanism through which conditionality was applied to disabled people under Coalition Policy was through the ‘claimant commitment’ signed by those in the WRAG ESA (see section 3.3.1). Eight participants in this study were receiving ESA at the time of interview, of whom seven had transitioned onto ESA from the former IB. A further three had claimed ESA in the three years since its introduction, but were no longer in receipt of the benefit either because they had since retired, or had found work. One further participant had considered applying for ESA, but had been advised he would not be eligible.

Three of the eight participants on ESA were aware that they were in the Support Group, while a further three were unsure when first questioned whether they were in the Support Group or the WRAG. It was only after careful questioning that it transpired that they were probably in the Support Group – although this was never confirmed for certain. The consequences and implications of this uncertainty around what their status was and what information they had received about it will be discussed in greater in 5.5 below. Just two participants were aware that they were in the WRAG because they had been required to take part in training schemes. Only one, Liam (50) was aware of the threat of sanction associated with non-compliance with conditionality, though at the time of interview had not had a sanction imposed. Liam’s awareness of sanctions had come about as a result of a further important change as part of the transition to the new UC (see section 3.3.1), which was that conditions are imposed not just on the individual benefit claimant, but also at a household level (Tarr & Finn 2012). Liam and his wife, who was out of work in order

to care for him and her elderly mother but was not claiming benefits in her own right, had recently received separate letters informing them that she was expected to attend a work-focused interview:

- I: If she doesn't go [to work-focused interview]
what happens?*
- LIAM: Stop the money [...] they'll reduce my money.*
- I: So is she going to go?*
- LIAM: She's got no option, but she's going to tell them
[...] She's not asking to get paid for looking after
me or nothing, so to me, they can't withdraw the
money from her, or me. They can't.*

I asked him how he felt about this, and it was clear that he felt it was an intrusion into his private life. While he was happy to comply with the requirements of his benefits, he did not feel that the authorities had any right to question his wife as a non-claimant. However, he was resigned to the idea of having to comply, feeling that they had no other option. This is a significant change to the way that benefits are administered, and means that claimants are now accountable not just for their own actions but in some cases for the actions of other members of their households. Lister and Bennett (2012) have highlighted the gender implications of this move, particularly for the distribution of resources in households with children.

A further element of the conditionality regime for the WRAG was the requirement to participate in the Work Programme (see section 3.3.1). The scheme was intended to provide bespoke training and support to individual jobseekers and those on long-term sickness benefits such as ESA. The Work Programme experience of one participant in this study is discussed in Case Study 5.1 below.

Case Study 5.1 The Work Programme: George's story

George was fifty years old and had a learning disability. He lived independently in his own flat, but received help from a support worker based at an organization providing assistance to people with learning disabilities. George had been out of work for around fifteen years, but prior to this he had done some work through a sheltered employment programme for people with learning disabilities. In the 1990s he had worked in a laundry, but the job had only been available for a fixed period. George had then spent five years between 1995 and 2000 working as a kitchen porter in another sheltered employment scheme. He had found the work very difficult to manage, and had eventually left because of stress. He described having had disagreements with other staff and said he felt that he was not getting sufficient support from the management.

After leaving his job George had claimed IB until 2009 when he was informed that he would need to apply for the new ESA. He had received support with completing his ESA forms and was accompanied by a support worker when he attended his assessment with ATOS. Unfortunately, George's application for ESA was not successful and he was moved onto JSA. During the interview, he talked regularly about this period, and it was clear that he had faced financial hardship as a result of the change. He had also had to start attending regular appointments with the Job Centre during this time. George successfully appealed the decision not to award ESA in the WRAG and had his benefits reinstated about six months after his initial rejection. However, he was still required to attend regular re-assessments to confirm his continued eligibility.

Since moving to ESA, George had had several interactions with the Work Programme and with two providers in particular: Ingeus and Remploy. He was also getting support with numeracy and computing skills from a local charity. George spoke of attending courses with Remploy and Ingeus on at least four separate occasions, and had recently received a letter informing him of a place on another course with Ingeus. George described this experience of moving from one work programme provider to another as being like 'going round in circles'. I asked him how he felt about working and whether he wanted to find employment and he felt strongly that he wanted to work. However, he was also clear that it had to be the right job for him. He mentioned several times in the interview that it was a difficult time to be

looking as many people were being made redundant at that time, and he felt that this would make it harder for him to find work.

George faced multiple barriers to the labour market, but was keen to engage with paid work. However, the support available was not sufficient to enable him to make a positive transition into employment. George's experiences were also mirrored in those of Liam (50), who had also had interactions with the work programme. Liam had only spent a short period of time with a work programme provider. He had been reassessed for ESA annually since 2009, but had been rejected each time requiring him to appeal for up to six months each time. He was not required to participate in the work programme during these appeal periods. However, he felt that the time he did spend on the Work Programme had not provided him with sufficient help and support to enable him to find work in the future:

*All they're doing is sitting there wasting time actually.
They're only filling out forms [...] And the government,
they're putting out all this money to companies like that
when they should be [using] it to help folk. (Liam, 46)*

The insecurity of his benefit status was also inhibiting his engagement with the scheme, making it harder for him to be able to benefit from it.

Both George and Liam's experiences of the work programme support research which has highlighted widespread problems in the operation of welfare to work schemes including the Work Programme (Lindsay et al. 2007; Finn 2008; Rees et al. 2013). In particular George's experience of 'going round in circles' is characteristic of 'creaming and parking' (Finn 2008) that is a common feature of the payment by results model of contracting (Weston 2012). Rees et al. (2013) have found that this practice was endemic in the operation of the Work Programme, meaning that those in greatest need of support were losing out.

At the time of interviewing, the reforms were still in the early stages of implementation, and only a very small number of participants in this study had been directly affected by them. However, the experiences of those involved had not been

altogether positive, and neither participant felt better equipped for moving into employment as a result of participating in the schemes. This represents a significant challenge for policies that make the receipt of benefits conditional on participation in employment support schemes, and calls their fairness into question. This is particularly so when the schemes involved are not delivering positive results for those furthest from the labour market.

Participation in the work program is open to those in the Support Group on a voluntary basis, however none of the participants in this study had availed themselves of that opportunity. This was perhaps unsurprising, and as will be evident in the next chapter, participants in the support group were terrified of doing anything that may be taken as evidence of their fitness to work which might result in the loss of their benefits. However, this did mean that individuals in the support group who may have had some future capacity for work in the medium to long term were having their opportunities restricted. This served to reinforce the binary between those active citizens in paid work, and the 'passive recipients' on benefits. A significant challenge for policy which aims to reduce the longevity of claims. Participants in this study who were part of the Support Group, as previously discussed, had positive orientations towards work, and those of working age may have been able move into work at some point in the future if their condition improved sufficiently. However, the emphasis on conditionality meant that opportunities available to them to access support to move into work at an appropriate pace for them were limited.

5.4 'Getting organized': responding to the climate of fear

The third dimension of Lister's taxonomy relates to 'getting active'. Discussion in section 3.5.2 highlighted that the Coalition's tenure in office saw the emergence of new groups of disabled activists responding to the reforms taking place. Participants in this study had mixed views about the role of activism. Seven were involved in some form of disability activism, of whom two had been inspired to become involved because of the current round of welfare reforms:

I feel it's important as disabled people that we're leading the fight back about this, and, not just the welfare cuts but in general, trying to get equality for disabled people, so that we can take our rightful role in society (Anthony, 46)

The remaining five had been involved in the disabled peoples' movement since before the current round of reforms had been initiated, and were continuing to work to counter to the changes they and other disabled people were experiencing. However, one participant felt that the movement had become complacent over time:

I feel the dictum that says you are not oppressed until you feel oppression, is true. Now, in the 60s we were segregated, we were discriminated against and that was something critical. But today, we've got the equality act, and we've got community-based care, so we're not feeling as oppressed as we did. (Pat, 67)

Pat felt that the gains of the movement in advancing the citizenship agenda for disabled people had left them ill equipped to respond to the challenges they were now facing. This echoes Morris's (2011) evaluation of the challenges facing the disabled people's movement after the successes of the 1990s and 2000s (see section 2.6.2). However, Pat was similarly sceptical about the ability of the new activist groups to take on the new challenges.

The majority of participants were not involved in any form of activism. This is perhaps surprising, given the high proportion of participants recruited through DPOs (see section 4.5.1). However, most participants were active as volunteers for their communities rather than involved in activism, per se. Indeed, one participant was concerned that such activities could be viewed as counter-productive and create a negative image of disabled people:

Well, sometimes when I look at the campaigning side of it, and it just seems to be somebody screaming

constantly. I want this, I want that, I need this, and I need that. That's fine, but there's ways of asking for things. You know, there's other ways of doing things. OK, you can lobby parliament and lobby government, but you know, when I see [them] on the streets, the visible presence, sometimes it makes me cringe.
(Lewis, 46)

Other participants felt that activism was unlikely to change things, or to bring about significant improvements in their circumstances. While some were already politically involved and continued to be so, the vast majority did not see this bringing them any direct benefit. Instead, interviewees in this study were absorbed with everyday strategies of coping with the reforms they were facing on a very individual level. They were trying their best to protect themselves, and preparing for the worst but hoping for the best. This is a theme that is considered in greater detail below.

5.5 'Getting (back) at'? Experiencing powerlessness in the face of uncertainty and insecurity

The final dimension of Lister's (2004) taxonomy relates to agency expressed through 'getting (back) at'. This conception recognizes that not all forms of agency are enacted positively, but nevertheless provides an alternative perspective on the narrative that describes 'dependency' as a form of negative agency that is employed to cheat the system (Lister 2004; Wright 2011). At a discursive level, dominant narratives have tended to draw an unflattering distinction between the negative agency of benefit claimants 'shirking and scrounging' at the expense of people engaged in the positive agency of paid employment (Lister 2004; Garthwaite 2011; Baumberg et al. 2012; Pemberton et al. 2016). The Coalition's narrative around welfare reform has therefore emphasized policy responses that have sought to correct negative agency through the imposition of conditionality. In contrast, Lister (2004) has called for this form of agency to be recognized as a legitimate response to the denial of citizenship rights to people living in poverty. Lister (2004) also includes forms of resistance against stigmatizing narratives in her discussion of

'getting back at', however this element will be addressed in Chapter 6. Instead, this section considers the challenges faced by participants in negotiating the fast pace of welfare reform in an increasingly insecure policy environment. Interestingly, little evidence was apparent of participants actively working to cheat the system through the exercise of negative agency. Instead they were engaged with an ongoing struggle to keep up with the changes they were facing.

Participants in this study demonstrated a high level of awareness of welfare reform process and fiscal austerity in general terms, although they knew surprisingly little about the specific details of these changes. Just under a quarter of participants had responded to the reforms by making a concerted effort not to worry until they felt they had something concrete to worry about. This was an attempt to gain some control over something they felt that they had little direct influence over. While they could not change what might happen to them, they were at least able to determine how much energy they expended worrying about it:

I don't think it's worth worrying about. Because, I know from my own situation that it could make me feel worse, you know? It could make me ill thinking about it. And at the end of the day I would rather not think about it. (Harry, 60)

However, this also reflected a sense of resignation to an uncertain future. While they were aware that changes were coming that would be likely to affect them, participants did not feel that there was anything that they could do in response other than try to cope as best as they could. While the decision not to worry, or not to take action could be seen as a type of agency in the form of 'getting by' the sense of powerlessness expressed by participants in the face of this suggests that there may be limits to the expression of agency in the face of immense structural changes such as welfare reform (Dagdiveirien et al. 2016).

The sense of powerlessness was reinforced by the lack of information available about what the changes would mean for them on an individual level. Around a quarter of participants were unsure when questioned what the changes might mean

for them. One participant had only become aware of wider issues around welfare reform after having been approached to take part in this study, although she had already experienced changes to her benefits as part of the move to UC. Similarly, as discussed in section 5.3.4, three participants in receipt of ESA were unsure whether they were in the Support Group or WRAG, and what the difference might mean for them.

Those participants who were likely to be affected by proposed changes that had yet to take effect, such as the move from DLA to PIP (see section 3.2.2) and the proposed closure of the ILF (see section 3.5.3), were similarly unsure about how they might be impacted. It is possible that this was partly due to the significant level of media coverage given to the reform process, which took place well in advance of changes coming into effect (see section 3.5). It was clear that the awareness of the generality of change, without knowledge about the specifics of what it would mean for them, was very unsettling for participants. At least half expressed cynicism over the motives of policy makers behind the reforms, as well as a sense of injustice about how they felt they were being portrayed:

I think [if I lost my benefits] it would more be emotional because I would feel like I was being called a cheat or whatever. That for the past five years I've had something that I shouldn't have had. (Catriona, 29)

It is clear from this quote that some of the demonizing rhetoric employed in support of welfare reform (Garthwaite 2011; Briant et al. 2013) was having an impact on how they viewed themselves in relation to the proposed changes. Participants felt that any future loss of benefit status would be evidence that they were trying to manipulate the system, rather than having been in genuine need of assistance. The impacts of this are discussed in greater detail in the next chapter. Participants' concerns were contributing to a sense of anxiety and fear about future reforms that was overtaking the determination not to worry about the changes. This was expressed by at least three quarters of participants:

What else is going to come round the corner? I think everyone's just thinking, my God, if they're going to cut another twelve billion, where's all that going to come from? So there's a continual fear among disabled people and definitely within me. We're all thinking, 'what else are they going to do?' (Pat, 67)

The climate of fear was exacerbating their sense of powerlessness over the situation facing them, and contributed to an acute sense of vulnerability. There was a strong feeling of precariousness among participants, a feeling that at any minute something could happen that would undermine their security:

Every day I wake up and wait for that little brown envelope to come through the door, telling me that I've got to go for an interview, and I'm going to have my benefits taken away. (Adrian, 50)

...

Every time a brown envelope comes through the door from them it's like this is it? [...] And I thought is it coming? Is it coming? You just don't know, you just do not know, what's going to come through your door. (Sheila, 62)

...

You don't know what's around the corner when it comes to benefits. I mean you could get a letter the next again day saying they could take you off your benefits. Now that would drive anybody up the wall. (George, 50)

The language in these quotes mirrors that expressed by participants in another study by Garthwaite (2013) which articulated 'the fear of the brown envelope'. For participants in Garthwaite's study, as in this one, the brown envelope epitomized the insecurity of their situation.

Those involved in this study were also finding it increasingly difficult to negotiate the complexities of the benefits system, and in particular, the pace of change that they were experiencing. This provides an important counter to arguments that benefits are too easy to claim, and that it is too easy for individuals manipulate the system for their own personal gain. This study found little evidence in support of the allegations that the system was beset by fraud. Again, while the climate of fear may have made participants unlikely to open up about fraudulent claiming if they were doing so, the fear and vulnerability expressed in the face of reforms suggests that they were indeed genuine. The only example of behaviour that could be viewed as 'getting (back) at' in the way that Lister (2004) describes was from a participant who had found ways to source tobacco on the black market so as to avoid paying VAT. However, this was a fairly minor misdemeanour and was not related to his eligibility to claim benefits. Overall, participants were largely baffled by the changes taking place, feeling that the benefit system was increasingly out of their control.

The experiences of powerlessness exhibited by participants in this study highlight the importance of continuing to recognize the role of structure in constraining and shaping the exercise of agency (Hoggett 2001; Dagdiveiren et al. 2016). While individual participants may have been able to draw on savings or other resources to protect themselves to a greater or lesser extent, the scale of proposed reforms as well as the climate of fear generated by media narratives supporting them was simply overwhelming. Nevertheless, there is also a danger in viewing these responses as a form of passivity. Hoggett (2001) discusses powerlessness as containing elements of reflexivity. Individuals may feel powerless, but in being conscious of these constraints are still able to express agency. The extent to which participants recognized their limitations in the face of structural factors varied considerably. Flint (2008) has argued that the struggle to cope with structural barriers may be internalized as personal failure. This is particularly the case where coping mechanisms among those in poverty are normalized as every day occurrences. As the next chapter demonstrates, powerlessness in the face of structural obstacles can affect individuals' thoughts and experiences (Hoggett 2001) and can therefore have a profound psychological effect.

5.6 Summary

This chapter has explored the expression of agency by people in receipt of disability benefits using Lister's (2004) taxonomy of agency 'getting by, getting out, getting (back) at, and getting active'. Theories emanating from the New Right have tended to emphasize behavioural explanations for benefit claiming, and aimed to correct negative agency through compelling people into work. These ideas are based on a somewhat two-dimensional conception of agency (Wright 2012). The findings reported in this chapter add weight to arguments that call for policy to be based on a more pluralistic understanding of agency (Hoggett 2001; Wright 2012). Participants in this study exhibited a range of different agencies in the ways they used their benefits to meet their own needs, often drawing a clear distinction between benefits and other income, and feeling a responsibility to use these funds as intended. These findings also stand in contrast to narratives that portray those in receipt of benefits as feckless and workshy. Overwhelmingly, interviewees spoke positively about the benefits of work both on an individual and societal level. They were also engaged in a range of voluntary and other activities, which enabled them to contribute to their communities. However, many faced considerable barriers to finding and retaining work. While the Coalition's policy approach placed a strong emphasis on participation in the labour market, and drew disabled people increasingly into conditionality, this had not resulted in a rise in labour market involvement for those in this study. Strikingly, despite the rhetoric, the majority of participants in this study were not subject to conditionality. Nevertheless, they were strongly affected by the climate of fear generated by the reforms. While some had responded to this by 'getting active', the vast majority were feeling increasingly powerless in the face of change. The findings presented here therefore serve to challenge some of the dominant assumptions about the agency of those in receipt of disability benefits, while serving as an important reminder that structural barriers continue to shape individuals' lives in many ways.

The next chapter examines the reforms which took place between 2010 and 2015 as characteristic of a crisis in disability as an administrative category (Stone 1984; Roulstone 2015). The coalition sought to resolve this crisis through an intensification of medical assessment for eligibility to disability benefits. Chapter 6 explores some of the unexpected consequences of the culture of assessment as a form of 'welfare

surveillance (Vaz & Bruno 2003) which emerged through discussions with research participants.

Chapter 6 Redrawing the disability category

6.1. Introduction

The reform of ESA/IB and DLA/PIP has been characterized as a redrawing of the disability category in response to a perceived crisis. In what ways has this reform impacted on the experience of claiming and using disability benefits? In what ways have disabled people been affected by popular and media narratives supporting the reforms?

Discussion in section 3.2 highlights the way in which reforms to disability benefits which took place just prior to and during the Coalition Government's tenure in office were reflective of a perceived crisis in disability as an administrative category (Stone 1984; Roulstone 2015). This was largely achieved through an increased emphasis on medicalized testing based on biopsychosocial indicators (Shakespeare et al. 2016). The reforms were supported by the creation of a public narrative that increasingly viewed disabled people as workshy and undeserving of state support (Garthwaite 2011; Briant et al. 2013). The previous chapter has demonstrated that participants in this study had strong, positive associations with work, but faced considerable labour market disadvantage. This chapter focuses instead on the process of negotiating the redrawn disability category. It begins by exploring experiences of applying for and being assessed for disability benefits. It then moves on to examine some of the impacts of the popular discourses and in particular the hardening of attitudes towards disabled people⁵.

6.2. Changing application and assessment processes: Negotiating entry to the disability category

Section 3.2 highlights the ways in which an increased focus on medical testing has supported the redrawing of the disability category. This section explores experiences

⁵ Sections from this chapter appear in the following article published by Cambridge University Press: Manji, K. (2017). Social Security Reform and the Surveillance State: Exploring the Operation of 'Hidden Conditionality' in the Reform of Disability Benefits Since 2010. *Social Policy and Society*, 16(2), 305-314. doi:10.1017/S147474641600052X

of negotiating entry to this category. Participants in this study talked at length about their experiences of applying for and being assessed for benefits. This was particularly pertinent for those who had claimed ESA since 2009. While only one participant had been called to apply for the new PIP, interesting similarities also emerged for participants who had recently applied for DLA. These similarities suggested that some of the thinking underpinning the new PIP was being adopted in DLA assessments in the interim. Eight participants were receiving ESA at the time of their interviews, while a further three had claimed ESA in the past. Four participants had claimed DLA in the previous five years, while a further two had experienced changes in their circumstances that required them to attend an assessment for DLA, although none had yet transferred to PIP.

It is interesting to note, however, that despite the media coverage of the assessment process and the fear and anxiety expressed by participants about the experience of undergoing the assessment, the majority of IB claimants (four out of seven) had transitioned to ESA without incident. Of those four, two, Harry and Anthony, had been able to transfer from IB to ESA without attending a WCA, and had been placed in the support group on the grounds of the evidence provided in their applications. All three had received support from welfare rights organizations in negotiating their transfer (see section 6.2.3), and had also had some experience of using the benefits system in the past, which clearly gave them an advantage. They had all taken a strategic and determined approach to completing their forms and had sought advice from welfare rights advisors in negotiating the process, and this may account for their successful transition. However, in retrospect, the smooth transition did not detract from the anxiety they had experience in anticipation of the change, or the disruption the move had caused them.

6.2.1 Jumping the first hurdle: applying for benefits and completing the form

When discussing the experience of applying for benefits, the first challenge most participants faced was in completing the form:

My wife has a degree, or two. I've got various higher education qualifications. It took us two days to do the forms. Even though we'd done similar forms before. (Adrian, 50)

Participants spoke of having found the forms, and in particular those for ESA, extremely complicated to complete. Three commented on how inaccessible they had found the experience, including having to complete forms by hand. This was viewed as particularly frustrating for a form intended to establish eligibility to a disability benefit. Again, the majority of participants had eventually sought assistance from Welfare Rights Services to help them with filling them in (see section 6.2.3).

A further challenge was the extent to which the forms enabled participants to adequately express the reality of living with their impairment. Four participants had fluctuating conditions or mental health problems and felt the forms were too narrowly focused on physical indicators, which prevented them from being able to describe the impact of their individual impairments on their day-to-day lives. This was a concern expressed both by participants claiming ESA and, in recent years, DLA. Two participants also expressed concerns over the length and complexity of the forms that they had to complete:

The form was quite substantial, and [...] had to be completed in writing which I thought was quite inappropriate. You weren't allowed to do it on the computer, and obviously my tactility and my writing is rubbish. (Harry 60)

There was also a feeling that the questions weighed heavily on the need for medical evidence, as is evident from Fiona's experience in case study 6.1.

Case study 6.1 Applying for DLA: Fiona's story

Fiona was 28 and worked as a civil servant and was also completing a part time PhD. She lived with her husband. When she was 10 years old she had started experiencing pains in her

legs which she was told were 'just growing pains'. However, by the age of 15 the pain had become intolerable and she needed crutches to help her get around. Her family took her to a physiotherapist for treatment and she also saw a number of orthopaedic specialists. Unfortunately, none of the specialists she saw was able to diagnose the cause of the pain.

In addition to the pains in her legs, Fiona also experienced periods of intense fatigue and when she was 18 she was diagnosed with ME - also known as Chronic Fatigue Syndrome. She was about to start university and was advised by her doctor not to take up her place, although Fiona was determined not to let the diagnosis set back her education. She applied for DLA for the first time at around this time, hoping that it would enable her to get additional support at university. However, her claim was rejected on face value, because although she'd been formally diagnosed with ME, she did not have a medical diagnosis for the pains in her legs.

Fiona applied again for DLA when she was 21, and was visited in her home by a doctor who carried out an assessment of her eligibility. Her application was again rejected because she did not have a diagnosis for her leg problems. Fiona described feeling very disheartened by the experience of being rejected twice, and resolved not to apply again. However, when she was 23 she went to see a new physiotherapist who asked her to go back and look into her medical notes from when she first started receiving treatment. Hidden away in the notes was a diagnosis for her condition: sacroiliac joint dysfunction. Encouraged by having a formal diagnosis Fiona sought support from her local Citizens Advice Bureau and again re-applied for DLA. This time, within a week of submitting her application, and without requiring an assessment visit from a doctor, she was awarded the high rate of care and mobility components.

Fiona was delighted at finally being awarded DLA and felt that it had since made a huge difference to her quality of life. However, she was also frustrated by the process she had been through, and the length of time it had taken. She felt that there had been no change in her circumstances or the way that her impairment affected her on any of the previous times she applied and when she was successful. She believed therefore that the decision to grant her DLA had been based only on having a medical diagnosis, rather than on an understanding and assessment of her needs.

Fiona's experience of applying for and being rejected for DLA over many years suggests that medical criteria had long been an important indicator in assessments for the benefit. This finding contrasts with one of the discursive justifications for the change to PIP which was that the benefit was too easy to claim (see section 3.2.2).

6.2.2 Satisfying the assessors: experiencing 'independent assessment'

Unsurprisingly, participants also talked in detail about their experience of undergoing assessment for ESA and DLA. Ten participants had been assessed for eligibility to either ESA or DLA in the previous five years. While ESA was assessed by the WCA (see section 3.2.1), eligibility for DLA had been based largely on the strength of the application form. In certain circumstances, this was backed up by a visit to the applicant's home by an independent doctor. Whatever format the assessment had taken, the experience of being assessed was talked about almost without exception as having been a very frightening and negative experience. Half of the participants who had been through ESA or DLA assessments spoke of having felt degraded by the process:

It was terrifying, and it was a horrible experience. You know, it was very demeaning that you had to basically you had to put yourself as nearly dead. [...] I didn't want to be doing that. (Lewis, 46 – ESA assessment)

...

It's a really, really disempowering experience because you are an object, you suddenly become an object and it's almost like your agency is completely stripped from you and particularly there's no kind of ... there's no focus on a person's feelings at all. (Catriona, 29 – DLA assessment)

Again, the similarities in the views of participants claiming ESA and DLA in recent years were striking, suggesting that the assessment process for DLA was already starting to mirror some of the more stringent elements of the WCA. However, one participant who had claimed DLA within the previous three years felt that although it had been uncomfortable, the visit from a doctor had been preferable to having to attend an assessment centre. Thomas (33) had received an at-home assessment after appealing a decision to turn down his application for DLA. He had found that speaking to the doctor in his home environment enabled him to demonstrate the reality of how his impairment affected him more accurately than if it had been in an

artificial environment. He was therefore very concerned that this was something that was changing under the move to PIP, which will introduce a more standardized medical assessment similar in format to that of the WCA (see section 3.2).

The increasing requirement to attend formal assessments was also apparently having a deterrent effect on the decision to apply for benefits in the future. At least two participants felt that the experience had been so negative they would consider not applying again:

To me I would honestly rather make myself ill going out to work than to go through that [again]. I hated, I just found that whole experience horrific. (Fiona, 28 – ESA and DLA)

However, one participant was concerned that ‘giving up’ was exactly what the government wanted, and that she should therefore persevere:

I guess I’m in conflict with myself because I know that if everybody just said, ‘oh well, never mind, I just won’t have it’, actually I’m sure that’s how the government will save quite a bit of money. There will be lots of people who say, ‘you know what, that’s just not worth it to me’. (Catriona, 29)

As with the forms, participants expressed concern that the assessments were not well suited to understanding the everyday reality of living with their impairments. Around a quarter who had been through assessments felt that they had taken place in artificial environments, or had focused on tasks that bore little relation to the barriers they faced. This was also an issue raised by participants on DLA when discussing the transfer to the PIP and the decision to restrict access to the mobility component of DLA to those who are unable to walk 20 metres (the criteria for DLA had previously been 50 metres; see section 3.2.2):

It absolutely terrifies me [...] I don’t think I could walk my 20 metres, but one day I could struggle and maybe get there

very slowly, but most days I couldn't walk that. (Sheila, 62 - DLA)

Again, this was particularly concerning for participants with fluctuating conditions who may experience different levels of impairment on different days. However, those with more stable conditions were also worried about the change.

These concerns, combined with the widespread media reporting of the high number of successful appeals against the WCA, had contributed to a strong sense of mistrust about the impartiality of the assessment process, and even the qualifications of the assessors:

Some of the reports by the doctors are absolutely unbelievable. [...] saying that you've walked, that you get up and you can walk fifteen, twenty yards without a problem. [...] Just because you could, you know, get up off your seat and walk a wee bit, that was it. You could do fifty yards. They're paid money to tell that. (Donald, 64)

Another feature of the ESA reforms, as well as more stringent assessment criteria, was the move to more regular reassessments. Given the discomfort and anxiety expressed when discussing assessments, many participants were understandably very worried about being reassessed more frequently:

You've no idea the period. Again you hear stories of some people it's every three years and others it's every three months. So you sit there every day, waiting for the post to come. [...] It's Chinese water torture, you just don't know when the next one's coming. (Adrian, 50)

Participants with long-term impairments that are unlikely to change also felt frustrated that this was not being taken into account.

There was also a feeling of confusion about what PIP might mean for participants who had recently been awarded DLA. Three participants had started claiming DLA within the previous three years, and two had been granted indefinite awards in the six-month period before the interviews. This was despite this status being abolished under the PIP (see section 3.2.2). This caused considerable confusion and uncertainty for the participants who were unsure whether they would be called for reassessment for PIP or not.

I had quite a few letters at the start of the year explaining that PIP was coming and that I was going to have to go through PIP. And then when I spoke to them a few times they said no it's not coming to your area, and then they've said that it's [DLA award] indefinite, and I'm still not 100% sure what indefinite means. (Fiona, 28)

6.2.3. Getting support to negotiate the redrawn disability category

The demands of negotiating an increasingly complex field had led a large proportion of participants to seek help from welfare rights and other support organizations when initiating a claim or before attending an assessment. Eleven out of 23 participants had received support from an organization that provided either general welfare rights advice, or support to individuals with a particular impairment type. Overwhelmingly, participants felt that this had had a positive impact on their claim, with five of the 11 having sought support only after receiving a negative outcome from an earlier claim. One participant had found out that she might be eligible for DLA after contacting a welfare rights advisor about the Blue Badge scheme:

I think at the time I was quite indignant, I said 'all I really want is the Blue Badge, I don't need the DLA.' And he said 'well, you're kind of shooting yourself in the foot really if you don't apply for it.' [...], and every time since that I've had to fill in a form, I've just gone back to the welfare rights people

[...] it does make the process so much more doable.
(Jayne, 61)

Two participants who didn't seek support at the time of their claim subsequently felt that they would have benefitted from this, and were planning to seek out help in the future.

These experiences serve to highlight the critical importance of the role played by welfare rights advisors and a range of public and voluntary agencies in Scotland in helping people to apply for benefits to which they are entitled. However, with the changes taking place across the benefits system, and constraints on local authority and other budgets, welfare rights services are coming under increasing strain (Dryburgh & Campbell 2012).

The experiences of participants who had been through assessments to determine their eligibility for benefits suggests that the process was becoming tighter and harder to negotiate. This was the case both for those applying for ESA and for DLA in recent years. The move towards more intensive medical testing to determine eligibility for disability benefits suggests that these experiences are likely to become more common. The process of assessment is intended to ensure that support is granted to those in greatest need. However, the experience of participants in this study has demonstrated that this may be achieved at a cost to the individuals undergoing the assessment. All of the participants who had undergone assessment were eventually granted either ESA or DLA, and were therefore deemed 'legitimate'. However, the anxiety expressed at having to go through the assessment process, combined with the sense of indignity experienced in being assessed was serving to undermine participants' sense of self. These findings are not unexpected, and confirm concerns raised by civil society organizations and others at the time that the reforms were proposed (Scope 2012; Campbell et al. 2012). The next section will explore some of the more subtle and unexpected ways that changes to eligibility to benefits were found to be impacting on participants.

6.3 Hidden conditionality: the operation of surveillance and self-surveillance in the reform of disability benefits

As discussed previously, the majority of participants in this study were not expected to meet conditions in exchange for their benefits. Nevertheless, the discourse around conditionality generated by government narratives and media coverage of reforms (see section 3.5) meant that the threat of losing or being found ineligible for benefits was ever present. Again, this is very much in line with Stone's (1984) conception of disability as an administrative category, where social or and moral understandings of who is and is not deserving of support are critical to where the boundary between work and need is drawn (see section 2.3). The sense of powerlessness participants articulated in response was profound. This section explores some of the unexpected psychological impacts of the changes. Most interestingly, these findings imply that awareness of conditionality as a policy driver, whether or not applied to individuals in this study, appeared to be having an impact on the way in which benefit recipients behaved.

Just under half of participants described having to take steps to meet social expectations about 'good' benefit claiming behavior in order to demonstrate deservingness for their benefits. Participants were most aware of being expected to act in certain ways, and adjusting their behavior in response, when going through an assessment for either ESA or DLA. This was explicitly not indicative of an intention to cheat the system or to lie about the severity of their condition, but was seen as part of the requirements of demonstrating genuine eligibility for the benefits they sought. Individuals talked of feeling that they had to give particular emphasis to things that they could *not* do as opposed to things that they *could*. At least four commented that this had gone against their natural inclination, which was to focus on the positives of their situation:

If someone were to ask me [...] how far can you walk without it being sore, I think I would probably exaggerate how far I could walk [...] and then I was confronted with a form where actually if you were to do that, that's the difference between getting something and not getting something. (Catriona 29)

Having to focus on the negatives was not only unpleasant, but also challenged the way participants viewed themselves and their impairments, impacting on their sense of self. One participant, Fiona, talked with dismay at being encouraged by a welfare rights advisor to alter her appearance ahead of an assessment:

You feel as if you're putting it on... I was told [don't] be too smart in what you are wearing, and don't make an effort with your hair, [...] wear odd socks, literally look like you're not well. (Fiona 28)

Fiona felt that this was necessary to prove her case, but described this as having made the assessment even more degrading for her. Clothing is an important indicator of status, and can carry significant stigma for those whose mode of dress visibly identifies them as 'other' (Goffman 1963). This stigma is heightened when applied to disability or impairment which has historically been viewed as a deviation from the norm (see section 2.3). Appearance was of great personal importance to Fiona, who had gained weight due to pain relief medication she had been prescribed to manage the pains in her legs. She had been successful in losing a lot of weight in the year or so prior to our meeting, and felt a sense of achievement in having done so. She was also careful not to reveal her impairment to people outside her immediate family because of the stigma associated with being a benefit claimant. Being asked to alter her appearance in order to fit with expectations of what a disabled person *should* look like therefore constituted a denigration of her identity.

Changing behaviour in response to the expectations of authorities has been highlighted as a common response to the experience of surveillance (Vas & Bruno 2003; see also discussion in section 3.3.2.1). A small proportion of participants also described feeling judged by the assessors for demonstrating particular characteristics or lifestyle choices. One participant was angry at discovering that the assessor knew what brand of tobacco he smoked, saying he felt that he was being spied upon.

*Why do they put that down on the medical report? [...]
They're saying, ah, he's smoking, we're giving him too much
money. (Liam, 50)*

The sense of being under surveillance in assessments was frequently carried over into everyday life. This was discussed by around half of participants who had been on ESA. The feeling of being observed and judged was not restricted to government or agencies acting on behalf of the government, but also included feelings of judgement by members of the same community as highlighted in case study 6.2.

Case study 6.2 Hidden conditionality and surveillance: Adrian's story

Adrian was 50 years old and lived with his wife in a small rural town. He was originally from England and had moved to Scotland eleven years previously following a nervous breakdown. Prior to that he had worked as a relatively senior civil servant, a job he had loved, but had been unable to return to following his breakdown. Adrian experienced a number of mental health problems, including obsessive compulsive disorder and agoraphobia. He had previously received treatment as an outpatient and continued to take medication. Adrian also told me that he had experienced strong suicidal urges.

Adrian and I met on the social networking site Twitter after I put out a 'Tweet' calling for participants to take part in this study. He responded by stating that people would be foolish to participate because the DWP would be likely to find out and they would lose their benefits. I was concerned his reaction might deter other potential participants, so I responded and made it clear that I had no connection to the DWP and no intention of 'shopping' participants. After assuring him of my credentials and that he would remain anonymous in this study, he eventually agreed to take part.

Throughout the interview, it was clear that Adrian was very worried about the possibility of being found fit to work. He initially claimed DLA and IB but transferred to ESA in 2009 and was placed in the WRAG. He successfully appealed this decision and was later moved to the Support Group, and as a result was not subject to any formal conditionality. However, he was very concerned that that status was tenuous, and felt that he could be required to return to work at any time.

Experiencing agoraphobia meant that Adrian found new situations very difficult, and tended to avoid leaving the house unless he was with his wife, and was going somewhere he had been before. However, his fear of leaving the house was compounded by the fear of losing

benefits. He was active on Twitter and followed debates around welfare reform as an observer, but did not get involved because he was concerned that the DWP were monitoring him. He was also reluctant to reveal his benefit status to people living in the town because he was worried that they would question his eligibility to those benefits. He had a friend who occasionally took him out hill walking, a hobby he had enjoyed, and Adrian had travelled the world with this friend prior to becoming unwell, but he was reluctant to go out too frequently, again in case this was seen as evidence of a recovery.

Adrian expressed real frustration at his situation and concern that his fears had left him increasingly isolated. He was conscious that this was not good for his condition, and was setting back his recovery, but he felt he had no option, given his worries about losing benefits. He felt that the system was working against itself in this way, making it less, rather than more, likely that he would be able to make a full recovery and no longer require his benefits.

This echoes Dennis' (2008) concept of 'sousveillance', or surveillance from the bottom up. Adrian felt that his community would be likely to report him if he behaved in ways they deemed inappropriate for someone in receipt of benefits if they knew about his status. The complex interaction between Adrian's mental health problems and his fears about his benefit status reflect a worrying trend among those who have been through the WCA in recent years. Barr et al. (2016) have found that far from improving recipients' health, the testing regime has resulted in a decline in their reported mental health and an increase in suicide rates.

Two other participants described experiencing something akin to 'sousveillance' (Dennis 2008) or judgmental attitudes among members of their communities and the fear that if they behaved inappropriately, members of the public would report them to the authorities. As a result, only their immediate families were aware that they claimed benefits. This was not because they felt that they were doing anything wrong that would lead them to be reported, but rather because their impairments were unseen, or tended to vary, so they did not feel that they fitted in with the traditional understanding of what a disabled person looked like, and they were therefore less likely to be seen as deserving. These findings echoed Garthwaite's (2015) work on benefit stigma in the North of England. This had caused individuals to become increasingly isolated as a result of efforts to conceal their status.

The experience of living under 'welfare surveillance' (Hennman & Marston 2008) had a significant impact on participants' daily lives affecting who they interacted with, and what activities they felt they could take part in. One participant had even decided to put off starting a family with her husband because she was worried that her benefits would be stopped if she came off her medication in order to conceive. She felt that stopping a course of medication would be seen as a sign of recovery rather than a decision to exercise reproductive choices.

As I have argued elsewhere (Manji 2016) the 'hidden conditionality' experienced by participants in this study, like formal conditionality, arose from assumptions within the benefits system about how recipients *should* behave. Interviewees were keen to distance themselves from the 'scrounger' narrative (Garthwaite 2011). They felt they were all genuinely seeking support to help them to overcome additional costs, because their impairments were such that they were unable to work or they faced significant labour market disadvantage as a result of discriminatory attitudes. They also felt that they had gone to considerable lengths to meet the formal requirements to prove their eligibility, as evidenced in the granting of benefits. However, the narratives underpinning reforms mean that many felt that their eligibility remained in question. They had therefore adopted practices associated with self-surveillance (Foucault 1991; Vaz & Bruno 2003) in order to demonstrate their conformity with rhetorical expectations about how benefit recipients should behave. The following section explores some of the ways that these behavioural assumptions and hidden conditions were impacting on participants' day to day lives, how they were viewed by their communities, and how they viewed themselves in turn.

6.4 Experiencing resentment and vindictiveness: a consequence of hidden conditionality?

An important consequence of drawing disability benefits into debates around worklessness was that participants commonly described being perceived as having stigmatized identities, both as disabled people and as benefit claimants. Several participants discussed having experienced bullying and harassment as part of the course of their daily lives. For many this was explicitly linked to their status as

disabled people with visible impairments, or living in supported accommodation, and making them easily identifiable as 'other' within their communities. However, what was interesting was the extent to which this experience of disability discrimination was increasingly becoming bound up with negative attitudes towards people on benefits. In the past, disabled people may have felt more protected from 'scrounger rhetoric' (Garthwaite 2011; Briant et al. 2013) as a result of being perceived as being more deserving of state support (Roulstone & Prideaux 2012). However, it appeared that as policy became more stringent in determining eligibility, this was being reflected in a greater sense of disbelief and mistrust by the general public at their eligibility to benefits. In this sense the 'sousveillance' (Dennis 2008) described by Adrian and others as fear of being reported, was also exhibiting as attempts by the community to take matters into their own hands.

Of the 23 participants, nine said they had had experienced a hardening of attitudes towards them or a sense of disbelief in their status as disabled people. Incidents of this kind were largely bound up in media narratives around scrounging, with participants facing a growing perception that they were not really disabled but rather trying to cheat the system in some way:

You see the general public are starting to believe all this [rhetoric] thinking that, 'Aha, these people are at it, they've been getting an easy ride'. (Anthony, 46)

This is reflected in some of the informal and community elements of the hidden conditionality discussed above. Participants with both visible and unseen impairments spoke of being affected by these attitudes, although those with unseen impairments felt that they faced additional barriers to being believed:

Because I look fine, that's the worst thing about it. It's a terrible thing to say, but if I was in a wheelchair it would be so much easier, because people would understand it a bit better. (Fiona, 28)

This echoes findings by Briant et al. (2013) that people with unseen impairments were likely to be viewed less sympathetically in public and media discourses around welfare reform. The negative attitudes they faced were frustrating and often upsetting, particularly, as in one case, when they came from participants' own families. However, more concerning was the perceived increase in harassment or physical abuse that some participants felt they had experienced. Six participants had experienced such incidences ranging from verbal abuse to physical assault. In contrast to the negative attitudes, these instances were overwhelmingly experienced by participants with visible impairments or whose status was more apparent in some way. One couple were subjected to several months of abuse and intimidation from a gang harassing residents living in supported accommodation for people with learning disabilities. They felt that they were easily identifiable because of where they lived, making them an easy target.

Case study 6.3 Hate crime in the community: Michael and Hayley's story

Michael and Hayley were both affected by learning disabilities, and lived in their own flat in a complex managed by a local housing association for individuals with learning disabilities. They had been married for ten years at the time of the interview. Though neither were in work, they were both active in local voluntary and advocacy organizations for people with learning disabilities.

They and other residents in their block had been subject to several months of abuse by a gang of local youths who would hang around near their development in the evenings. Generally, this involved shouting abuse or making intimidating comments to residents who passed them by, making it hard for them to go out in the evenings. They had also had beer cans thrown at their windows and glass bottles smashed in their garden. On one occasion the gang had tried to gain entry to the flat while Hayley had been home alone. She had been able to lock the door before they got in, but the incident had left her terrified. Michael had repeatedly reported these incidents to the police, but felt that he was not being taken seriously. Eventually the housing association had put up new fencing around the development, making it harder for the gang to gain entry.

Hayley had also been targeted on public transport. She had been tied to a pole at the back of a bus and had abusive comments made to her. Michael was dismayed that no one on had come to Hayley's aid.

Participants who had experienced verbal or physical abuse shared a common sense of mistrust in the ability or willingness of authorities to deal with problems of harassment and hate crime against them. Only two had reported their incident to the police, and neither felt that their concerns had been adequately reported or addressed. The remaining participants had seen little point in contacting the authorities, or feared repercussions if they did so. However, their experiences were having a lasting impact on them, with four participants stating that they felt less able to go out in public as a result:

I've been indoors a lot more, unless I've got support. I have got good support though, and they come and take me out, but it's not the same though. I like to be able to go out and just have a coffee. (Sophie, 47)

This was having a serious negative impact on participant's ability to live independently and be recognized as a valued part of the wider community. Quarmby (2011) cites examples of neighbours articulating resentment against disabled people as a common trend, due to the perception that they have certain privileges like accessible housing or adapted vehicles. However, the targeting of disabled people in acts of violence within their own neighbourhoods suggests an escalation from feelings of resentment to acts of vindictiveness (Young 2003; see also section 3.5.1). These findings are supported by research by Coleman and Sykes (2016) who found that disabled adults were more likely to be victims of crime than non-disabled adults.

6.5 Relocating the self in the face of vindictiveness

Given the increasing stigmatization of benefit claiming, the significance that participants associated with receiving benefits was of particular interest in this study. Nine participants spoke explicitly about what benefits meant to them, the vast majority of whom felt that they had enhanced their lives, and that they were entitled to claim them; overall, these nine participants viewed receiving benefits in positive terms. Only three participants felt that being on benefits was overwhelmingly

negative, describing it as shameful or something worthy of guilt or intolerance, as well as being made to feel beholden to the government:

I feel like I've got a label that I can't go out and work because I'm on disability benefits. The government make me feel like I can't have a job because I'm on these benefits. (Ailsa – age not disclosed - extract from field note)

However, even these three felt that there were still some positives to receiving benefits. Seven participants spoke of feeling that benefits granted them a sense of security, enabling them to get by in otherwise difficult circumstances:

They [benefits] were there for me at a time when I couldn't find a job. [...] so benefits gave me a start in life basically. They let me move into my own house, and they let me lead, the life I wanted to lead [...] without them I don't know where I would have been. (Dennis, 35)

Though a small number felt that some individuals were undermining the system by not actively seeking work when they were able (as discussed at section 5.3.1), the majority of participants were explicit in their rejection of the negative portrayals of people in receipt of benefits, and spurned the dominant narratives around scrounging. One participant expressed concern that not everyone used their benefits strictly for what they were intended, and felt that this was wasteful of resources when there were other people who were unable to get access to support when they needed it. However, she blamed the structure of the benefit system for this rather than the individuals concerned.

While participants were acutely aware of the growing stigma of their status, they were, on the whole, reluctant to pass this on to others. These findings stand in contrast to other studies which have highlighted a growing trend among those who are stigmatized and therefore stigmatize others in return (Chase & Walker 2012; Hoggett et al. 2013; Garthwaite 2015; Baumberg 2016; Pemberton et al. 2016). Baumberg (2016) found that these attitudes were particularly prevalent for

individuals living in areas with high claimant rates, which was not the case for most of the participants in this study. Their personal experiences of animosity and violence as a result of their benefit status may also have made them more sympathetic towards other people who use disability benefits, making the dominant narratives easier to reject.

While not wishing to overlook the role of structure discussed in the previous chapter, the discussion of what living on benefits meant to them also demonstrated a strong sense of resilience among participants. The process of claiming had often been difficult and participants felt that they experienced significant indignities in going through the process. Despite being subjected to discriminatory attitudes and even physical attack as a result of their status as 'claimants', the majority were still able to recognize the positives of the support they received. Nevertheless, there remained a strong sense of anger from the majority of participants at attempts to portray them in a negative light. Longitudinal research into attitudes to benefit claiming has suggested that, over time, people using benefits have come to internalize these discourses (Patrick 2015). The positive attitudes of participants in this study do not therefore suggest that this will not be a longer-term consequence of hidden conditionality.

6.6 Summary

This chapter has explored participants' experiences of negotiating an increasingly complex process of accessing and being assessed for disability benefits. The findings presented here support Roulstone's (2015) assertion that the reforms initiated by the Coalition Government between 2010 and 2015 sought to redraw the disability category by restricting access to that status. Overall, participants were finding it harder to gain access to disability benefits as a result of the redrawn category. Although only one participant had been called to apply for PIP at the time of interviews, the challenges with applying appeared to be consistent for both ESA and DLA. The application process was becoming harder to negotiate with forms becoming increasingly complex, and particular emphasis placed on medical criteria

to establish legitimacy to claim. This was particularly difficult for those with variable or fluctuating conditions.

Unsurprisingly, given media coverage of this, the assessment process was a prominent feature of participants' experiences of applying for benefits. Again, the findings presented here support concerns that the intensification of medicalized testing based on bio-psychosocial indicators (Shakespeare et al. 2016) is causing considerable anxiety, impacting on individual's health (Barr et al. 2016). The assessment was overwhelmingly discussed in terms such as 'disempowering' or 'undignified'. Given the similarities between the WCA and the new PIP assessment (see section 3.2.2), it is highly likely that these experiences will be replicated when existing DLA claimants are called for reassessment in 2017.

Despite the majority of participants being unaffected by formal conditionality, the climate of fear generated by media reporting of the reforms had led to the operation of a form of 'hidden conditionality' in the way in which benefit recipients behaved. This was evident in interactions with government agencies such as the need to dress or behave a particular way in assessments. However, it was also increasingly evident in the community too. Participants discussed feelings of being under surveillance at all times, and adopted practices of self-surveillance to demonstrate their deservingness for the benefits they received.

The climate of fear had also served to foster feelings of resentment and indeed vindictiveness against a group who were seen to be receiving favourable treatment at a time of austerity. Those involved in this study described a growth in disbelief over the veracity of their status as benefit recipients, and in some cases this had been articulated as hate crime. This was having a significant impact on their lives, causing some to exercise caution over whom they disclosed their status to, leading them to become more isolated as a result. Despite this, participants continued to demonstrate a strong positive association with benefits, describing the difference being able to receive additional financial support had made to them. On the whole, they had resisted engaging in stigmatizing or 'othering' behaviour towards other benefit recipients.

The next chapter examines the way in which the reforms between 2010 and 2015 impacted on disabled people's citizenship. It will look in particular at the experience of reforms which have adopted the language of citizenship (see section 3.4), drawing on concepts such as independence and self-directed support.

Chapter 7 Citizenship revived, or citizenship retrenched?

7.1. Introduction

Policies adopted both at Westminster and at Holyrood between 2010 and 2015 drew heavily on the language of the disabled people's movement, emphasizing concepts like independence. To what extent have these policies advanced disabled people's citizenship status during this period?

The disabled peoples' movement experienced a number of significant successes during the 1990s and 2000s, not least in the introduction of legislation for DPs. Indeed, by the mid-2000s the social model of disability was accepted as the defining approach to disability across government (see section 2.6.2.3). However, the period since 2010 has seen a somewhat different approach. The previous chapter explored the way in which the Coalition Government sought to redraw the disability category through increased reliance on medical testing and the creation of a moral narrative on deservingness. As discussion in Chapter 6 demonstrated, this has led to disability once again having become a stigmatized identity. While redrawing the disability category has been a common responses to a *perceived* crisis in the disability category (Stone 1984), an unusual feature of this 'crisis' has been the extent to which the Coalition Governments' approach has adopted the language of the disabled people's movement to justify their reforms (Roulstone 2015; see also section 3.4). This is especially evident in the framing of the new PIP which emphasizes independence – a major prerequisite of equal citizenship for disabled people (see section 2.6.1.1). This chapter provides an evaluation of the extent to which the Coalitions' linguistic support for independent living is reflected in the lived reality of their reforms. The chapter also explores the extent to which new approaches to the organisation of social care in Scotland (see section 3.4.1) have sought to advance the citizenship of disabled people living there.

The chapter begins by exploring participant's experiences of the new PIP (section 7.2). This policy was only in the early stages of implementation at the time that interviews were conducted. However, the findings presented here confirm findings

from the previous two chapters about the uncertainty generated by the reform process. The extent to which these changes have promoted a positive approach to disability citizenship is considerably less certain. The experience of participants awaiting announcement on the future of the ILF add further weight to these concerns (section 7.3).

Section 7.4 examines whether new approaches to the organization of social care in have enabled the advancement of the citizenship agenda in Scotland. Firstly, the extent to which participants had been able to realize the objectives of choice and control in their daily lives as well as in the provision and management of their care prior to the change is explored (section 7.4.1). While some participants were exercising considerable choice and control, many others lacked opportunities to realize this. The ability to manage their own care arrangements was not an easy or straightforward experience, however. This was largely due to the increased burden of administration that local authorities expected in exchange for public funds in the form of DPs.

Section 7.4.2 provides an early analysis of the impacts of changes to the provision of care and support for disabled people in Scotland following the passage of the Social Care (Self-Directed Support) (Scotland) Act in 2013. Again, while this policy change had enabled some participants to exert more choice and control over the provision of their care arrangements, this had not been the case for all. These findings add further support to concerns highlighted in the emerging literature on SDS. These have argued that in the context of fiscal austerity and constrained local government budgets decisions on SDS packages are being based not on the individual needs of the recipients, but rather on financial considerations (Pearson & Ridley 2016; see also discussion in section 3.4.1). This will have significant implications for the ability of disabled people to exercise choice and control in the future, and may see their citizenship further constrained.

7.2 PIP: promoting independence and advancing citizenship?

Discussion in section 3.4 explores the way in which the Coalition Government justified their redrawing of the disability category with reference to the language of the disabled people's movement. This was never more so than with the decision to rename the reformed DLA the 'Personal Independence Payment' (PIP).

Nevertheless, the conception of 'independence' understood by the Coalition was very different from that articulated by disabled people themselves (see section 2.6.2.2). Twenty-one out of 23 participants received DLA, and so the change was expected to affect the overwhelming majority of those involved in this study.

Interviews for this study took place relatively early on in the process (Autumn 2013–Spring 2014), and only one participant had been called to apply for the new benefit. As discussed in section 3.3.2, the transition had been beset by delays and was not expected to conclude until 2018 (Scottish Government 2014b). Hayley had completed and returned her application in January 2014, but by the time of her interview in April 2014, had still not heard back from the DWP about when she might be called for assessment. It was likely therefore her claim had been caught up in the delays affecting the new policy. This section therefore provides an early insight into participant's expectations of the new benefit.

The considerable media coverage surrounding the change meant that participants were mostly aware that the change was coming, although echoing discussion in section 5.5, there was still considerable uncertainty over how they thought they might be affected. The delays in processing applications had exacerbated participants' confusion about when the changes would take effect:

I've not been sent anything. I've got no information [but] if I didn't know any better, I would have thought I would have been reassessed before now. (Dennis, 35)

Other participants had received contradictory information from the DWP regarding when they might be called to apply for the new benefit.

It's very ambiguous. I'm more confused about what it is I could get and why and what is happening after I read that letter, because they don't make any sense, they're not clear. (Catriona, 29)

Having access to clear and accessible information is key to enabling disabled people to exercise choice and control over their lives. However, this early insight suggests that this was not something that was being prioritized as part of the move to PIP.

In addition, given the uncertainty over when participants could expect to be affected by the changes, there was also a lack of clarity over what moving to the new benefit might mean for them in a practical sense. Five participants were convinced that they would lose out as a result of the move to PIP. This was either because they felt that the new criteria were not suited to recognizing their impairments, or because they felt they were likely targets for a money saving exercise. Nine participants were determined not to think about what the changes might mean for them, or were entirely unsure about how they might be affected:

I think there's going to be a few years of discontent, you know, in terms of individuals who are rejected for it. And you know, I think I'll probably be in that category. I'll probably be going through an appeals process. I'm not sure what the appeals process is, I'm not, I've not looked into that. So, take one thing at a time. (Harry, 60)

...

I think my benefits will possibly drop quite a lot after getting reassessed. I haven't been called for reassessment yet, but by the time that all happens things will have changed, so I'm hoping kind of hard not to worry too much [...] I'm not going to start and get myself into a right panic just now. But I know a lot of people are. (Sophie, 47)

Around a quarter of participants in receipt of DLA expressed scepticism over the motivations behind the change to PIP. They were unconvinced by the emphasis on independence, and felt that the change was motivated more by the cuts agenda:

They already said before they started the reassessment process, that twenty per cent of people are going to be coming off that, now that tells you in itself what's motivating it. How do you know that twenty per cent of people are going to come off it without having done the reassessment process, and it shows you it's quite clearly driven by about saving money. (Anthony, 46)

As with the other reforms discussed throughout these finding chapters, participants' perspectives were heavily influenced by media reporting of the reforms. As highlighted in section 3.5, this contributed to a climate of fear around welfare reform, whether or not the coverage was supportive or critical of the changes taking place. The uncertainty expressed over the changes taking place compounded the feelings of insecurity and powerlessness discussed in section 5.5. When considered alongside the fear of the new assessment process, and some of the other impacts of reforms discussed in Chapter 6, this early insight suggests that the reality of the new PIP was failing to live up to the promise of its name.

7.3 The proposed closure of the ILF: a step backwards for independent living?

The ILF was established in the 1980s, and as discussed in section 2.5.3, although it came about somewhat by accident, it soon became a highly valued supplement to local authority community care. On coming to power, the coalition proposed to close the ILF with funding being devolved to local authorities in England and Wales, and to the Scottish Government (see section 3.5.3). The Scottish Government have since established an ILF Scotland scheme and opened this to new members, although at the time of interviews there was still considerable uncertainty over the future of the scheme. Following the announcement that the fund was to close, ILF had started to

conduct transfer interviews with beneficiaries in order to explore how they had used the scheme, and how they might manage when it closed. Four participants in this study received support from the ILF, and for the most part spoke warmly about the support it enabled them to receive in daily life, as Case Study 7.1 illustrates.

Case Study 7.1 The Independent Living Fund: Sheila's Story

Sheila was 62 and lived with her husband Steve in an adapted local authority bungalow. They had been married for forty years, and had two adult daughters. Sheila had worked as an administrator for much of her life, but had to give up working in the early 2000s after being diagnosed with degenerative disc disease. The condition affected her mobility, making it difficult for her to walk, stand, or sit for any period of time, and meant that she was in constant pain. Sheila had received a DP from her local authority since 2003 (see section 2.6.2.2), which she used to employ personal assistance through an agency. She had also received ILF since 2004, and used this to organize personal assistance for things not covered by the local authority, such as engaging in social activities. This had enabled her to take up various hobbies such as craftwork and baking. She had also been empowered to get out and about and live an independent life, doing things she enjoyed such as going to the cinema, the hairdressers, or going clothes shopping.

In 2012, Sheila had had a reassessment from her local authority as part of the move towards SDS (see section 7.4.2), and it was the first review of her DP in ten years. At the review, she asked the social worker for an increase in her hours of care, because she felt that her condition was deteriorating, and that she needed more assistance with household tasks. However, the council refused, citing budgetary constraints caused by the roll out of SDS. They suggested instead that she use some of her ILF funding to pay for more personal assistance at home. Sheila was very angry at this suggestion, because she felt that her ILF and DPs were intended for two very different things. She felt that her community care was already barely covering the things it was intended for, and resented having to give up her support for IL in order to supplement the 'life and limb' support she received from the local authority.

Sheila had had her transfer interview in 2011, and had described to them the difference that ILF had made to her life. Before she started receiving ILF she had been very isolated, and felt unable to leave the house. She spent much of her day watching television or on her computer. Her husband Steve had been her main carer at that time, and had also been working full time. He had had to get up at 6am to go to work, and then come home and do all of the domestic tasks like cooking, cleaning, and household food shopping. Sheila described how he quite often he didn't get to bed till after midnight, only to get up at 6am the following

day. He was also in a state of constant worry about Sheila while he was at work, concerned that she might fall and injure herself while he was away. The support Sheila received from the ILF and through her DP had enabled him to stop worrying about her during the day, and had meant that Sheila had assistance to do more of the cooking, cleaning, and shopping, as well as engage in her hobbies, giving her and Steve more quality time to spend together as a couple.

For her part, Sheila had talked to the ILF reviewer about the difference the funding had made to her life. She felt that her life had been immeasurably enriched by being able to use ILF funding to purchase personal assistance, and was terrified about what her life would become if she lost this support.

It was clear that the uncertainty over the future of the ILF was yet another source of anxiety and worry for participants'. Three out of four participants who received ILF felt that they would lose much of their independence if they had to rely on funding from their local authority alone. However, one participant, Bill, was less concerned about the source of his funding, as long as he received continuity of care. The different administrative requirements associated with his DP and ILF funding made it complicated for him to manage his care (for more on this see section 7.4.1.2), so a single source of funding would make things simpler for him. However, he was concerned about the way in which the transfer would be managed. Like Sheila, Bill had recently had his transfer interview from ILF and had found it an uncomfortable experience:

I would call it degrading. Asking you very personal questions outside your care needs: 'how much do you earn? How much do you have in savings? Do you have a partner?' It's nobody else's business! (Bill, 51)

Bill's description of the transfer interview echoes the experiences of participants who had been assessed for ESA and DLA in recent years (section 6.2.2).

Vanessa also received support from the ILF and was extremely concerned about what loss of funding would mean for her. She was due to have her transfer interview the week after we met, and was already marshalling her arguments for them.

Vanessa used her ILF funding to fill the gaps between support she received from the local authority and from the Access to Work scheme. Her local authority covered her support over night, but only one hour during the day, which was insufficient to help her get ready for work. She therefore used her ILF to fund extra time in the morning to enable her to get ready. As discussed in section 6.3, appearance is an important signifier of stigma, and for Vanessa being appropriately dressed for work was of great importance to her professionalism as well as her sense of self. She also used her ILF to enable her to take part in social as well as political activities, and felt that the loss of this would severely impact on her independence:

I wouldn't be able to go out and about, I wouldn't be able to do any political activism [...]. So, it would have a huge impact. I don't know where the money would come from. The local authority don't have it, and they wouldn't give it, but they don't have it. (Vanessa, 32)

Though existing beneficiaries of ILF have been transferred to the new ILF Scotland from June 2015, the anxiety experienced while the decision on ILF funding was being made exacerbated their existing fears and anxiety. This was therefore a period of considerable uncertainty for those taking part in this study.

7.4 Self-directed Support: promoting citizenship or marketization by another name?

While the rhetoric around PIP may not have lived up to expectations, reforms taking place at a local level in Scotland have provided some potential for a different approach. Discussion in section 3.4.1 highlighted the drivers behind the introduction of SDS in Scotland. Interviews for this study took place just prior to the implementation of SDS in April 2014. However, local authorities in Scotland were encouraged to prepare for implementation well in advance of this time. The findings reported here therefore provide an early insight into the experiences of the new policy by disabled people living in Scotland. This section begins by examining the extent to which participants were exercising choice and control over their care

arrangements at the start of this period. It then goes on to explore their experiences of the move towards SDS in order to examine the extent to which SDS was enhancing their citizenship through enabling greater choice and control.

7.4.1 Exercising choice and control? Participant experiences of Scottish Community

Care policy

This sub-section looks at the ways in which participants in this study were exercising choice and control over organization of their care arrangements at the time of interviews. It begins by exploring the different approaches to care provision, contrasting those that promote independent living with more traditional approaches to local authority community care. It also explores some of the challenges that participants faced in being able to manage their care arrangements. Finally, it considers the role of informal caring from friends and family.

7.4.1.1. Choice and control versus traditional service provision

All participants in the study received some form of support in their day-to-day lives, whether from friends and family, a local authority care package, or other forms of funding for social care, such as DLA and ILF (see section 2.5 for a discussion of community care policies). Thirteen of the 23 participants received support from their local authority whether through a DP or traditional services provided for them by an agency or the local authority. All but two used this for tasks traditionally associated with personal and social care in the home, such as washing or dressing, as well as assistance with cleaning and food preparation.

Eight participants also used local authority-funded support packages to get assistance outside of the home, helping them with shopping and other domestic tasks as well as leisure pursuits and general assistance to enable them to be out and about in their communities. The ability to make decisions about how their support was organized and delivered was highly valued by participants. It also enabled them to do things they might not otherwise be able to do:

We go out to museums, art galleries, we just go out for coffee, something that I don't feel able to [alone] do you know? Which is good. It gets me out the house. (Sophie, 47)

Like several other participants in this study (see section 6.4), Sophie had experienced harassment when out on her own in public. Being able to use her social care package to get out and do the things she wanted to was very important to her. Two participants had used their packages to fund places at a day centre, again enabling them to get out of the house. Another participant had used her social care package exclusively outside of the home, because she did not want to have strangers in her home.

The ways in which participants employed their package to arrange their social care varied considerably, as did the extent to which they were able to exercise choice and control over them. Eight participants were in receipt of a DP from their local authority and had used this to purchase personal assistance, either through an agency, by employing their own PAs, or a combination of the two. Six talked directly about how this had added value to their lives:

My friends would tell you that I'm a control freak anyway, that it's about that. It's really [...], because I can employ them, I've formally got a job description. [...] But it's as much, I suppose [...] about assisting me to do things, rather than them doing things for me. Now there are times when I have to say to them 'will you do this' you know and they just go ahead and do that. But for the majority of the part I try and be involved in that too. (Susan, 62)

This echoes Briesenden's (1986) definition of Independent Living that was adopted by the disabled people's movement (see section 2.6.1.1). The sense of being involved in her care, and being *supported* to do things, rather than having things done *for* her was critical for Susan, and epitomized the value of having choice and

control over her care package. Other participants talked about DPs as having given them considerable autonomy as well as flexibility to decide how best to meet their own needs:

It means security, it means being able to go out and do things, not feeling anxious about going out and being on my own, having to go to the toilet. Very fundamental things like that, you know? [...] It means that I can do things that would be more difficult to do if I didn't have the support. Some things I just couldn't do at all. Other things I might be able to do but it would be more hassle and awkward and difficult.
(Pat, 67)

Five participants did not use DP, but were receiving more traditional community care services provided either directly by the local authority, or by agencies contracted to work on the council's behalf (see section 2.5.3). Two participants expressed frustration at the lack of flexibility this enabled them over when and how their support was delivered, feeling that this arrangement was not really meeting their needs:

They [agency] don't do a good job of it at the best of times [but] they keep mucking up [my wife's] rota, which doesn't help. Keep giving us inaccurate information. (Michael, 41)

Michael's wife Hayley also expressed frustration that she had been unable to get the support she needed outside the home, such as helping her with shopping. Another participant felt that the support he had was adequate to meet his needs, but had found the experience of requiring support in his home to be very disempowering:

What I can't accept is this situation where I feel I can't do a lot of stuff. I feel frustrated, I feel lost, a lot of the time. [...] the feeling of desolation, of isolation, you just feel so inadequate. And even in your own home you feel so inadequate a lot of the time. (Lewis, 46)

This description of the disempowering nature of traditional service provision contrasts starkly with the empowerment that those in receipt of DP described when discussing their care arrangements.

7.4.1.2 Challenges to the exercise of choice and control

Participants using DPs had experienced a range of administrative and other demands that meant that exercising choice and control often came at a cost to their time and energy. The ways in which the introduction of SDS has either helped or hindered this will be discussed in section 7.4 (see also discussion in sections 2.4.2.2 and 3.3.3). This section instead focuses on experiences of using DPs prior to the introduction of SDS.

While the participants who had historically used DPs valued the flexibility they brought to enable them to meet their own needs, meeting some of the institutional requirements put in place by local authorities was challenging. One of the most basic issues was how local authorities determined the level of support available through a DP. Different authorities have different approaches to converting assessed need into hours of care in a DP. For many participants, the processes used by their own authority appeared un-transparent or even arbitrary. Four participants expressed frustration with this process, feeling that the focus was too much on the hours or minutes spent, rather than the opportunities that funding opened up to them.

The requirements of monitoring and reporting how funding had been used were another cause of frustration, particularly due to the level of detail some participants were expected to report in:

Every time there's a [payment] on your bank account, you have to explain that, and you have to provide the detail about the number of carers, if they're paid at enhancements.
(Susan, 62)

Monitoring requirements also varied according to the source of funding used, as was touched on in section 7.3. Five participants received financial support to pay for personal assistance in addition to their local authority packages, including the ILF and the Access to Work Scheme. Each of these organizations had their own monitoring requirements for the funding they provided, and they often differed considerably from those required by the local authority:

So the ILF only ask me to account for my funding once every two years [...] Local authority want every six weeks initially, and then every three months [...] and Access to work you have to apply for it and account for it every month. [...] my PA's wages are made up by all three. So I have to look at [their] payslips and have to work out how much of that came from which.

Participants also described facing challenges in meeting their obligations as employers. This has been identified as a particular tension in debates around personalization (Pile 2014), particularly with regards to preventing exploitation among an already undervalued and low-waged workforce. Those involved in this study who had responsibility for employing their own PAs⁶ took their responsibilities to their employees very seriously, and a number took particular steps to ensure that their employees were treated fairly and reasonably. This included recognizing different levels of education and training in staff pay grades, as well as paying enhancements for antisocial hours, and recognizing requests for flexible working arrangements. One participant also organized nights out and social events to give staff members who work in isolation opportunities to get to know each other.

While they took their own responsibilities to their staff very seriously, interviews revealed concerns that these obligations were not being adequately recognized by organizations providing funding. These concerns were particularly acute given the context of cuts to local government funding, and the introduction of SDS at a time of

⁶ Numbers of staff employed by participants varied from 1 to 8 depending on the size of the package they required, and what their needs were.

financial scarcity (see Pearson et al. 2014; Pearson & Ridley 2016). Participants were conscious that their funding arrangements could change and be reduced which put their employee's financial security at risk as well as their own. One participant had had direct experience of having to make staff redundant following the death of his wife with whom he shared a joint package of support:

I had difficulties finding the money to pay the four redundancies because the ILF were slow to recognize my legal responsibilities as an employer. [...] The ILF merely thought the money was there to spend on 'care', not to meet the duties and legal responsibilities of an employer. (Pat, 67)

SDS in Scotland is intended to increase the amount of choice and control individual disabled people have over their care arrangements (see section 3.4.1), and it is likely that the number of people employing their own staff will go up as a result. Local authorities therefore need to ensure that they are providing adequate support for and recognition of the responsibilities of acting as an employer.

In addition to their responsibilities as employers, participants also felt that the local authority and care providers did not recognize the relationships that exist between a disabled person and their PA. The frequently intimate personal care tasks required of PAs meant that this was an absolutely critical relationship to those involved in this study. Having a good relationship based on trust was therefore vital to ensuring that disabled people maintain choice and control over their care arrangements, and were able to live free from coercion and abuse. Five participants had had PAs who had been with them for a number of years, and talked about the closeness of their relationships with them. One participant had become so close to her PAs that she had asked two of them to be bridesmaids at her forthcoming wedding. Another talked of the feeling of grief she experienced when her council-employed care worker of twenty years retired:

I went through her mother's death, the death of one of her grandchildren, so we were really close. [...] I used to get the same Christmas present as her daughters. I was on kind of

that same level of in the family [...] it was very difficult after she left. (Sophie, 47)

Again, local authorities and social care agencies were not always sympathetic to strong relationships that developed between care users and their staff:

She [PA] actually got in trouble for being over friendly with me. I'm not supposed to talk about her family. I mean she's here all day today. What the hell do you talk about? [...] if someone's coming in to you every day, you are bound to get sort of personal. (Sheila, 62)

The personalization agenda, and the idea of increasing choice and control that social care recipients have over their support arrangements, is still relatively new and, particularly in Scotland, is part of a developing framework. Since the introduction of the first DP schemes (see section 2.5.3), CILs have provided support to individuals on DPs to meet their obligations as employers, including accounting and payroll services. However, there were only two CILs operating in the central belt of Scotland at the time of interviews. While both services were expanding their reach, they were still geographically bounded and had limited funding so were not able provide support to all who need them. This picture then was a far cry from that imagined in *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit 2005) which called for the establishment of a CIL in every local authority area by 2010 (see section 2.6.2.3).

7.4.1.3 Support from friends and family: supplementing and enhancing formal care

All but three out of 23 participants received some form of informal support from friends and family. For those in receipt of social care packages, this was over and above the support they already received, and often constituted a different, more emotional form of support. For those not in receipt of social care, three still had relatively high support needs and were reliant on help from their family or spouses in their day to day lives.

I've never had a care package in my life. I've been very fortunate as far as I'm concerned that the people who have met my care needs have been people that love me. Before I met and moved in with my girlfriend it was my parents, and it's my parents that do it now when my girlfriend's at work during the day. So I've never had a care package. (Anthony, 46)

Anthony had relatively high support needs, but felt strongly that care should be based on a reciprocal familial relationship rather than a financial interaction. Other participants spoke of the importance of the emotional support they received from their spouse as well as the practical support. For Adrian, who experienced depression and other mental health problems, the support he received from his wife was absolutely critical:

Without her, I would have killed myself by now, because she's the only thing that's keeping me alive at the moment. (Adrian, 50)

The remaining participants received assistance from friends and family on a more informal and ad-hoc basis. However, this assistance was still highly valued by them.

The sample also included two couples where both spouses had individually taken part in the study, each of whom provided mutual informal care to their partners. Both members of each couple received their own package of formal support from their local authority, although inevitably there was some pooling of resources. Participants also spoke of the importance of the emotional support they received from members of their wider families as well as their friends:

[We get] a lot of support from friends and family. Couldn't survive with just the council support. Need that informal support, emotional support too. (Dennis, 35)

Participants were clear about the value they placed on having informal support mechanisms from family and friends. However, in the climate of local authority cutbacks, where increasing emphasis is being placed on informal care, those who were also in receipt of social care packages were clear that the support from family and friends could not replace their formal arrangements. Exercising choice and control can be difficult when negotiating complex and unsympathetic structures involved in formal care (see section 7.4.1.2), but there is an added dimension when the carer is a family member or spouse. Participants had experienced frustrations when family members had done things they thought would be helpful, but had ended up causing them more difficulties:

My sisters [...] visit now and again, and although they don't mean it, they'll tidy up [...] and I'll not really notice that until [...] I go to find something [and it's not there]. (Peter, 50)

Peter had a visual impairment and had organized his home so that he could find things easily. His sisters' well-intentioned tidying had frequently caused him to misplace household and other items, which caused him considerable frustration. Such situations could be emotionally charged, making it harder for the individual to deal with in a way that preserved their autonomy. As a result, the majority of participants in receipt of formal care arrangements were keen to maintain a separation between formal and informal care tasks. This enabled them to continue exercising choice and control over their care arrangements while also enjoying the benefits of informal care without risking delicate family relationships.

7.4.2 Self-Directed Support in Scotland: renewing the citizenship agenda in Scotland?

Section 3.4.1 discussed the introduction of SDS in Scotland as part of a variety of approaches towards more personalized delivery of care. Uptake of DP in Scotland has historically been lower than England due to concerns about the marketization of care (Riddell 2006). However, as discussed in Chapter 3, the thinking behind SDS has more in common with marketization approaches such as personalization, than

DP which were campaigned for by disabled people themselves (Pearson & Ridley 2016). This section examines participants' experiences of the new SDS approach in order to examine its potential for enhancing citizenship through enabling more disabled people to exercise choice and control. Interviews for this study took place between November 2013 and July 2014, a time when many local authorities were making preparations for the Community Care (Self-Directed Support) (Scotland) Act becoming law (2013). As a result, many had begun to implement provisions to make SDS a reality for social-care users. These findings therefore represent an early snapshot of how SDS is being rolled out in local authorities in Scotland, and the impact the change is having on existing social care users.

At the time that interviews took place, seven out of the 13 participants in receipt of social care packages had been through a social care reassessment with their local authority as part of the move to SDS. One participant who was not receiving social care had also been involved in consultation by his local authority as part of their work to prepare for the act, because he was involved in a local SDS user group.

7.4.2.1 SDS and the local government funding crisis

Participants expressed some caution over the introduction of SDS. Most broadly welcomed the change and the reasons behind it, but were worried about what it might mean for them in practice, particularly in the context of local government budgetary constraints:

My concern is that there's not enough support, not enough infrastructure to make sure that people are able to use SDS properly. And there could be a lot of mismanagement and inappropriate use of SDS. There could be a real question placed over the future of SDS if people are not helped to manage it. And I don't mean monitoring. I mean help to use the system properly. (Pat, 67)

These concerns echo findings by Witcher (2014) that, without adequate support to make use of the new provisions, many disabled people will fail to benefit from the changes taking place. Pat had worked as a social worker in his professional life and felt that social work departments were becoming too focused on financial decisions, and the reality of tight budgets. This was causing them to lose sight of what could be achieved through the new system. Reiterating concerns expressed in section 5.4, Pat felt that the disability movement in Scotland had become too close to government, and too involved in the provision of DPs and supporting the introduction of SDS to be able to effectively lobby for change.

Other participants were also concerned that local authorities were using SDS as a smokescreen for cutting social care budgets:

I've worked in social work, and I know how difficult it is to balance resources [...] it's not an easy thing to do, and it's not easy for people to have to decide on priorities, [...] but] it was clear from the start that [SDS] was about a cost cutting agenda. (Susan, 62)

These concerns were particularly acute for participants who were already using DPs (which fall under Option 1 of the new SDS legislation; see section 3.4.1) prior to the introduction of SDS. Four participants had already experienced a reduction in their care packages as a result of the changes.

Case Study 7.2 Self-directed Support: Vanessa and Dennis's story

Vanessa (32) and Dennis (35) owned their own flat and had been living together for a year at the time of our interview. Their local authority had been one of the pilot areas for SDS in 2010, and had since started reassessing different client groups in anticipation of the Act coming into force. Vanessa and Dennis had both been reassessed for their social care funding around the time they moved in together. Vanessa's assessment was triggered by her moving from a different local authority, while Dennis's assessment was a part of the wider reassessment process. Between them, Dennis and Vanessa employed seven PAs, five of whom were employed by Vanessa, and two who were employed by Dennis, although in practice they both used all seven members of staff to meet their needs. Both worked full time,

and had been living independently and directing their own support arrangements for over ten years.

For many years Dennis had used an 'indirect payment' scheme (see section 2.5.3) to cover his personal assistance, which meant he was able to hire his own staff and decide when and how his care was organized, but that he did not handle any funding directly. Crucially this system meant that he did not have any monitoring or reporting requirements on his funding. However, with the introduction of SDS, the indirect payments scheme was being phased out⁷. Dennis had decided to move to a DP as a result of this change, but had done his best to delay the process, taking his time to complete forms and return paperwork. As a result, Dennis had only been receiving his DP for one month at the time of our interview. The process of moving to a DP had been a complicated one, and Dennis encountered a number of challenges along the way, including that the initial figure produced by the council's Resource Allocation System had proposed a significant cut to his allocated hours, from 31 to 23. Dennis had contested this and with the support of his social worker had eventually secured an assessment of 35 hours.

Vanessa had also experienced problems with her assessment. She had moved from a different local authority to be with Dennis, but expected to be assessed for a similar package of support to that she had received before. However, her initial assessment proposed a cut of 16 hours a week to her overall package. Vanessa had higher support needs than Dennis, and therefore used a complex package of support from three different agencies to organize her care (see section 7.4.1.2). While she had previously been able to balance these to ensure she received 24-hour assistance, her new assessment resulted in gaps when she had to manage without support. Like Dennis, Vanessa contested the assessment, but her social worker refused to back up her claim. Dennis and Vanessa had been able to pool some of their care allocation to cover some of these gaps, but this was having an impact on Dennis in subtle ways, for example, he was only getting help to shave once a week, rather than two or three times as had previously been the case.

These findings echo those of Pearson and Ridley (2016), who identified the tendency of local authorities involved in the test sites to focus on finance and budgetary considerations before outcomes. SDS has been implemented in a period of unprecedented constraint on local authority funding (see discussion in section 3.4.1). While additional sums were made available to promote innovation in the test sites, local authorities were expected to implement SDS from their declining core

⁷ Third-party arrangements are possible under SDS Option 2, but Dennis's Local Authority had decided to close down the existing system, and were yet to develop a new one to replace it.

budgets. However, as Pearson and Ridley (2016) have highlighted, the way in which some local authorities have used SDS to implement cuts to their social care budget has the potential to significantly undermine the original aspirations of SDS. These findings suggest that the implementation of SDS may have reduced rather than increased the amount of choice and control that existing users have been able to exercise.

7.4.2.2 Community care charges: passing on the costs of care

One consequence of introducing SDS at a time of unprecedented financial constraint has been an increase in charging for social care. As discussed in section 3.4.1, while personal care for adults over the age of 65 is provided free of charge, local authorities in Scotland can require recipients of social care to pay a contribution towards the cost of their package of support. Participants in this study were affected by charging policies in a variety of often inconsistent ways. Four participants were living in areas that had abolished care charges for all age groups, so were not having to pay towards the cost of their social care. Another participant was over the age of 65 and so did not have to pay a charge on his personal care, but was still charged for what was defined as 'domiciliary care' (cooking, cleaning, etc.).

One participant paid her contribution directly to the ILF, and this was deducted from the care component of her DLA. She was therefore exempt from local authority charges. Five participants were fully liable for charges, one of whom was expected to contribute 50% of any income he earned over a threshold of £120 per week. Another was retired, but was aged under 65 and so was being charged £560 per month for her care. She received £324 per month for her DLA care component so was having to meet the additional £236 out of her own pocket.

Decisions on who was liable for charging varied across local authorities as well, with some exempting those in receipt of the lower or middle rate care component, but not the higher rate from the means test. Often this was a rather arbitrary decision that bore little relation to the amount of care actually used by the individual, as illustrated by Case Study 7.3.

Case study 7.3 Community care charges: Lewis and Peter's stories

Lewis and Peter attended the same day centre, and were recruited jointly through a contact on the board, although they were interviewed separately. They were both members of the board of trustees, and had been attending the centre for a number of years.

Both Lewis and Peter had undergone assessments for SDS the previous year, and were using SDS Option 3. The council paid for blocks of places at the day centre, and they had each been allocated a place on the basis of their assessments. In addition to attending the centre, Lewis also received home help one day a week, but Peter's attendance was his only form of social care. Neither Peter nor Lewis was in employment at the time of their respective interviews, so going to the centre was an important source of social and emotional support through the relationships they had built there.

Peter received the higher rate of DLA and had been informed a month or so before our interview that the new charging policy being introduced as a result of SDS meant that he would have to pay £57.10 per week to cover his contribution. This was more than he could afford on a weekly basis and had therefore decided to stop attending the centre. He had also resigned his place on the board. Peter insisted that he had lots of friends and family, so was not likely to become socially isolated as a result of the change. However, it was clear how big a part of his life the day centre had been for him. Not attending was going to have a big impact not just risking social isolation, but removing what he saw as an important opportunity for him to contribute to his community through volunteering on the board.

In contrast, because Lewis was on the middle rate for DLA, he was exempt from the charge and was able to attend the day centre, and receive his home help without having to pay a contribution towards this.

The varied experiences of community care charges described by participants in this study underlines the postcode lottery of care that has been characteristic of community care since the 1970s (see section 2.5.3). This has important implications for disabled people's mobility. Moving from one local authority to another, for example, for work could mean not only a different community care assessment (as in Vanessa's case; see Case Study 7.3), but also a different charging regime. Local authorities are understandably concerned about further centralization of their powers, and are keen to maintain their role in delivering frontline services to communities. It is undoubtedly the case that they are well placed to do so. However,

this should not come at the cost of enabling disabled people to live independent lives.

7.4.2.3 Embracing the options for choice and control or business as usual?

One of the aims in the introduction of SDS was to address the historic underrepresentation of DPs users with mental health problems and learning disabilities. This was to be achieved by enabling greater flexibility over the way in which people were able to direct their support arrangements through the four different SDS options (see section 3.4.1). At the time of interviewing, local authorities were still getting to grips with their obligations under the new Act, and working out what the different options would mean for service users in practice. Discussions with participants raised some concerns that some local authorities, including those who had been involved in the pilot projects (see Ridley et al. 2011), were not promoting the full range of options available, and were instead favouring traditional service provision (SDS Option 3). Again, Lewis' experience provides a useful illustration of this (Case Study 7.3). Lewis had undergone an assessment for SDS with his social worker, but had been put off the idea of moving to a DP, partly because he was worried about the additional obligations of becoming an employer:

There's a lot of people terrified of it. Because they're then bound by employment laws and all that gambit. Do they have to have fire extinguishers in their house? You know, there's a whole host of issues that it brings in. (Lewis, 46)

This is very a legitimate concern, as discussed in section 7.4.2.1. However, the options contained within SDS should have enabled Lewis to increase the amount of choice and control he had over his care arrangements without directly employing staff. Option 2 provided the opportunity for service users to direct their own support, but with the local authority managing their budget on their behalf. This was similar to the original 'indirect' payments model pioneered by disabled people in some local authorities in the 1980s (see section 2.6.2.2). I asked Lewis if he had been given any other options for his care. He told me that he had been put off looking at other

options because his social worker had warned him that he risked losing his support during the transition. Instead, Lewis had been given a list of approved providers from which he could 'choose' who delivered his home help service. This suggests that some local authorities may not be fully engaging with the potential that Option 2 presents for a different approach to DP. Again, this echoes findings by Pearson & Ridley (2016), who found that in April 2015, 70% of local authority service users were still receiving support under Option 3 (traditional service provision) and only a fraction of local authorities had users under Option 2. Similarly, a survey of SDS users found that 44% of respondents were unaware of the changes to support, and only 33% had been made aware of all of the options when they met with someone to discuss their support (Ramasawmy 2016). Additionally, the survey found that only a small proportion of respondents were using Option 2, and even fewer were aware of, and understood, how it could be used to support them (ibid). This means that the opportunities for increased choice and control presented by SDS may not be being realized.

Another important feature of the legislation for SDS was to encourage a shift in emphasis away from task and time, towards a more outcomes focused approach to delivering social care (see section 3.4.1). Local authorities were therefore expected to support service users to identify the outcomes they wanted to achieve as a result of receiving a social care package, rather than the particular tasks that they want to have done. This represents a significant change in thinking around social care and there was some scepticism among existing DPs users that this shift would be significant enough to overcome the reality of constrained budgets. One participant had experienced a positive change in her arrangements as a result of the new outcomes focused approach. Sophie had used traditional home help services for 20 years, but had recently been assessed for SDS. She had felt that she wanted more support with getting out and about in her community, and had been granted a DP to employ a PA to help her do this. However, she felt that the change, although positive, had come at the cost of her ongoing need for more traditional support:

The thing that really annoyed me was when [local council] came back and said, yes you can have [a DP] but you can't use it for housework. [...] I can't wipe stuff up, and if I

started walking on wet floors I'd end up with broken legs. I slip and fall anyway, and it's just going to get really dangerous. So I do use it for housework; I just don't tell them. (Sophie, 47)

Sophie's experience suggests that a balance needs to be struck between the traditional approach of task and time and an outcome focused approach that empowers participants while still enabling their needs to be fully met. These two cases also highlight the differential interpretations being made of the SDS in different local authorities.

At the time of writing, the implementation of SDS in Scotland was still in the early stages and it is acknowledged that it represents a significant change from traditional service provision, and will therefore take time to adapt to. Interviews in this study were conducted only very early on in this process, with most of them taking place before the Act had become law. However, this early snapshot does raise important questions about the approach of some councils to this process. The legislation explicitly emphasizes the importance of enabling social care users to exercise greater choice and control in the provision of their care arrangements. The supporting documentation also foregrounds issues such as equity, human rights, and the importance of taking a person-centred approach to care. The experiences of participants in this study suggest that for some local authorities the process has instead remained focused on issues related to resource allocation and time, rather than what social care users can do to achieve their own objectives. Given the reductions in the Scottish Government block grant to local authorities since 2012, and the continuing freeze on revenue from the council tax (Spowart 2012), it is perhaps unsurprising that resource continues to be a pressing concern when implementing the changes. However, as discussed throughout this thesis, disabled people have faced an uncertain future as a result of changes to benefits at a UK level and the challenges to their financial security that has entailed. SDS has the potential to offset some of these losses, and it would be unfortunate if it ended up compounding them instead.

7.5. Summary

This chapter has provided an evaluation of policies introduced between 2010 and 2015 that have drawn on the language of citizenship. While the 1990s and 2000s saw significant strides forwards in the citizenship agenda, the period from 2010 to 2015 has seen these gains challenged. The chapter began by exploring the impact of recent policy changes relating to independent living at a national level. It found that while the Coalition have explicitly drawn on the language of the disabled people's movement in the framing of the PIP, this discursive support for IL has not been reflected in the early days of implementation of this policy. Instead, delays and lack of information were causing difficulties for participants. This has compounded the sense of powerlessness articulated in Chapter 5. Similarly, although the ILF was used by only a small proportion of participants, uncertainty over the closure of the fund was also causing anxiety and concern for participants, many of whom had gained greater choice and control in their lives as a result of support from the scheme. The ILF Scotland was established in July 2015, providing support for existing ILF beneficiaries in Scotland as well as opening up the scheme to new members. However, the announcement of that was made only after the interviews for this project had been concluded. The period of uncertainty over the future of the fund was therefore an issue of acute concern, and served to further undermine the Coalitions claims to the language of citizenship.

Finally, this chapter provided an early insight into the impact of changes to the provision of social care in Scotland through the introduction of SDS. This policy had considerable potential to pioneer a different approach to that being pursued by the Coalition Government at Westminster. This section began by exploring the extent to which participants in this study were supported to exercise choice and control in their daily lives at the start of the period under consideration. It found that while a small group in receipt of DPs were exercising considerable choice and control over their care arrangements, the vast majority were restricted by traditional forms of local authority provision in addition to informal care. Where DPs had enabled greater control over support arrangements, this often came at a cost in terms of the additional burdens of administration and of acting as employers. Services were not well set up to recognize the challenges this brought to individuals, and often

compounded the difficulties faced. This has been a long-term problem for DPs users and was identified in early research into DPs in England and Scotland (Pearson 2000).

The introduction of SDS had considerable potential to increase the amount of choice and control that service users have within the system. While the change had benefited some participants, the challenges of implementing the new approach at a time of local government funding problems were making the benefits harder to realize for others. The outcome of this was that the process was being perceived by some participants as little more than a cost cutting measure, particularly where it was being combined with changes to local authority charging policies. These findings also suggest that opportunities to exercise choice and control within the various SDS options may still be being restricted to particular client groups, with some client groups being actively deterred from options that involve more choice and control. This supports findings by Pearson and Ridley (2016) that local authorities have been resistant to exploring the full range of options under SDS, preferring instead to prioritize traditional service provision.

This chapter demonstrates that where policies designed to support disabled people to exercise choice and control over their care arrangements have worked well they have had a significant positive effect on the ability to achieve independent living. However, where choice and control have been secondary considerations to those of finance and budgeting, this has served to limit access to independent living. Adopting the language of citizenship without ensuring the involvement of disabled people in shaping the design and implementation of policy does not therefore guarantee a positive outcome. The next chapter concludes this thesis by outlining the ways in which the findings in this and the previous two chapters contribute to knowledge. It also presents a number of recommendations for future policy in this area, before discussing recommendations for future research.

Chapter 8 Conclusion

8.1 Introduction

This study has examined the impacts of changes to disability benefits which took place between May 2010 and May 2015 on disabled people living in Scotland. The findings presented in the previous chapters have contributed to knowledge in this area in four key dimensions. Firstly, they have added weight to literature highlighting the limitations of approaches to policy which take a narrow view of human agency by demonstrating the many and varied ways in which disabled people in receipt of benefits can and do act. A consequence of the restricted view of agency highlighted by this study, has been the extent to which policy has served to disempower disabled people, restricting their capacity to contribute to society through work or other means. Secondly, findings contribute to literature conceiving of disability as an administrative category, and provide evidence of the impacts of this on disabled people themselves. Thirdly, this thesis has drawn connections between literature exploring processes of ‘welfare surveillance’ and those highlighting ‘vindictiveness’ as a consequence of neoliberal discourses on benefits. Finally, this work has provided an early snapshot of the operation of new approaches to the organization of social care in Scotland. While the outcomes-focused approach of SDS had considerable potential to increase disabled people’s choice and control in their daily lives, this had been undermined by the local authority funding crisis. Budgetary considerations had therefore taken precedence over expanding the citizenship agenda.

This chapter draws together the discussion of findings presented in Chapters 5–7 in order to demonstrate this contribution. It begins by restating the research questions and synthesizing key findings arising from each of these. The way in which these findings contribute to knowledge is outlined alongside a brief discussion of the bodies of literature they help to inform. The contribution of this thesis is important not only in terms of the way in which it informs academic debates, but also in relation to future policy. Significant changes to the constitutional status of Scotland and the devolution settlement have taken place since the conclusion of fieldwork for this study, making this all the more pertinent. The second section of this chapter

therefore outlines a number of policy recommendations for both Westminster and Holyrood. This was a small study with limited resources, and it is in the nature of such studies that they often raise more questions than answers. The penultimate section will therefore indicate issues that require further investigation.

8.2 Synthesis of findings

Research undertaken for this study was concerned with answering three questions:

- 1) *Policies promoting a conditional approach to the receipt of benefits are based on certain assumptions about recipient's agency. To what extent are these assumptions reflective of individual disabled people's attitudes to benefits and the labour market? In what ways have disabled people been affected by the intensification of conditionality?*
- 2) *The reform of ESA/IB and DLA/PIP has been characterized as a redrawing of the disability category in response to a perceived crisis. In what ways has this reform impacted on the experience of claiming and using disability benefits? In what ways have disabled people been affected by popular and media narratives supporting the reforms?*
- 3) *Policies adopted both at Westminster and at Holyrood between 2010 and 2015 drew heavily on the language of the disabled people's movement, emphasizing concepts like independence. To what extent have these policies enhanced disabled people's citizenship status during this period?*

This section briefly synthesizes the ways in which the findings outlined in Chapters 5–7 have answered these questions. The profile given to welfare reform during the Coalition Government's tenure in office has meant that there is a considerable literature concerning the impacts of the changes on different groups across the UK. This thesis therefore makes a general contribution to these literatures. However, it is also among the first substantive pieces of work to examine the impacts on disabled people living in Scotland. As highlighted in the introduction to this chapter, the thesis

also makes a specific contribution across four key dimensions: firstly, to debates around the agency and assumed agency of those in receipt of disability benefits; secondly, to the understanding of disability as an administrative category, and the implications of this for policy; thirdly, in connecting literatures concerning the narrative trends around reform to those concerning surveillance, vindictiveness, and resentment; and finally, to the literature on ‘personalization’ in health and social care and the emerging body of work on the impact of SDS in Scotland. This section outlines this contribution in more detail, with reference to some of the relevant bodies of literature in this field.

8.2.1 Debating conditionality through structure and agency

- 1) *Policies promoting a conditional approach to the receipt of benefits are based on certain assumptions about recipient’s agency. Therefore, to what extent are these assumptions reflective of individual disabled people’s attitudes to benefits and the labour market, and in what ways have disabled people been affected by the intensification of conditionality?*

Discussion in section 3.3.2 explored some of the theoretical underpinnings of policies which make the continued receipt of benefits conditional on certain behaviours, as well as highlighting some important critiques of these approaches. Narratives supporting welfare reform have tended to focus on negative agencies depicting benefit recipients as either passive or as cheats. Policy responses have therefore emphasized the need to correct negative behaviours and ‘activate’ individuals into employment. Findings presented in Chapter 5 explored the ways in which agency was expressed by people in receipt of disability benefits, using Lister’s (2004) taxonomy of agencies ‘getting by’, ‘getting (back) at’, ‘getting out’, and ‘getting organized’ as a conceptual frame. A key finding highlighted in this chapter was that individuals who used disability benefits express a range of different and varied agencies. However, these were becoming increasingly constrained as a result of financial pressures and worry over their future benefit status.

Discussion in Chapter 5 began by exploring the different and varied ways in which those involved in the study used the benefits they received to meet everyday living costs, as well as to cover the additional costs of impairment. Findings presented in this section shed light on the range of coping strategies employed by people using benefits, expanding Zeilizer's (1989) concept of 'special money'. Participants were keen to emphasize that they were using benefits 'as intended', but they also demonstrated considerable agency and creativity in the way they managed these to meet their needs. Benefits such as DLA can be used both in and out of work, and those in work often made a distinction between employment income and benefits, ensuring that they used their benefits 'as intended'. In this sense payments took on a greater meaning and were used as a form of 'special money'. Respondents demonstrated the considerable value that receiving benefits, in particular DLA had brought to their lives. Nevertheless, in the context of welfare reform and the aftermath of the financial crisis many were finding that 'getting by on benefits' was becoming an increasing struggle. They had adopted a range of everyday coping strategies, including curbing spending and budgeting for future losses. Those with income from work or occupational pensions were finding this easier than those who received benefits alone. Respondents' feelings about their circumstances were also strongly influenced by gender norms, which demonstrated the continued relevance of applying a gendered lens to the process of 'getting by' (Kempson et al. 1994). Those involved in this study were facing an increasingly uncertain future. Many were aware that reforms were on their way, but were unclear about how they would be affected by these. This made it very difficult for them to plan and anticipate, meaning that their ability to 'get by' was likely to be reduced in the future.

The second section of Chapter 5 discussed attempts to 'get out' of the benefits system typically through trying to find paid work or increasing hours/boosting earnings. These findings challenge some of the thinking underpinning conditionality policy which suggests that those in receipt of benefits are unwilling rather than unable to work (Mead 1997; Murray 1990). A third of participants in this study were already in work, while a further third had worked for many years prior to retiring. All but one participant had had some experience of employment, although those who

were not in work felt that they had legitimate reasons for not being so. They also described facing considerable barriers to finding and retaining work.

Narratives supporting welfare reforms have tended to prioritize work as the hallmark of 'active' citizenship. Those involved in this study demonstrated that disabled people can and do make a range of contributions to society whether they are in work or not. Nearly all took part in some form of volunteering activity on a regular basis, although this was partly reflective of the sampling method employed to recruit participants. Volunteering opportunities were discussed as having provided considerably more flexibility than the paid labour market, making it easier to be involved. Participants felt that they had gained significantly as a result of their volunteering activities and described feeling that they were 'giving something back'. However, the negative discourses around welfare reform were making this harder for some, a theme which was developed in Chapter 6. These findings give support to arguments within disability studies that call for the reframing of citizenship and the labour market in order to recognize the contributions that disabled people already make (Morris 2004; Barnes & Mercer 2005).

Findings presented in Chapter 5 also add weight to literature critiquing the efficacy of contracting arrangements in employment support epitomized by processes such as 'creaming, parking and churning' (Finn 2008; Rees et al. 2013). Despite the policy emphasis placed on conditionality, the majority of those involved in this study were not expected to meet conditions in return for their benefits, and none had experienced sanctions. Those in the WRAG had varied understandings of the conditions imposed on their continued receipt of benefits. The chapter also highlighted a lack of clarity over the work programme and who was expected to take part in it. Participants who had received support through the WP felt that they had been cycling from one scheme to the next without seeing positive outcomes in improved employment prospects. Though participation in the WP is voluntary for those in the Support Group, none had taken advantage of this support. It is possible that the punitive elements of conditionality had acted as a deterrent to individuals who might have benefitted from taking part but were unlikely to be able to return to work immediately.

Finally, Chapter 5 explored agency as expressed through ‘getting active’ in response to welfare reform. The period in question witnessed a rise in new groups of disabled activists campaigning against welfare reform. A number of respondents in this study had been inspired to become politically active. Others had been involved in earlier activist campaigns through the disabled people’s movement including the campaign for DPs. Again, this was partly reflective of the sampling strategy employed in this study which involved working with DPOs to recruit participants (see section 4.5.2). Nevertheless, as discussed in section 3.5.2, the impact of new activist groups was not widespread (Pearson & Trevisan 2015). The majority of respondents were not convinced by the potential of activism to improve their situation, and instead expressed a sense of powerlessness in the face of the changes taking place. This was compounded by the scale and ambition of the coalition’s welfare reform programme as well as the ‘climate of fear’ generated by some of the discursive elements of welfare reform (see section 3.5).

The findings presented in Chapter 5 provide an important counter to debates driving welfare reform that have drawn distinctions between indigent benefit claimants, and ordinary, hard-working people (Baumberg et al. 2012). They also give support to literature calling for a more pluralistic approach to the understanding of human agency in the context of benefit claiming (Hoggett 2001, Wright 2012). In particular, they add weight to arguments that policies which assume a narrow capacity for agency may be ineffectual because they bear little relation to the lived reality of those in receipt of benefits (Hoggett 2001). These findings also demonstrate the ongoing relevance of Lister’s (2004) taxonomy, enabling an understanding of the complex interplay of different agencies that can be exhibited by people experiencing poverty. Many of the interviewees in this study were in work or had considerable labour market experience, but also faced significant barriers to continued or future employment. They also demonstrated a range of different forms of agency, not least in the way in which they used declining incomes to meet their needs, as well as preparing for future losses. Agency was also evident in the range of volunteering activities listed, in as well as through engagement with new activist groups. These findings have highlighted that policies which are based on a two-dimensional conception of agency may miss the many and varied ways in which people can and do act. The goal of such policies is to stimulate activity within a narrowly framed

world of work. However, by undermining the value of other forms of contribution they run the risk of closing off opportunities for civic engagement.

While retaining a pluralistic approach to understanding human agency, discussion in Chapter 5 also provided evidence in support of debates relating to the continued relevance of structure in the experience of social policies. While Hogget (2001), Lister (2004), and Wright (2012) all emphasize the importance of recognizing agency, they caution that this should not be to the exclusion of agency. The importance of this is evident in concepts such as 'resilience' that were popular with the Coalition, but tend to individualize the challenges that are faced by people experiencing financial constraint (Dagdivierien et al. 2016). Chapter 5 also highlighted the overwhelming sense of powerlessness experienced by participants in the face of changes they had no control over. However, the ability of participants to 'get by' on their benefits, or to adapt to anticipated changes, was very much dependent on their social circumstances. This serves to emphasize that individuals ability to take action are therefore still constrained by certain structural factors that shape the boundaries in which they act (Hogget 2001).

8.2.2 Evidencing disability as an administrative category and charting the rise of 'welfare surveillance'

- 2) *The reform of ESA/IB and DLA/PIP has been characterized as a redrawing of the disability category in response to a perceived crisis. In what ways has this reform impacted on the experience of claiming and using disability benefits? In what ways have disabled people been affected by popular and media narratives supporting the reforms?*

Chapter 2 highlighted that the way in which disability is understood by policy makers has an important bearing on the way in which policies are experienced by disabled people (Drake 1999). Findings presented in Chapter 6 contribute to arguments that the reforms pursued by the Coalition Government represented a redrawing of disability category. These findings build on the work of Stone (1984), who first

conceptualized disability as an administrative category. Stone's analysis was initially developed over thirty years ago, and focused largely on policy processes rather than on the lived experience. Nevertheless, as demonstrated throughout this thesis, her conception of disability continues to hold relevance in the present day. This has been underlined by the more recent work of Roulstone (2015) who has updated Stone's analysis in light of the Coalition's welfare reforms (see section 3.2). Again, while making an important theoretical contribution, Roulstone's work is based largely on narrative accounts of newspaper cuttings, rather than through interviews with disabled people themselves. Chapter 6 explored participants' experiences of negotiating this restricted category. It found that the process of applying for disability benefits was becoming increasingly complex. This was particularly so for those seeking to transfer from IB to ESA, although those applying for DLA were also finding the assessments more restrictive, even prior to the migration to PIP. The emphasis given to medical criteria in determining eligibility had presented challenges to those without medical diagnoses for their impairments, or who experienced variability in their conditions. Many participants felt that the forms were restrictive and prevented them from adequately expressing the way in which their impairments affected them in daily life. The findings presented in Chapter 6 therefore provide empirical support to both Stone (1984) and Roulstone's (2015) theses, grounded in the lived experience of disabled people. In doing so they provide an insight into the experience of negotiating the redrawn disability category.

Inclusion in the disability category has historically involved exempting those who qualify from the requirement to participate in paid work. An important mechanism for controlling entry to the disability category has therefore been the ability to apply objective criteria to validate the existence of 'disability' (impairment) (Stone 1984). The extent to which medical testing can accurately or fairly assess capacity for work has been a contentious matter in the literature (Baumberg et al. 2015; Shakespeare et al. 2016). Section 3.2 highlighted the influence of the BPS on approaches to assessing eligibility (Waddell & Aylward 2010; see also section 3.2.1.1) as well as discussing critiques of this approach (Roulstone 2015; Shakespeare et al. 2016). Findings in Chapter 6 examined participants' experiences of assessment. Respondents articulated a sense of fear and mistrust over the impartiality of the assessment, expressing concerns that it had been designed to catch them out. This

was compounded by the increased regularity of assessments and the uncertainty over what this might mean for individual claimants. Assessments were also experienced as invasive and demeaning. Some had found the experience of being assessed so traumatic that they were considering stopping their claim rather than go through it again. The availability of advice and support to enable them to negotiate the complex applications and assessment process was critical to obtaining a positive outcome. However, pressures on funding and the growing demands of the restricted eligibility criteria were making this support harder to access. These findings contribute to debates around medical testing of 'fitness to work' by providing empirical insights into the experiences of these assessments.

A further contribution made in Chapter 6 was through the application of literature on surveillance and self-surveillance to the experience of disability benefit claiming. The concept of 'welfare surveillance' (Henman & Marston 2008) has received growing attention in this regard though discussions surrounding the mechanisms required to enforce conditionality policy. As I have argued elsewhere (Manji 2016) the findings presented here expand on the concept of 'welfare surveillance' to demonstrate the ways in which official expectations contribute to a form of 'hidden conditionality' in operation both in the context of and outside of the assessment process. The emphasis placed on continually meeting the requirements of medical assessments in Coalition policy led participants to feel that they were under surveillance, causing them to adopt 'self-surveillance' (Foucault 1991; Vaz & Bruno 2003) techniques in order to meet the expectations placed upon them. Individuals spoke of feeling that they had to conform to certain behavioural expectations around how disabled people 'should' behave. This involved emphasizing things that they were unable to do, rather than things that they could. They also spoke of dressing in a particular way to attend assessments in order to signify their conformity with 'what was expected' of a disabled person. These expectations were informal and therefore subtle, but no less real. Those involved in this study felt scrutinized by official agencies of the state, but also by members of their own communities.

That these processes were adopted not only in the context of formal assessments, but also in response to the fear of surveillance from communities was an important insight. Findings went on to draw connections with these processes, which can be

likened to a form of 'sousveillance' (Dennis 2008), with literature on 'vindictiveness' and 'resentment' as social consequences neo-liberal welfare reforms (Young 2003; Hoggett et al. 2013). Section 3.5 discussed the ways in which discursive elements of the Coalition's reforms had contributed to a climate of fear for disabled people. The findings presented here have demonstrated that these fears are well founded given the growing public hostility towards disabled people. This was evident in experiences of harassment and hate crime against participants in this study. A distinction was apparent in the treatment of those with visible and unseen impairments, although both groups had been affected by this trend. Those with unseen impairments had experienced a growing sense of disbelief in the legitimacy of their disability status. Those with more visible impairments had experienced more violent incidents, including targeted harassment and physical assault. This was having a negative impact on their sense of self, generating feelings of shame at receiving benefits among a small proportion of participants.

This study has also differed in an important respect from much of the emerging literature on the social consequences of 'vindictiveness' and 'resentment'. This has generally pointed to the internalisation of these debates by individuals living in poverty, as is evident in studies which have explored the experiences of benefit recipients experiencing shame over their status, and co-shaming as a result (Chase & Walker 2012; Garthwaite 2015; Baumberg 2016). While a small number of participants in this study echoed some of these sentiments, the vast majority were explicit in their rejection of these narratives. They were also keen to highlight the positives that receiving benefits had brought to their lives, despite the indignities they had experienced in claiming them. They also shared a sense of solidarity with other benefit recipients. Nevertheless, despite the fact that co-shaming was not a strong feature in this study does not mean that the internalization of negative rhetoric will not be a longer term consequence of the reforms. The participants in this study were largely well educated, and many had a history of involvement in activist groups, so may therefore have been more likely to challenge dominant narratives than to internalize them.

In summary, findings presented in Chapter 6 have revealed the impacts of a destructive undercurrent of blaming in narratives on welfare reform. The increasing

reliance on medical testing to demonstrate eligibility to disability benefits has served to reduce the disability category. However, it has also resulted in a diminished conception of disability in the public consciousness. While disabled people have historically been viewed as ‘deserving’ of assistance (Stone 1984; Roulstone 2015), the recent round of reforms has seen a shift in this status. This has generated feelings of mistrust and resentment against disabled people who do not meet cultural expectations of appropriate behaviour. That these feelings of resentment have increasingly caused people to ‘act out’ against disabled people perceived as undeserving or in receipt of preferential treatment is a worrying trend. Though the cultivation of this narrative was intended to build popular support for the changes, an unintended impact may be that disabled people become less able to participate in public life, including in the labour market. A longer-term consequence of the Coalition’s programme may therefore be that disabled people become more isolated from society. This could lead to increased demand for out-of-work benefits and additional pressures on the public purse, which could undermine the original intentions of the reforms that have taken place.

8.2.3 Interrogating the language of citizenship

- 3) *Policies adopted both at Westminster and at Holyrood between 2010 and 2015 drew heavily on the language of the disabled people’s movement, emphasizing concepts like independence. To what extent have these policies enhanced disabled people’s citizenship status during this period?*

Chapter 7 of this thesis examined a divergence from the traditional approach to redrawing the disability category evident in the Coalition’s welfare reform agenda. Stone (1984) outlined that social and moral understandings about the boundary between work and need are an important influence of where the disability category is drawn. That these became more conservative during the Coalition’s tenure is clearly evident from findings presented in Chapter 6. However, Roulstone (2015) has observed that while cultivating a blaming narrative around benefit recipients, the language used by the Coalition to justify the changes closely mirrored that of the disabled people’s movement. This study has contributed to the understanding of this

important contradiction by examining the way in which policies presented in the language of citizenship have been experienced by disabled people themselves.

The chapter began by exploring impacts of the move from DLA to PIP and the proposed closure of the ILF. Only one participant had been called to migrate to PIP at the time of interviews, although a striking finding was the lack of knowledge among participants as to what the move to PIP would actually mean for them. Delays in implementation had also meant that, while the majority of those in receipt of DLA were aware that something was due to change, few were sure when this would happen. This compounded the sense of uncertainty discussed in Chapter 5. Discussion of the reasons for the move was tinged by discourses around cost savings for government. Participants were sceptical that the new benefit would enhance their experience of independent living, and were concerned that it would lead instead to reductions in their quality of life.

Discussion in the first part of Chapter 7 also explored the impact of the proposed closure of the ILF, as well as plans to devolve it to the Scottish Government. While the Scottish Government have since established a new ILF Scotland which safeguards existing members while at the same time opening the scheme to new applicants, at the time of interviews there remained considerable uncertainty over the future for those in receipt of ILF. Participants who used ILF discussed the way in which they used it to live independently, enabling them to take part in activities that would not be covered by their local authority care packages. The proposed closure was therefore a further cause of anxiety. One participant was unconcerned, provided his level of support remained the same. However, the rest were anticipating a reduction in their support, and worrying about how they would manage. Findings in this study therefore develop Roulstone's (2015) observation to suggest that the use of language may merely have been an attempt by the Coalition to obfuscate or conceal their true intent. Despite adopting the language of the disabled people's movement, the Coalition's policies may instead serve to reduce disabled people's independence, setting back their ability to live independently and further eroding their citizenship status.

The second section of Chapter 7 contributed to wider debates around ‘personalization’ of social care by exploring the implementation of SDS in Scotland. In doing so it has provided an important insight into the perspectives of service users on these debates. Research into service users’ experiences of the policy change took place as part of the evaluation of the SDS test sites (Ridley et al. 2011). Similarly, small-scale pilot projects have focused on the potential for the new policy to enhance choice and control for those in receipt of SDS (Witcher 2014). These qualitative findings have been supplemented by evidence from a pilot survey into users’ experiences (Ramasawmy 2016). The findings presented here therefore contribute to an emerging body of literature into user experiences of SDS.

The majority of interviews took place before the SDS Act came into effect, although local authorities were encouraged to take steps to prepare for the change well in advance of this and many of the participants had already begun to feel the effects of the move. The section began by exploring the extent to which participants felt that they were able to exercise choice and control in the organization of their social care. It found that those who had used DPs to employ PAs were able to exercise considerable choice and control. However, in some cases this came at a cost in terms of the administrative burdens they faced in managing their DP. Those who were using traditional services appeared to have significantly less choice and control over how their care was organized. Participants also spoke about their experiences of informal care, and the importance of the support they received from their friends and family. Nevertheless, they were keen to highlight that familial relationships were very different from formal care arrangements and came with their own tensions over the exercise of choice and control.

Participant’s perspectives on SDS were heavily influenced by their experience of cost cutting measures and the need for budgetary constraint emphasized by councils in conducting assessment. While the move to SDS had been broadly welcomed by interviewees, many had reservations over the extent to which the promised improvements would be realized. This was particularly so given the context of the local authority funding crisis in Scotland. Participants who had already received SDS assessments felt that these had focused more on budgetary considerations than on achieving the individual’s expressed outcomes. These concerns were exacerbated

by the decision of some local authorities to combine the introduction of SDS with a renewal of their charging policy. Experiences of participants in this respect served to underline the postcode lottery (Morris 2004) that continues to exist in local authority community care, reducing the potential for individuals to exercise choice and control. Participants' experiences also highlighted that many authorities were struggling to overcome path dependencies (Pierson 1998) in relation to the provision of social care, and were therefore not exploring the full potential provided by the four SDS options. The findings here therefore also add weight to research by Pearson et al. (2014) and Pearson and Ridley (2016) who have emphasized that the implementation of SDS may have been the 'right policy at the wrong time.' The wider literature on 'personalization' elsewhere in the UK (Beresford 2009, 2014; see also section 2.6.2.2) has highlighted that policies have tended to see control resting with professionals, rather than with disabled people themselves. Similarly, discussion of the implementation of DPs in Scotland highlighted the increased administrative burdens on service users, and the reluctance of councils to cede control to individuals (Pearson 2000; Riddell 2006). This thesis has demonstrated that, so far, SDS not been a revolution in social care, and many of the old challenges have persisted with councils continuing to take a paternalistic approach to disabled people's capacity to exercise choice and control.

Chapter 7 demonstrated that, despite explicit reference to the language of 'independence' and citizenship, the overall trend during this period was towards a reduction in the amount of choice and control participants were able to exercise. Although explicitly framed as enhancing independence, participants were concerned that the emphasis on cost savings would mean that the new PIP would result in a reduction in their support. Fears over the closure of the ILF compounded this. ILF was highly valued by those who used it, and the proposed closure had been a significant source of anxiety. The introduction of SDS had considerable potential to overcome some of the limitations of traditional service approaches, and indeed offset some of the changes taking place nationally. While the move had resulted in improvements for some, this had not been realized for the majority of those who used social care. Those who had been using DP for some time were also experiencing a reduction in the amount of support they received. This was having a negative impact on their ability to live independently within their communities. While

there were some good news stories, the overall picture of SDS was that it fell some way short of realizing its potential.

8.2.4 Understanding the cumulative effect of reform

Discussion in Chapters 5–7 has focused on examining particular elements of the Coalition’s reform agenda. However, as highlighted in section 3.5, these reforms did not take place in isolation. Table 4.1 provided an overview of the different benefits claimed by participants and highlighted their often-overlapping nature. Participants in this study used a range of different benefits and payments to support them to live independently. They therefore had to negotiate changes taking place to different elements of their support package at once. In the early days of the Coalition’s term in office they faced regular calls to examine the cumulative effect of all the changes taking place (Lister & Bennet 2010). Early attempts were also made to capture some of this both qualitatively and quantitatively (Wood & Grant 2010, 2011; Wood 2011, 2012; Duffy 2013). When taken in their totality then, the findings presented in this thesis contribute to this cumulative understanding. The scale of the reforms which took place between 2010 and 2015 meant that disabled people faced significant uncertainty over their future security. While participants in this study were able to demonstrate considerable agency in the way that they managed their funds to meet their needs, this was becoming increasingly difficult. The overwhelming message to come out of this thesis is that disabled people in this period were experiencing an insecure future with erosion of their basic support, and regular questioning of their eligibility from both the authorities and their own communities.

8.3 Policy implications

It is in the nature of both policy and politics that change can happen very quickly and without much notice. It is also in the nature of PhD studies that they are long and protracted processes which may take some years to yield results. The policy and political context in which this study began was therefore in many ways very different from that in which it concludes. The 2014 referendum on Scottish Independence has seen among the most profound of these changes. While the result was 55.25% in

favour of remaining within the UK (Electoral Management Board 2014), the closeness of the result has seen a change to the constitutional settlement for Scotland, with the planned devolution of new welfare powers in the Scotland Act (2016). Likewise, the Coalition who introduced many of the reforms under examination in this study have been replaced at Westminster by a Majority Conservative Government, and more recently by a new Prime Minister in the form of Theresa May. The General election of 2015 also saw the election of 56 new SNP MPs to Westminster, while in March 2017 Scottish First Minister Nicola Sturgeon announced that she would be calling for a second Independence following the decision by the UK to withdraw from the European Union (Carrell 2017). As a result the question of Scottish Independence is likely to persist for some time.

In the final days before the 2014 referendum, fearing the tide was against them, the leaders of the three main Westminster parties pledged their commitment to new powers for the Scottish Parliament in the event of a 'No' vote. A cross-party commission (Smith 2014) took evidence from the five main political parties in Scotland as well as representatives of civil society, publishing recommendations in November 2014. These included the devolution of powers over a number of welfare benefits including disability benefits such as Attendance Allowance, Carers Allowance, DLA, and PIP (Smith 2014). The Commission also recommended the devolution of powers to create new benefits in areas of devolved responsibility, provided that these were to meet additional needs not already addressed in the benefits system. However, the majority of social security spending was to remain reserved to Westminster, including UC and Pensions (Smith 2014). Though symbolically significant, the changes only related to a small proportion of overall UK government spending on benefits. Scotland's share of the overall benefits bill in 2013/14 was equal to £17.5 billion. The benefits proposed for devolution would account for £2.6 billion, or 14.6% of the total benefit bill for Scotland (Scottish Government 2015c).

The Scotland Act (2016) received royal ascent on 23 March 2016. It amended the Scotland Act 1998, and therefore gave the Scottish Parliament certain exemptions in the field of welfare and taxation, rather than new powers, *per se* (Spicker 2016). Nevertheless, the change is an important one, and will mean that there is scope

potentially for the Scottish Parliament to develop a new approach to the benefits it has power over. The extent to which this is likely to result in a new Scottish welfare settlement is again a matter of contention (see 1.2). The Scottish Parliament has tended towards fiscal conservatism in the past, freezing council tax and not making use of existing tax powers (Rummery & McAngus 2015). The post referendum period has also seen an element of political retrenchment with pro-union parties reluctant to promote divergence for fear of contributing to the independence cause (ibid). Similarly, the pro-independence parties have focused on the limitations of their new powers when compared to the opportunities presented by full independence (Rummery & McAngus 2015). The detail on what the Scottish Government plan to do with the new powers is also yet to emerge. A consultation was carried out over the summer and autumn of 2016 looking into what a new Scottish Social Security System might look like, and this is expected to result in legislation to be laid before Parliament in June 2017 (Scottish Government 2017b). The return of the constitutional debate somewhat reduces the potential for experimenting and embedding change through exercise of the new welfare powers.

The extent to which participants in this study were aware of the differences between the Scottish and UK social policy contexts varied considerably too. The media narratives around the reform, as well as the Scottish Government's rhetoric meant that the Coalition, or at least 'Westminster' were widely seen to be at fault for the reforms they were experiencing. However, it was unclear how far participants were aware that the impetus for SDS had come from the devolved Scottish Parliament, particularly where assessments were being conducted by their local authority. Where individuals had experienced reduced budgets, they were clear in apportioning blame to the local authority, however the role of the Scottish Government in bringing about the policy change that led to their changed circumstances was not generally acknowledged.

The issue of Scottish Independence was not something that was explicitly discussed as part of the interviews for this project, however unsurprisingly it arose though conversation with some participants. One participant was actively involved in campaigning for a 'Yes' vote, while another was a member of the 'Better Together' coalition campaigning for a 'No'. Two further participants expressed their hopes for a

‘Yes’ feeling that this would be likely to bring an end to the changes they were facing. A further two participants expressed concerns about future economic stability following a ‘Yes’, and were planning to vote ‘No.’ The individuals views on independence did not appear to have affected their views on where to lay the blame for the reforms. However, as previously stated this was not information that was routinely asked of participants in the course of interviews. In retrospect this might have provided a further interesting dimension to the data presented in this thesis, particularly given the centrality of welfare powers to the Scotland Act. However, I was hesitant to pursue this line of questioning at the time, given my own active involvement in the ‘Better Together’ campaign. I was concerned that this line of questioning might result in my views becoming known and therefore discourage participants who were supporters of ‘Yes’ from opening up to me about their experiences of the reform. Likewise, it might also have caused them to present a particular view of the reforms in an attempt to influence my own views.

The recommendations outlined below are separated into general policy recommendations, those relating to benefits that continue to be reserved, and those that will be devolved to the Scottish Parliament. The final section reflects on wider changes that need to take place in order to promote a citizenship agenda in disability policy in Scotland.

8.3.1 General recommendations for disability policy

Discussion throughout this thesis has highlighted that the way in which disability is understood by policy makers has an important bearing on how policies are experienced by disabled people (Drake 1999). Findings in Chapter 5 have demonstrated that the Coalition’s approach to policy saw disabled people facing an increasingly uncertain future, and experiencing a growing sense of powerlessness as a result. Chapter 6 further demonstrated that the discursive trends cultivated by the Coalition in support of their reform agenda saw disabled people increasingly stigmatized and marginalized within their communities as a result. Nevertheless, as demonstrated in Chapter 7, a genuinely inclusive disability policy requires more than a change in language. The mantra of the disabled people’s movement has long been

‘never about us without us’. Disabled people are experts within their own lives and are therefore best placed to influence policy which directly affects them. The following are therefore principles which could form the basis for an inclusive approach to disability policy.

An inclusive disability policy should:

1. *Define disability in a way that recognizes ongoing and historical structural discrimination experienced by disabled people, while also recognizing their capacity for individual agency.*
2. *Involve disabled people and their organizations at all levels of policy making.*

8.3.2 Recommendations for policy reserved to Westminster

Disability benefits such as DLA and PIP will be devolved to the Scottish Parliament under the Scotland Act (2016). However, Westminster will retain control over UC, including ESA. This is complicated somewhat by provisions for the devolution of some elements of Employment Support in the Work Programme (Spicker 2016). The implications that this has for future policy therefore remain to be seen. The key findings of this study in relation to ESA relate to the assessment process and the work programme. Findings in Chapter 6 highlighted that the experience of the assessment process was frequently degrading to participants. This was largely as a result of the emphasis on medical criteria and functional limitation, which often did not allow those with variable conditions and others to express the reality of their impairment. The frequency of assessment was also a worry for those with long-term or static conditions. This chapter also highlighted the need for greater awareness of the invasive nature of assessments. While it is important that individuals whose conditions are likely to deteriorate should have the opportunity to request greater support, many individuals with static conditions will not need such regular reviews. A fairer and more transparent system may also result in administrative savings, reducing pressure on assessors, and decreasing the need for costly appeals. In early Autumn 2016, Damian Green, Ian Duncan Smith’s successor as Work and Pensions Secretary, hinted at a possible change in policy in this regard when he recommended that six-monthly reassessments of those with conditions that are

unlikely to change should be abandoned. This would be a positive change and go some way to address the indignities experienced by participants in this study.

Recommendations for assessment processes:

3. *Eligibility assessments should take account of capacity for work, the availability of appropriate work, and the potential for adaptations that would allow the individual to participate, rather than simply functional limitation. They must be conducted fairly and enable the individual to be viewed holistically.*
4. *Where public perception demands the need for independent' assessment, these should be supported by evidence from a practitioner with an ongoing relationship with the individual such as their GP.*
5. *The regularity of assessments should seek to better reflect the likelihood of changing needs.*
6. *Disabled people should be involved in developing as well as testing the efficacy of assessment processes, without detriment to their status.*

While some elements of the work programme will be devolved, it is likely that Westminster will continue to play a role in shaping employment support. It is crucial therefore that this takes account of the value of other contributions made by disabled people outside the labour market.

7. *Volunteering activities should be viewed as legitimate forms of 'work-related activity' for those in the WRAG and should not be penalized.*
8. *Individuals in the Support Group should be encouraged and supported to take part in volunteering without triggering a change in status.*

8.3.3 Recommendations for policy devolved to Scotland

The Scottish Government are still consulting on what they describe as a 'social security system for Scotland' (Scottish Government 2016). Section 3.2.2 highlighted the similarities between the WRAG and the proposed test to establish eligibility for the new PIP. This was also reflected in the similarities in findings in sections 6.2.2 and 7.2. The recommendations for fair assessment processes above therefore apply

equally to the Scottish Government should they propose to make changes to the assessment for PIP when the benefit is devolved. As noted in section 3.5.3, the Scottish Government have sought to steer a different path to welfare reform than the UK Government by mitigating some of the impacts of the reforms in Scotland. The below are recommendations that relate to the approach taken to the powers that the Scottish Government will gain through the Scotland Act 2016.

Policy makers have a profound influence on public narratives which set the context for policy changes. The cultivation of a blaming and stigmatizing narrative has been an ongoing trend in welfare reform since the 1970s, with disabled people increasingly being drawn into the 'undeserving' category. This thesis has clearly demonstrated the impacts that this has had on disabled people's security, well-being, and sense of self. The devolution of disability benefits therefore presents an important opportunity to challenge this:

9. *Policy makers should work with disabled people and representatives of the Scottish media to challenge stigmatizing narratives around disability and the receipt of benefits.*
10. *Any changes to existing arrangements should seek to emphasize the contributions that disabled people make to society, and be contextualized as helping to advance disabled people's citizenship.*

The devolution of employment support for disabled people in the Scotland Act (2016) relates to schemes that run for over a year (Spicker 2016). This provides some potential to the Scottish Parliament to develop employment schemes that challenge the 'creaming parking and churning' model evident in the current work programme. The intricacies of how this will relate to the work programme, and the implications around conditionality are yet to be established, but will be key to the ability to pilot a new approach:

11. *Support to enable people to find work should be provided free from the threat of punitive sanctions⁸.*
12. *Support should be available regardless of proximity to the labour market and participation should not be taken as evidence of fitness to work.*
13. *Activities should take account of disabled people's aspirations and be tailored to their own needs.*
14. *DPOs should play a key role in the design and delivery of work schemes.*

This study has found that welfare rights advice is critical to enabling people to negotiate the complexities of the benefits system. A Scottish welfare system should be as simple and straightforward to access as possible. However, it should also be acknowledged that the experience of certain impairments, as well as the educational disadvantage experienced by disabled people, will mean that some people will find it harder to access their entitlements. The Scottish Government already play an important role in supporting the voluntary sector in Scotland. This provides unique opportunities to invest in and sustain high quality welfare rights advice services.

15. *The Scottish Government should support the voluntary sector to enable the provision of high-quality independent welfare rights advice services.*

Findings presented in Chapter 7 in relation to the implementation of SDS in Scotland highlight this as a missed opportunity on the part of both the Scottish Government and local authorities. One of the biggest challenges highlighted was the issue of local government funding. However, evidence from SDS pilot projects has consistently demonstrated that choice and control will not always mean an increase in spend (Witcher 2014).

⁸ In late November 2016 it was announced that the Scottish Government had won agreement from Westminster that the Scottish Work Programme would be voluntary and that non-participation would not incur sanctions. However the detail of this and how it relates to the Westminster led WP is yet to be determined (see <https://www.theguardian.com/uk-news/2016/nov/22/scotland-voluntary-work-sanctions-benefits-holyrood>).

16. *Local authorities should be supported and encouraged to embrace the full range of options available under SDS to enable the expansion of choice and control to new user groups.*
17. *Social care users should be made aware of all the options open to them and supported to make the best choice for their circumstances.*
18. *Local authorities should empower front-line staff to exercise creativity in working with disabled people to achieve their desired outcomes.*
19. *Personalization will increasingly see disabled people taking on new roles as employers. Disabled people should be supported to meet their obligations to their workforce*

8.4.4 Renewing the citizenship agenda in Scotland

The 2014 referendum stimulated discussion across Scottish civil society about the type of society we would like to see. Likewise, the approach taken to mitigation of policies such as ‘the bedroom tax’ as well as the discourse surrounding new powers over social security signals the potential for a different approach to disability policy. The extent to which the new powers will deliver on this promise remains to be seen. Nevertheless, this does present an opportunity to renew the wider citizenship agenda for disabled people in Scotland. While this thesis is an academic work, I embarked upon it as an activist keen to contribute to bringing about change for disabled people in Scotland. I also feel a responsibility to those who took part in this study to make recommendations that go wider than the immediate policy context. The achievement of full citizenship for disabled people will require more wholesale change than that described above. The following recommendations therefore attempt to look beyond these in order to set out a more ambitious agenda for change.

Discussion throughout this thesis has highlighted the organisation of employment as a significant barrier to disabled people’s inclusion in society. This has been supported by findings in particular in Chapter 5 which noted that despite articulating a positive orientation to work, many participants faced very real barriers to being able to find and retain employment. Addressing these barriers will require fundamental

restructuring of the labour market. A further finding from this study was that, while many participants found work difficult to engage with, the vast majority were actively involved in volunteering. However, the contribution that disabled people's volunteering activities makes to wider society is often unrecognized.

20. The labour market should be reformed to meet the needs of disabled people, ensuring flexibility over working hours and a decent rate of pay. The provision of personal assistance and other adaptive devices should be met by employers and from the public purse.

21. The contributions made by disabled people in the form of volunteering and as employers should be accorded equal value with work in public policy.

Discussion in Chapter 7 has also highlighted the importance of having choice and control over support to live independently. This has an important bearing on disabled people's access to the labour market as well as their ability to participate in citizenship more generally. While SDS provides some potential to bring about change in this area in the short to medium term, the findings of this study have highlighted that issues of funding for local authorities have limited its potential. The Scottish Government will shortly acquire significant new revenue raising powers through the Scotland Act (2016). This provides potential to pursue a different approach to funding and organizing social care. Likewise, the bringing together of non-acute health services with social care in 2015 provides a context in which this could take place:

22. The Scottish Government should establish a commission into the future of social care in Scotland. With representatives from health, local government, the voluntary sector, and, crucially, service users, the commission should be tasked with exploring new thinking into the organization and funding of social care.

23. The commission should explore in particular the potential for using new tax revenue raising powers to fund the recommendations they make.

8.4 Recommendations for future research

This was a small-scale study with limited resource, and involved only a relatively small group of participants. Many of those who came forward to take part in the study had not been affected by reforms such as conditionality and sanctions. Fieldwork also took place quite early on in the reform process. While the Coalition set out an ambitious program on coming to power, delays meant that many of the reforms under consideration had not yet happened at the time of interviews, and others were abandoned after interviews had taken place (see section 3.5). It is also important to consider whether the political and social climate at the time of interviews may have influenced those who came forward and the perspectives they presented. The discursive elements of welfare reform were present throughout the fieldwork phase, and some of these narratives may have encouraged participants to present a particular perspective in order to differentiate themselves from the 'other'. Nevertheless, the lack of co-shaming that was evident in their accounts suggested that the majority genuinely rejected stigmatizing discourses, rather than simply viewing themselves as exceptions to this. This is, however, only a very early snapshot of impacts of reforms. The contribution outlined above, while important, is therefore necessarily limited. This final section outlines some suggestions for areas that would benefit from further investigation.

- *A more inclusive labour market:* Discussion throughout this thesis has highlighted the need for changes to the labour market to make employment more inclusive of disabled people. There is an important role to be played by research in helping to inform what this might involve.
- *Surveillance and self-surveillance:* This was an important finding from this study, but one which would benefit from further exploration to examine whether it is a more widely felt phenomena. The finding emerged through the data, rather than through direct questioning of participants, and therefore it would also be interesting to investigate how conscious individuals are of the processes they adopt in response to 'hidden conditionality'.
- *Challenging dominant narratives:* This research has focused intensively on the impact of the rhetoric surrounding welfare reform on those affected by the changes. That other studies have found evidence of benefit recipients adopting

and internalizing the same narratives suggests that these are becoming deeply embedded in the public consciousness. Robust research is therefore much needed into how such narratives can be challenged and replaced by more positive perspectives of disabled people, as well as benefit recipients in general. Such research has the potential to involve disabled people as well as other benefit recipient groups in leading investigations as well as piloting possible solutions.

- *The impact of PIP:* Due to delays in implementation, none of the participants in this study had completed the process of transferring from DLA to PIP. This is a significant change for disabled people, the impacts of which will need careful examination, in particular given the claims to support increased independence. While the Scottish Government may decide to take a different approach when PIP is devolved, the process of transfer is unlikely to halt in the short term. Research could also help to inform a Scottish approach.
- *ILF Scotland:* That the Scottish Government have taken steps to preserve the ILF in Scotland and open it to new members is to be welcomed, and will be a huge relief to those who rely on it to enable them to live independently. However, the new scheme is still in its infancy and it remains to be seen whether it will successfully retain the best elements of its parent scheme. Concerns around sustainability need to be explored, and in particular whether the additional £5 million the Scottish Government has pledged to enable the scheme to open to new members will be sufficient to meet demand. The extent to which the new scheme acts to promote the citizenship of disabled people is also worthy of investigation. While the Scottish Government have echoed the values of the former scheme, the board and staff of ILF Scotland are dominated by those with a background in voluntary provision, rather than disabled people themselves. This is a missed opportunity to put disabled people at the centre of policy decisions.
- *SDS:* The implementation of SDS presented a unique opportunity to pursue a different approach to social care policy in Scotland. This study has provided an early snapshot of service users' experiences of the change. However, more research will be needed as SDS becomes more established to see whether over the course of time the policy becomes better embedded. Again, this has the

potential for creative research into how to promote choice and control to new groups of service users. One of the biggest challenges for the new policy approach has been the financial climate, and it is unlikely that this will change significantly in the next parliamentary term. As a result, research on ways to promote increased choice and control for service users within this context is much needed.

8.5 Summary

This chapter has provided a synthesis of key findings from this thesis as well as detailing the ways in which it has contributed to knowledge. It has also outlined a number of recommendations for policy arising from these findings. Finally, it has provided an overview of some of the significant ongoing gaps in the literature with recommendations for future research.

Appendix I: Interview schema

Understanding experiences of UK benefit and welfare policies for people with individual support needs

Thank participant for agreeing to take part in research. Interview will take approximately 40 minutes to one hour and will cover a range of themes related to their experience of benefit changes.

Explain that the purpose of this research is to understand how changes to benefits are affecting people living in Scotland. The interviews will be used for my PhD and I will be interviewing a number of other people, too. I may use findings in papers for publication and/or conference papers.

Remind participant that I will record the interview; confirm they are still happy with this.

Admin:

- *Make sure have read participant's information – clarify anything unsure of.*
- *Complete consent form and offer chance to choose pseudonym.*
- *Remind that will remain anonymous – only I will know that they have participated.*
- *Confirm they don't have to answer all questions, and can terminate interview at any time at own request.*
- *Explain some questions may seem pretty obvious but just give as full answers as possible.*

Icebreaker

- Ask them to start by telling a little bit about themselves:
 - Home and family life?
 - What do with time: work, leisure, hobbies?
 - Why did they decide to participate in the study?

General themes/prompts – aim to draw on these if necessary

- *Personal finances*
- *Independent living – improvements? Decline?*
- *Emotional well-being*
- *Impact on condition*
- *Work and conditions/sanctions*
- *Impact on provision of services e.g. community care/Direct payments etc.*
- *Disability status...*

Main part of interview

1. Do they have disability or impairment? How do they feel this affects them in day to day life?
2. Do they get any support to assist them in everyday life?
 - a. What does this involve? Personal assistance, transport, etc.?
 - b. Do they get help from family/friends?
 - c. Do they get any financial assistance such as DLA, ILF, IB, ESA?
 - d. How do they use DLA/ILF/IB/ESA?

General themes/prompts – aim to draw on these if necessary

- *Personal finances*
- *Independent living – improvements? Decline?*
- *Emotional well-being*
- *Impact on condition*
- *Work and conditions/sanctions*
- *Impact on provision of services e.g. community care/Direct payments etc.*
- *Disability status...*

3. What has been the experience of getting support they need?
 - a. How long have support arrangements been in place?
 - b. If they receive financial support, how did they first start receiving this support? What did they have to do?
 - c. Did they get any support to claim? If so, from whom?
 - d. Have they ever received a sanction on their benefits?
4. Is the financial support they receive sufficient to meet their needs?
 - a. What do they use benefit for? Do they distinguish between specific benefits in the way they spend it, or is it part of the general mix?
 - b. Have they experienced financial strain since moving on to benefits (if relevant)?
 - c. What does claiming this benefit mean to them, if anything?
5. Have they experienced any changes in the support they receive in last three years?
 - a. Have they had a reassessment for any part of their support from the council?
 - b. If they claimed ESA/IB, DLA, or ILF, have they had a re-assessment? Was this routine or unexpected (in case of DLA or ILF)?
 - c. If they experienced a change, what did they know about changes and where did they get information about this?
 - d. How have any changes in above affected them?
 - i. Emotions?
 - ii. Physical health and well-being?
 - iii. Financially – conditions and sanctions? Financial strain?
 - iv. Social life/activities outside the home?

- e. How are they affecting participant's family/household?
6. We know government are proposing changes to benefits including closing ILF, changing DLA to PIP. Do they think this is likely to affect them?
- a. If so, what do they expect will be the impact?
1. Emotions?
 2. Physical health and well-being?
 3. Day-to-day activities?
 4. Employment?
 5. Housing?
 6. Financially – conditions and sanctions? If so, what kind of impact?
 7. Social life/ activities outside the home?
 8. Relationships?

General themes/prompts – aim to draw on these if necessary

- *Personal finances*
- *Independent living – improvements? Decline?*
- *Emotional well-being*
- *Impact on condition*
- *Work and conditions/sanctions*
- *Impact on provision of services e.g. community care/Direct payments etc.*
- *Disability status...*

Close

Is there anything they would like to tell me about that we have not covered?

- *What next:*
 - *Will type up transcript and analyse. As previously stated will send copy to them and welcome to ask for bits to be removed if not happy.*
 - *Complete questionnaire.*
- *Thank them for taking time out to talk to me and give gift voucher.*

Appendix II: Ethics approval



University of Glasgow | College of Social Sciences
Staff Research Ethics Application Outcome ☐

Ethics Committee for Non-Clinical Research Involving Human Subjects

Postgraduate Student Research Ethics Application Outcome ☒

Application Details

Application Number: 400130011

Application Type New ☐

Resubmission ☒

Applicant's Name Kainde Manji

Project Title Understanding the impact of welfare reform on disabled living in Scotland

Date application reviewed (d.m.yr) 23/10/13

Application Outcome

Approved

Start Date of Approval (d.m.yr) 23/10/13

(blank if not approved)

End Date of Approval (d.m.yr) 31/12/14

If the applicant has been given approval this means they can proceed with their data collection with effect from the date of approval.

Recommendations (where application is Not Approved)

Please note the comments below and provide further information where requested. All resubmitted application documents should then be uploaded. You must include a covering letter in a separate document (uploaded as the **Resubmission Document** online) to explain the changes you have made to the application.

Major

Minor

Comments (other than specific recommendations)

The applicant has incorporated all changes and suggestions into documents and we are now happy to give approval.

Please retain this notification for future reference. If you have any queries please do not hesitate to contact Terri Hume, Ethics Administrator.

End of Notification.

Appendix III: Participant Information



Information for participants

1. Study title and Researcher Details

Understanding the experience of UK welfare and benefits policy on people with individual support needs living in Scotland.

Kainde Manji k.manji.1@research.gla.ac.uk

2. Invitation paragraph

'You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. You can discuss it with others if you wish. You can also ask me if there is anything that is not clear or if you would like more information. Please also take time to decide whether or not you wish to take part.

Thank you for reading this'.

3. What is the purpose of the study?

Research suggests that more people in Scotland claim benefits due to individual support needs than expected, given the size of the population in Scotland. At the same time, the UK Government have made a number of changes to the way some of

these benefits are paid across England, Wales, Scotland, and Northern Ireland. The changes include creating new benefits. One new benefit is the Employment Support Allowance (ESA). This has replaced Incapacity Benefit. Personal Independence Payment (PIP) has been created and will replace Disability Living Allowance. The purpose of this study is to find out about the experiences of people in Scotland who have individual support needs, and the way that these policies are affecting them.

4. Why have I been chosen?

You are being asked to take part in this study because you have individual support needs (such as an impairment or long-term health problem) or have claimed (within the last three years and for a period of at least two years) any of these benefits:

- Incapacity Benefit / Employment Support Allowance
- Disability Living Allowance / Personal Independence Payment
- Independent Living Fund
- Severe Disability Premium
- Disability element of Working Tax Credit
- Community care / self-directed support

If this does not apply to you, then you may have been given this information by mistake and you can just ignore this information.

If you do have individual support needs or have claimed one of these benefits recently and for a period of two years or more, I would like to talk to you about your

experiences. This will involve a short interview where we will talk about what these policies mean to you.

5. Do I have to take part?

It is entirely up to you to decide to take part. You should think about this carefully and if you want to, you can talk to other people about this, too. If you do decide to take part, you are free to change your mind and stop participating in the project at any time. You do not need to give a reason for this. You should also be aware that if you decide not to take part, this will not affect any benefits you receive or any support or services you receive from support organizations.

If you would like to talk to me more about what taking part will mean then you can email me at k.manji.1@research.gla.ac.uk

6. What will happen to me if I take part?

If you do decide to take part I would like to meet you to talk to you about how welfare and benefits policies affect you and your family. We would meet for about 40 minutes to one hour in a place that suits you. This could be your home, or a community centre, or the offices of a support organization, whichever is easiest for you. If you agree, I would like to record our conversation. No one else will be able to hear the recording, or listen to it afterwards. The interview will be between you and me, but if you would prefer you can have a friend, Personal Assistant, or support worker with you at the time.

I may want to speak to you again in a few months' time to see if your views and experiences are the same as they were the first time we met, or if they have changed at all. Again, this meeting will take around 40 minutes to one hour. You may not be asked to take part in a second interview, and you do not have to take part in this if you do not wish to.

7. Who will know that I am taking part?

Only I will know that you are taking part in this study, but if you would like a support organization to know about it, too, you can tell them. I will keep any information you give me in a locked filing cabinet or on a password-protected file on my computer. You can also choose a different name to be called by in the study, or I can choose one for you. Once we have had our interview, I will type up everything we have said, and give you a copy of this. If there is anything in there that you are not happy with, you can ask me to take it out.

8. What will happen to the results of the research study?

The results of the study will be written up for my PhD. I may also write up smaller articles for publication in academic journals, or even blogs. You will never be named in any of these papers, but will be given the name you or I have chosen so that no one can identify you. Any other identifying information that you might give me during our interview, such as names of friends or family, or places that you live or work, will also be removed or changed. I will also send you a summary of the findings from the research project to keep.

9. Who is organizing and paying for the research? (If relevant)

The study is being funded by the Scottish Government and the Economic and Social Research Council and is being organized by myself as part of my PhD.

10. Who has reviewed the study?

The study has been reviewed and approved by the University of Glasgow College of Social Sciences Ethics Committee.

11. Contact for Further Information

For more information please contact Kainde Manji k.manji.1@research.gla.ac.uk

If you have any concerns regarding the conduct of the research project, you can contact the College of Social Sciences Ethics Officer by contacting Dr Valentina Bold at valentina.bold@glasgow.ac.uk

Appendix IV: Consent form



Consent Form

Title of Project: Understanding the experience of UK welfare and benefits policy on people with individual support needs living in Scotland.

Name of Researcher: Kainde Manji k.manji.1@research.gla.ac.uk

-
- ☐ I confirm that I have read and understand the participant's information sheet for the above study and have had the opportunity to ask questions.
 - ☐ I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
 - ☐ I consent to this interview being audio-taped.
 - ☐ I acknowledge that copies of transcripts will be returned to me for verification.
 - ☐ I understand that I will remain anonymous in this research and will be referred to by a pseudonym in any publications arising from the project.
 - My preferred pseudonym is.....
 - ☐ I understand that I may be contacted again in a few months' time about participating in a second interview, but I understand that I can chose not to take part.
 - ☐ I would be happy for you to send me occasional (every few months) updates on the research. My preferred method of contact is:
 - ☐ Phone
 - ☐ Email
 - ☐ Text
 - ☐ Twitter

☐ I agree / do not agree (delete as applicable) to take part in the above study.

Name of Participant

Date

Signature

Researcher

Date

Signature

1 for participant; 1 for researcher

Appendix V: Recruitment text for organizations

[for newsletter]

Experience of UK benefits policies

Do you have long term health problems, a disability or additional support needs?

Are you aged 18–55?

Do you receive any of the following benefits?

- Incapacity Benefit / Employment Support Allowance
- Disability Living Allowance / Personal Independence Payment
- Independent Living Fund
- Community care / Self-directed Support

If so, I would like to talk to you about **your** experience of claiming, and how UK government benefits policies affect you. To take part please email k.manji.1@research.gla.ac.uk

[letter for direct mailing]

Dear

I am a research student at Glasgow University, and I am working on a project looking at how disabled people and people with additional support needs in Scotland experience UK benefits policies. If you are aged 18–55 and currently claim, or have claimed (within the last three years and for a period of at least two years) any of these benefits:

- Incapacity Benefit / Employment Support Allowance
- Disability Living Allowance / Personal Independence Payment
- Independent Living Fund
- Severe Disability Premium

- Disability element of Working Tax Credit
- Community care / Self-directed Support

and would be willing to talk to me about your experiences, please contact me at k.manji.1@research.gla.ac.uk

Sincerely,

Kainde Manji
PhD Researcher
University of Glasgow

[Twitter]

Do you live in Scotland and receive ESA, IB, DLA, or ILF? Take part in research looking at YOUR experiences. DM @KaindeManji for more info

[Facebook]

Do you live in Scotland and receive ESA, IB, DLA, or ILF? Want to talk about YOUR experiences of UK benefits policy? Send Kainde Manji a message for more information.

Appendix VI: Emerging themes

- Anxiety over expected reforms:
 - Based on contact informing of changes – the ‘brown envelope through the door’;
 - Based on hearing about reforms through news, friends, family, etc.;
 - Specific worry for themselves;
 - Concern for disabled people in general;
 - Preventing from engaging with wider community or rehabilitation in fear of having benefits cut.
- Financial:
 - Planning for what wouldn’t do in event of changes;
 - Value of benefits decreasing while contributions (e.g. community care) increasing:
 - Impacts on individuals but also on PAs if using funding to pay PAs and value of that is not increasing over time.
 - Things that they have to go without as a result of changes: heating, holidays, clothes, DVDs, etc.;
 - Doing things to save money: eating at day centre, heating only one room, growing veggies, buying tobacco on the black market, ‘being canny’.
- Sense of injustice, e.g. having to fight for what they have;
- Impact of anxiety/changes on condition:
 - Indivisibility of mental health problem from anxiety over reform – feedback loops.
- Process of becoming disabled;
- System being wasteful elsewhere but penalizing those in need:
 - System justified in changing, but creating fear for those deserving of support.
- Managing/using DLA:
 - Ringfencing for specific access/mobility-related things or food, i.e. ‘special money’;
 - Part of the mix;
 - Part of contribution for community care or Motability vehicle, i.e. not something they can control;
 - Tied to self-respect, i.e. able to contribute something to the household.
- Managing care arrangements;
- Historical challenges with the system, i.e. reform is not new;
- Assessment process:
 - Indignity, invasiveness;
 - Capturing fluctuating conditions, i.e. best days and worst days;
 - PIP focused on mobility, i.e. impact on people with mental health problems;

- How to present themselves and circumstances at assessments, i.e. think about their worst day. Not lying, but having to give a certain impression. All feel uncomfortable about this.
- Small acts of resistance:
 - Delaying assessment process;
 - Refusing to pay contribution;
 - Or dropping out of support system altogether.
- Knowledge:
 - Being in the know/part of the system – an advantage to some, but not being so a huge disadvantage to others;
 - Absolute critical centrality of welfare rights advisors in gaining positive outcome.
- ILF:
 - Enabling independence 'my husband doesn't have to worry about me';
 - Significance of 'more than life and limb';
 - Difference it makes to life;
 - Anxiety over future of fund;
 - Judicial review, i.e. 'I may still be OK, but what about others?';
 - Didn't get in on time, was closed by time heard about it;
 - Would make life easier if all money came from single place.
- PIP:
 - Vagueness: understandable given vagueness of policy timeframe and repeated changes. People don't seem to know what is going to happen or if they are going to be affected;
 - Indefinite awards, i.e. but what about PIP?;
 - Retirement, i.e. who will be affected at what stage.
- Support networks:
 - Friends;
 - Family;
 - Volunteering:
 - Almost all do some form of volunteering, but some underplay extent of this, or put off from doing more because of fear of reprisals – perception that if they can volunteer then they can work.
 - Activities;
 - Work, e.g. provides for a sense of self.
- Working:
 - Empowering and gives sense of self;
 - Has additional costs for disabled people that non-disabled people don't incur;
 - Impact on condition, i.e. managing work and condition can be challenging;

- Disabling barriers to the workplace, i.e. workplaces not being set up for disabled people either in terms of physical access or attitudes.
- Awareness of rights:
 - But frustration when these are being undermined.
- Self-directed support:
 - Reassessment causing stress/anxiety;
 - Perception of it as a cost-cutting measure;
 - Hard fought achievement, but is it adequately resourced?;
 - Local differences in whether losing hours or not. Some finding empowering, others losing out;
- Relationships with Personal Assistants:
 - Responsibilities of an employer is something not recognized by system;
 - Personal relationships develop over time but discouraged by some authorities.
- Hidden charges, i.e. on surface DP appear to be getting a good deal, but many forms of support come with hidden costs:
 - Community care charges;
 - Contributions to adaptations;
 - Mobility going to motability;
 - Care component going towards community care;
 - Charges from doctors and medical professionals to write supporting letters for application to ESA, etc.;
- Distinction between genuine disabled and not genuine;
- Experience of disability related hate crime;
 - Impact of this on independence;
- Giving up:
 - Changes will mean no longer eligible so why bother applying for PIP;
 - Contribution too expensive so stop going to day centre;

Appendix VII: Nvivo coding framework

- Applying
 - Appeals
 - Assessment
 - Behaviour
 - Surveillance or control
 - Process
 - Impact of applying
 - Re-assessment
 - Support
- Living on benefits
 - Adapting
 - Discrimination/hate crime
 - Hidden charges
 - Meanings
 - Othering
 - Passporting
 - Using benefits
- Experience of reform
 - Bedroom Tax
 - Bureaucracy
 - ESA
 - ILF
 - Knowledge
 - PIP
- Impact of reforms
 - Anxiety
 - Fear of the brown envelope
 - Luck or fortune
 - Financial
 - Impact on impairment
 - Loss of independence
 - Perceptions
 - Othering
 - Responses
- Life
 - Disability and impairment
 - Embodied experience of impairment
 - Disabling barriers
 - Education
 - Hobbies
 - Independent living
 - Political activism
 - Role of DPOs

- Support networks
 - Transport
- Personal assistance
 - Family and Friends
 - Getting support
 - Home
 - Technological aids
 - ILF
 - Enabling Independent Living
 - Managing care
 - Relationships with PA
 - Self Directed Support
 - Community care charges
- Work and Volunteering
 - Volunteering
 - Working
 - Access to work scheme
 - Attitudes to work
 - Barriers to work
 - Support to find work

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