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KAYLEIGH ANN GARTHWAITE

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**Kayleigh Ann Garthwaite**

**Incapacitated? Exploring the health and illness narratives of Incapacity**

**Benefit recipients**

**ABSTRACT**

Previous research has focused upon health, illness and identity, but the experience of receiving welfare benefits has largely been omitted. This thesis attempts to address this deficit by exploring the relationship between long-term Incapacity Benefit (IB) receipt and stigma in areas of North East England. Employing qualitative methodology, 25 IB recipients participated in the study, alongside 18 key stakeholders who worked with IB recipients. The narratives presented in this study uncover lives that are fraught with ill health and disability on a daily basis, accompanied by a strong sense of stigma, shame and frustration. Further, not all long-term IB recipients are resigned to a life on benefits – many possess a deep-seated desire to return to the labour market, including engaging in permitted or voluntary work – a sentiment which directly refutes any ‘dependency culture’ rhetoric. Tying all of this together is the construction and reconstruction of identity for long-term IB recipients. Stigma and shame arose as a result of the widespread suspicion of sick and disabled people; suspicion that was replicated in the views of some of the stakeholders involved in this study. Disturbingly, this led to a further distinction between ‘deserving’ and ‘undeserving’ amongst sickness benefits recipients themselves. Crucially, narratives were relayed against a backdrop of ongoing welfare reform which led to a dominant discourse of fear and insecurity for many participants who worried that their health would get worse, yet they could still be classified as ‘fit for work’. Fundamentally, this research calls for the need for a greater understanding of the lives of sick and disabled people, and an acceptance that being on sickness benefits is not the easy way out.

**Kayleigh Ann Garthwaite**

**Incapacitated? Exploring the health and illness narratives of Incapacity Benefit recipients**

**A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy**

**Department of Geography  
Durham University**

**2012**

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## **ABBREVIATIONS**

ADF	Adviser Discretionary Fund
CFS	Chronic Fatigue Syndrome
CMP	Condition Management Programme
DDA	Disability Discrimination Act
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
ESA	Employment and Support Allowance
GP	General Practitioner
IB	Incapacity Benefit
IBPA	Incapacity Benefit Personal Advisor
IVB	Incapacity Benefit
JCP	Jobcentre Plus
JSA	Jobseeker's Allowance
ME	Myalgic Encephalomyelitis
MS	Multiple Sclerosis
NDDP	New Deal for Disabled People
NHS	National Health Service
OECD	Organisation for Economic Cooperation & Development
PCA	Personal Capability Assessment
PCT	Primary Care Trust
PIP	Personal Independence Payment
PtW	Pathways to Work
SB	Sickness Benefit
SDA	Severe Disablement Allowance
SME	Small and Medium Enterprise
SLB	Street Level Bureaucrat
SSDI	Social Security Disability Insurance

SSI Supplemental Security Income  
SSP Statutory Sick Pay  
UC Universal Credit  
WBLA Work Preparation and Work Based Learning for Adults  
WCA Work Capability Assessment  
WFI Work Focused Interview  
WRAG Work Related Activity Group

## **DECLARATION**

I declare that this is my own work and has not been submitted for the award of a higher degree anywhere else.

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## CHAPTER ONE

### INTRODUCTION

Hardly a day goes by without people who receive sickness benefits being talked about either on the news, by politicians or by your next door neighbour. The media frequently use terms such as scrounger, cheat, lazy, scum, feckless, work-shy, and fraudster to describe sick and disabled people. Politicians use dehumanising terms such as 'stock' and refer to this 'stock' as being 'migrated' onto new benefits. Yet people who are sick and disabled are not a distinct group set apart from the rest of society. As this thesis will show, they are in fact, 'they' are 'us'. They are the mother who suffers from severe depression and wakes up screaming in the night due to night terrors from flashbacks as a result of being a child brought up in the Army. The daughter who suffered an accident at work aged only 28 which left her with chronic pain for life. The overweight man on the bus whose weight gain was caused by the steroids he has to take to control his severe pain from polyarthritis. The wife whose arthritis means she cannot even prepare meals anymore. The father who has been an alcoholic since the age of 13 after trying his first alcoholic drink aged only 4 years old. Sickness and disability is not something which happens in some distant place away from the rest of reality; it happens every day. Every day someone somewhere gets a diagnosis, has an accident, or is born with an illness or disability. These narratives are not unusual or out of the ordinary, yet they are often not heard – instead, they are kept out of sight in favour of tales of the 'undeserving' feckless work-shy. It is almost guaranteed that you will know someone who is affected by sickness or disability in some way. They are not work-shy, not feckless, not scum, not stock, not scroungers - just people. Chronically ill people; disabled people - people like you.

## Policy Context

The UK has 2.6 million people receiving sickness<sup>1</sup> benefits. The key sickness benefits are: Employment and Support Allowance (ESA) for new claimants from October 2008; Incapacity Benefit (IB) IB which provides support for people who cannot work because of an illness or disability which started before October 2008; and lastly Severe Disablement Allowance (SDA), a benefit which could be claimed before April 2001 by those unable to work for at least 28 weeks in a row because of illness or disability. In employing the term 'sickness benefits', it is essential to point out that this terms does not refer to Statutory Sick Pay (SSP) and only refers to the range of benefits that are paid to people because their health limits their ability to work. Rates of receipt of these sickness benefits have increased from 0.5 million recipients in 1975 to 2.6 million in 2007. By 2007, around 7% of the UK working age population was in receipt of health-related benefits, accounting for 11% of UK social security expenditure at a cost of around £8 billion per annum and amounting to 1.8% of gross domestic product (GDP) (Gabbay *et al.* 2011). At an international level, the OECD (2008) report that governments are spending twice as much on illness and disability as on unemployment benefits and warned that this strategy could prove to be costly in the current economic climate given that most individuals who are moved onto sickness benefits are more likely to never work again.

In May 2011, a total of 2.6 million people were claiming sickness benefits, of which around 700,000 people were claiming ESA, 1.7 million IB and 200,000 SDA (DWP 2011). Of the 2.6 million people claiming sickness benefits, 31 per cent have a claim duration of up to 3 years and 35 per cent have a claim duration of 10 years and over. Under the Employment and

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<sup>1</sup> Throughout this thesis, I will be following the DWP in using the term 'sickness benefits' as an umbrella term to refer to the range of benefits that are paid to people because their health limits their ability to work. The term will encompass Incapacity Benefit (IB), Severe Disablement Allowance (SDA) and Employment and Support Allowance (ESA).

Support Allowance regime, new claimants have to undergo the Work Capability assessment. From April 2011, IB recipients have also started to undertake this assessment. Surrounding this assessment process is the harsh re-emergence of a discourse that negatively labels sick and disabled people as 'scroungers' 'work-shy', 'feckless' and 'lazy'. On an almost daily basis, headlines lament the claimants who are 'undeserving' of any help and support. Therefore, a study which investigates long-term sickness benefits recipients becomes increasingly important in order to uncover the narratives and experiences of sick and disabled people who receive sickness benefits.

### **Thesis context**

It is equally important to provide a context to the thesis. The PhD is part of a wider project, *'Evaluating the impact of case management on the health of long-term Incapacity Benefit recipients in the North East of England'*, a three year programme funded by County Durham Primary Care Trust (PCT). In this context, long-term refers to people who have been receiving IB for three years or more. Across County Durham, 9.4 percent of the working age population receive sickness benefits, compared to a North East average of 8.4 percent and a national average of 6.5 percent (NOMIS December 2011). In some areas of County Durham such as Easington, this figure rises to 16%. In 2009, the National Institute for Health and Clinical Excellence (NICE) produced guidelines on the management of incapacity and sickness absence (NICE 2009; Gabbay *et al.* 2011) which recommended that case management approaches were the most effective in helping people with ill health return to work. NHS based organisation SALUS were commissioned to provide a 'health first' case management approach for long-term IB recipients in County Durham. This intervention included using telephone and face-to-face case management programmes to identify individual health needs and any other related barriers to employment, such as debt or

housing (Warren *et al.* 2012). Under the programme, those receiving IB are referred by their GP (or self-referred) to a case manager who in turn will facilitate access to a variety of supplementary health, social and vocational interventions such as social prescribing, conditions management, vocational guidance, and counselling. The central element of the research involves an evaluation of this intervention. Through a mixed methods approach, the evaluation will assess the impacts of the programme by comparing trends in health and employment/benefit status of IB recipients between intervention and non-intervention groups; undertaking quantitative data analysis, including economic evaluation and contextual analysis of place effects; and undertaking qualitative interviews with samples of programme users to understand narratives and experiences of IB recipients in more depth.

Alongside this, my PhD thesis is focused on exploring the narratives and experiences of those in a control group who have not undergone the intervention, but who are in long-term receipt of IB long-term. The control group comprises people who are long-term IB recipients in County Durham and South Tyneside. Lastly, it is important to note how the PhD project is distinct and separate from the wider project. In order to achieve this, it was decided that the intervention group that are the subject of the evaluation will not be included in the qualitative interviews. Instead, the focus of the PhD research will remain solely upon the control group cohort. This has ensured a clear separation between both elements of the research.

### **Aims and research questions**

Drawing upon the fields of social policy, sociology, geography and public health, the thesis represents an inter-disciplinary study of IB receipt. The research seeks to explore the relationship between long-term IB receipt and stigma in North East England, a region with some of the highest levels of IB receipt in the UK. A consideration of the construction of self

identity of people claiming IB long-term, amidst wider political, societal and media representations of IB recipients is a key aim of the research. Below, the key research questions of the study are outlined:

- What are the health and illness narratives of long-term IB recipients?
- What is the relationship between IB receipt and stigma in the narratives of IB recipients?
- How do people receiving IB construct their identity amidst political, public and media constructs of welfare 'scroungers'?
- How do people receiving long-term IB respond to welfare reform and the shift from a 'passive' to a more 'active' framing of ill health?

### **Argument and thesis**

There has been a noticeable scarcity of research exploring the interactions between ill health, disability and the experience of receiving welfare benefits. Whilst there have been a number of studies of the impact of welfare-to-work interventions on employment rates (Bambra *et al.* 2005), and much is known about the links between unemployment and ill health (Black 2008), far less is known about how welfare reform impacts upon individuals experiencing ill health or disability who are in receipt of sickness benefits. Equally, there is a long history of research that has focused upon illness and identity, yet the experience of illness, identity *and* welfare receipt is largely missing from such discussions. Studies of people receiving sickness benefits have tended to focus largely upon the labour market, work, employability (Kemp and Davidson 2010) and the changing nature of IB receipt in terms of gender (Beatty *et al.* 2010). With few notable exceptions (Riach and Loretto 2009; Wainwright *et al.* 2011) the issue of self identity and sickness benefits receipt has been

somewhat overlooked. This thesis aims to address this by providing a detailed insight into this relationship between ill health, identity and receiving welfare benefits.

An overarching theme that emerged from the narratives was one of a life 'before illness' and a life 'after illness'. Becoming ill did not just result in losing a job: it could mean losing a partner, home, friends, independence, confidence, identity and a sense of self. The findings show that many people described a daily routine filled with guilt, boredom, restlessness and frustration at not being able to do the things they used to be able to do. In addition, what this thesis crucially highlights is that being on sickness benefits is not a comfortable and carefully chosen lifestyle choice – instead, health and illness narratives revealed severe hardship for those receiving IB, particularly for people who were living alone and only had IB as their sole income.

Participants negotiated changes to their identity in varying ways - constructing new dimensions of self; validating their illness; and pursuing aspirations. A disabled identity was rejected by the majority of participants as it symbolised permanence and a lack of independence. Together with this was often the refusal to accept a claimant identity, largely as a result of the stigma and shame people felt at being associated with being a sickness benefits recipient. However, the transition onto IB does not necessarily result in a negative identity shift. This thesis argues that the term 'incapacity' masks a whole range of realities; pursuing new aspirations and goals allowed some participants to evade the negative connotations attached to being on IB and could be used to further challenge disparaging stereotypical views of sickness benefits recipients. Instead, new identities were created that included following different career paths, learning new leisure skills and accepting new identities. Such an account is essential if the experiences of long-term IB recipients are to be truly understood. Only then can IB recipients be helped towards future

goals and aspirations – whether that is related to improving health, returning to work, retraining or voluntary work.

Secondly, the research recognises that people receiving IB do not automatically class themselves as disabled; disability as a category was often rejected by participants, especially if their route onto IB was a result of an accident or injury. Whilst this thesis has not explored this particular concept, it should also not be assumed that all disabled people regard themselves as sick. This discussion highlights the need to avoid conflating sickness with disability as though they are one category, and vice versa. For example, if someone is registered disabled, it does not automatically mean they are sick, or that they will receive sickness benefits. This thesis illustrates that being faced with the label of ‘disabled’ was especially difficult for people to face; disability was perceived as having permanence, whereas many people in the study hoped their health would improve and could not accept they were disabled.

However, in certain instances, such as having to attend a Work Capability Assessment (WCA) or when applying for official assistance such as Disability Living Allowance (DLA), people felt they had to present themselves ‘on their worst days’ and portray themselves as being as ill as possible. This is problematic as in doing so, adhering to the label of ‘disabled’ - for example, people spoke of this in terms of receiving DLA or when applying for a blue badge - could have a negative impact upon their identity and could possibly inhibit peoples’ likelihood to return to work in the future. As a result, people are missing out on benefits that they are entitled to, purely because they do not like the language and terminology surrounding the benefit which is also tied into the wider pejorative discourse churned out by the government and the media. Therefore, the risk of hardship faced by long-term IB recipients could be worsened.

Thirdly, the majority of previous research on sickness benefits receipt fails to recognise the experience of claiming sickness benefits; something this thesis specifically addresses. This thesis has captured the essence of how current welfare reform can affect people receiving sickness benefits at a time of ongoing uncertainty and transformation. Exploring the narratives of long-term IB recipients at a time of tumultuous upheaval has shown that the reform process can cause relentless stress, anxiety and upset that can negatively impact upon peoples' health and their daily lives. What's more, a worrying dichotomy between 'deserving' and 'undeserving' sickness benefits recipients is being created and embedded amongst recipients themselves. This suggests that wider government, media and public discourse is impacting upon long-term IB recipients perspectives and the opinions of other sick and disabled people, constructing further distinctions between those perceived as 'genuine' and those who are deemed to be faking it.

Finally, the thesis argues that whilst stakeholders working alongside IB recipients recognise and continually negotiate the complex barriers faced by people receiving sickness benefits, a wider dialogue of deserving and undeserving is being created and embedded through negative stereotyping of sick and disabled people. Whilst such findings may not be wholly surprising, they should not be underestimated or dismissed. As growing negative publicity surrounds sick and disabled people facing welfare reforms, stereotypical views can and indeed do have a real impact upon the lives of sick and disabled people. Government rhetoric, media portrayals and public opinion of sickness benefits recipients may all play a role in shaping the stakeholders' perspectives, further exacerbating notions of 'deserving' and 'undeserving' amongst sick and disabled people.

## Thesis chapter outline

**Chapter Two**, a Literature Review chapter, will provide a backdrop for the rest of the thesis. To begin, this chapter will briefly provide explanations of key terminology and definitions (Incapacity Benefit, Employment and Support Allowance, etc) for ease of the reader. This will be followed by a history of sickness and welfare from the Old Poor Laws of 1601 to date. Discussions will reflect upon the historical context of welfare, taking into account how unemployed sick and disabled people were viewed in policy terms. This chapter will argue that whilst sick and disabled people have largely been exempt from such negative connotations, in recent years there has been a resurgence of an 'undeserving' discourse that negatively labels sick and disabled people. In doing so, the chapter will explore and discuss government responses to IB, noting when changes in rhetoric have occurred, particularly during recent decades. Throughout the thesis, attention will be drawn to the language used when talking about IB. This thesis argues that from politicians to the public, the media and beyond, a wider pejorative discourse surrounding IB and those who receive it, is growing.

A contentious question at the heart of the IB debate is whether the large numbers of IB recipients are due to ill health or unemployment. Beatty *et al.* (2000) suggest that regional differences in employment rates conceal forms of 'hidden unemployment'. For them, this concentration of 'hidden unemployment' in former industrial areas suggests that some regional economies have not fully recovered from the fallout of deindustrialisation, a conclusion also reached by a number of other researchers (see Turok and Edge 1999; Webster 2006; Theodore 2007). The following section of the chapter will discuss how health and illness narratives and identity have been represented in current literature, before posing the question of how people receiving IB long-term construct and reconstruct their identity amidst wider political, media and societal discourses. At present, available

literature in health and illness narrative research focuses upon the interplay between identity and work, including those in paid work and those seeking paid work. But what about the importance of the relationship between identity, illness and welfare receipt? Of course, much previous literature in the field of qualitative health sociology has explored the concept of self, identity formation and illness (see, for example, Parsons 1951; Charmaz, 1990; 1991; 1994; 1999; 2002; Anspach, 1979; Bury, 1982; Schneider and Conrad, 1981; Conrad, 1987, to name just a few). However, apart from notable exceptions (de Wolfe 2012; Wainwright *et al.* 2011) what is largely absent from such discussions is a consideration of the experiences of people with health problems who are receiving sickness benefits. This research seeks to address this shortfall and explore how identity formation occurs for long-term sickness benefits recipients.

**Chapter Three** is comprised of two parts. The first part focuses upon research design and theory. Firstly, justification for this research design will be outlined, before detailing the process of sampling, access and data collection. Employing the qualitative methodology of semi-structured interviews, a total of 25 in-depth interviews have been carried out with long-term IB recipients in the North East of England between March 2011 and August 2011. A further 18 interviews have been undertaken with key IB stakeholders from various organisations such as the Department for Work and Pensions (DWP), National Health Service (NHS), Condition Management Programme (CMP), welfare-to-work organisations and local charitable organisations. Data were coded and analysed using an approach based upon the premise of grounded theory, and assisted by computer aided qualitative data analysis software (CAQDAS) NVivo. Finally, this section of the chapter ends by outlining key ethical issues within the research.

The second part of the methods chapter focuses on reflexivity throughout the qualitative research process. This section introduces empirical evidence from qualitative interviews with long-term sickness benefits recipients and discusses how the researcher-researched relationship exists in a constantly evolving state in which the performance of both parties is highly significant at each stage of the research process. This section reflects upon the significance of identity for both the researcher and the researched, whilst considering how risk can enter the research process. In doing so, issues such as emotions, power and trust will be discussed.

**Chapter Four** focuses upon the pivotal moment in IB recipients' narratives of 'becoming incapacitated'. For many participants, the transition from 'non-incapacitated' to 'incapacitated' was a sudden and unexpected shift. How can that impact upon peoples' daily lives and their identity? Firstly, candid chronic health and illness narratives of the 25 long-term IB recipients will be considered alongside a framework of identity formation. The transition from being healthy and in paid employment to becoming 'incapacitated' and receiving sickness benefits can clearly be a deeply traumatic and painful process. It is not simply about health – the change encompasses family, friends, and status, signifying a complete transformation. This chapter focuses upon how people perceived and managed becoming 'incapacitated' – beginning with how the transition happened to how it was experienced. Next, the chapter examines the key changes that people identified as occurring when they began receiving IB, with an emphasis on identity formation and reformation, alongside a consideration of how stigma features in the narratives. Furthermore, the notion of a disabled identity will be examined in relation to the narratives. Most participants were reluctant to accept a disabled identity as it signalled permanence and a loss of independence. An equally powerful rejection of a claimant

identity can be found in the narratives which can be tied in with the stigma and shame experienced at being a long-term sickness benefit recipient.

**Chapter Five** explores the importance of social networks and community for IB recipients.

The significance of family, friends and key professionals such as GPs or welfare-to-work staff has been debated here; this will incorporate a consideration of caring responsibilities, including being cared for by others and the strain this can bring with it. Alongside this, the importance of professionals such as GPs and other stakeholders will be outlined, highlighting just how much influence others can have on participants' narratives – whether that is in a positive or negative way. Clearly, there is a relationship between stigma and social networks for many participants that is borne out of a reluctance to divulge their claimant identity to friends and family. Finally, the chapter will highlight how place can impact upon their daily lives; for example, in terms of proximity to social networks, job opportunities, transport, and lastly how stigma can be linked to living in particular areas – resulting in people preferring to '*keep meself to meself*'.

**Chapter Six** draws on IB recipients' perspectives on and experiences of work. For participants in this study, the importance of work was recognised as being integral to their identity, even if they were not planning on returning to the labour market. People spoke of work as being highly important to them, 'a way of life' – many were desperate to get back into work, yet were prevented from doing so either as a result of their health problems or disability, or due to what they perceived as a lack of jobs and supportive employers. Such evidence of work motivation goes against assertions of a 'dependency culture' evident amongst long-term sickness benefits recipients. Additionally, the chapter discusses how for people with backgrounds featuring higher educational qualifications such as degrees, finding the appropriate support to get back to work was seen as problematic, as many back to work courses focused on basic skills such as literacy, numeracy and CV writing. Lastly,

the chapter questions whether a reconsideration of paid work is required in order to make paid employment more accessible and flexible to fit the often complex lives of sick and disabled people.

**Chapter Seven** examines how welfare reform plays a part in the narratives, revealing a dichotomy of responses – firstly, the dominant discourse in the study is characterised by a deep seated fear of reform and what it could mean for participants. Daily fear and trepidation of impending assessments reduced some people to talking about worsening health and even contemplations of suicide. Secondly, a less-commonly held belief was that reform is a positive shift that will not affect them as they are, in fact, genuinely ill. Accompanying these beliefs was a discourse amongst long-term sickness benefits recipients themselves that separated genuine and thus ‘deserving’ sickness benefits recipients from the ‘undeserving’ who were not genuinely in need.

Again, the language and discourse employed not only by politicians but also by the media when discussing welfare reform will be considered here. The relationship between identity and welfare reform for participants will be outlined, including a discussion of the notion of entitlement. Entitlement was linked to ideas surrounding morals and the language used to describe sickness benefits. Interestingly, people spoke of under-claiming benefits. Instances of under-claiming such as those described here would never make it into government or media discourse about people receiving sickness benefits, yet it does occur. Finally, a reflection upon the future of welfare reform and what this could mean for IB recipients will conclude the chapter.

**Chapter Eight** explores key stakeholders’ experiences and perceptions of working with long-term IB recipients. In order to fully understand the experiences of IB recipients, it is necessary to consider the experiences and perspectives of the key welfare-to-work

providers, clinicians and advisers who work alongside IB recipients on a daily basis. Firstly, the chapter will examine available literature on the topic of the role of stakeholders within a welfare-to-work framework, reflecting upon the perceptions and the language discourse used, drawing on distinctions made between the 'deserving' and 'undeserving' poor. Secondly, this chapter will present empirical findings from 18 interviews with key stakeholders working with IB recipients. Discussions will focus upon barriers for both IB recipients and stakeholders themselves, language used when talking about IB and those who receive it, before finally considering the impact of ongoing welfare reform for both stakeholders and recipients. The concept of identity will weave throughout all discussions.

**Chapter Nine** is a discussion and conclusion chapter which draws a close to the thesis. The chapter begins with a summary of the overarching themes of the thesis, including how the findings relate to the research questions outlined at the beginning of the study. Following this will be a consideration of how the findings can be interpreted and related to existing research in the field. Whilst the thesis does not attempt nor claim to generalise to everyone who receives sickness benefits, some of the findings and conclusions are likely to extend to reflect the experiences of others receiving sickness benefits. Consequently, a consideration of future policy implications will be made in light of the findings, together with possible avenues for further research, before finally presenting overall concluding comments.

## CHAPTER TWO

### LITERATURE REVIEW

#### Introduction

To begin, this chapter will briefly provide a context to sickness benefits receipt in the UK, including explanations of key terminology and definitions that will be used (Incapacity Benefit, Employment and Support Allowance, etc) for ease of the reader. This will be followed by Part One of the chapter which begins with a history of sickness and welfare from the Old Poor Law 1601 to date. Discussions will reflect upon the historical context of welfare provision, taking into account how notions of 'deserving' and 'undeserving' have re-emerged in policy responses to unemployed sick and disabled people. Whilst sick and disabled people have largely been exempt from negative connotations and 'scrounger' stereotypes (Grant 2011) this thesis identifies that in recent years there has been a resurgence of the 'undeserving' discourse that negatively labels sick and disabled people. From politicians to the public, the media and beyond, a wider pejorative discourse surrounding IB and those who receive it is rapidly gaining momentum. As such, this chapter will explore and discuss government responses to IB, noting the changes in rhetoric that have occurred, particularly during recent decades.

The subsequent section seeks to address a contentious question at the heart of the IB debate which is whether the large numbers of IB recipients are due to ill health or unemployment. Beatty *et al.* (2000) suggest that regional differences in employment rates conceal forms of 'hidden unemployment'. They argue that this concentration of 'hidden unemployment' in former industrial areas, such as County Durham, suggests that some regional economies have not fully recovered from the fallout of deindustrialisation. On the contrary, health as the key reason for job loss will be debated, including a consideration of

epidemiological insights. Finally, this will lead onto wider discussions about the impact of place and, in particular, the history and local labour market of County Durham.

Part Two of the chapter focuses more specifically upon stigma, health and identity. Building on the content in Part One which discusses the language of policy when discussing sick and disabled people, this section will seek to address how the mass media and society tend to view people receiving sickness benefits. In addition, drawing on sociological literature Part Two will outline the relationship between stigma, health and identity in the current literature, tying this into the aims and objectives of the thesis.

### **Context and key terminology**

The UK has 2.6 million people receiving sickness benefits – far more than the number on unemployment benefits even at a time of recession. The key sickness benefits are: Employment and Support Allowance (ESA) for new claimants from October 2008; Incapacity Benefit (IB) IB which provides support for people who cannot work because of an illness or disability which started before October 2008; and lastly Severe Disablement Allowance (SDA), a benefit which could be claimed before April 2001 by those unable to work for at least 28 weeks in a row because of illness or disability. Rates of receipt of these health-related benefits have increased from 0.5 million recipients in 1975 to 2.6 million in 2007. By 2007, around 7% of the UK working age population was in receipt of health-related benefits, accounting for 11% of UK social security expenditure, at a cost of around £8 billion per annum and amounting to 1.8% of gross domestic product (GDP) (Gabbay *et al.* 2011). At an international level, the Organisation for Economic Cooperation & Development (OECD 2008) reports that governments are spending twice as much on illness and disability as on unemployment benefits and warned that this strategy could prove to

be costly in the current economic climate as most individuals who are moved onto sickness benefits never work again.

In May 2011, a total of 2.6 million people were claiming sickness benefits, of which around 700,000 people were claiming ESA, 1.7 million IB and 200,000 SDA (DWP 2011). Of the 2.6 million people claiming sickness benefits, 31 per cent have a claim duration of up to 3 years and 35 per cent have a claim duration of 10 years and over. To qualify for IB, claimants have to undertake a medical assessment of incapacity for work called a Personal Capability Assessment (PCA). Under the ESA regime, new claimants have to undergo the Work Capability Assessment (WCA). From April 2011, IB recipients have also started to undertake this assessment. The medical condition recorded on the claim form does not itself confer entitlement to IB or ESA. Claims for ESA, as in earlier sickness benefit regimes, have to be supported by medical evidence that the claimant is unfit to work. If in work, the claimant will already have been getting Statutory Sick Pay (SSP), sometimes contractual sick pay, for twenty-eight weeks, supported by medical certificates. If the claimant is in receipt of Jobseeker's Allowance (JSA), ESA can be claimed after two weeks of sickness. After thirteen weeks of claiming ESA at the JSA rate of £65.45 (DWP 2011), supported by GP certificates, claimants then become subject to the new WCA.

The WCA is administered by Atos, a large multinational company. It divides claimants into three categories: the Support Group, who are not required to undertake work-related activity, and are entitled to £96.85 per week after the assessment phase at the JSA rate; the Work Related Activity Group (WRAG), who are deemed fit for work with support and preparation, and receive £91.40 per week after an assessment phase at the JSA rate; and the 'Fit for Work' group, who are transferred back to JSA. So, for example, a decision on entitlement for a customer claiming IB would be based on their ability to carry out the

range of activities assessed by the WCA; or on the effects of any associated mental health problems. It is also important to note that where someone has more than one diagnosis or disabling condition, only the predominant one is currently recorded. The rates for sickness benefits receipt vary, with long-term (£91.40) and short term rates for IB, and for ESA there is a difference of almost £26 per week between the basic allowance (£65.45) and the support premium (£96.85). The ESA basic rate is now the same as the rate for JSA. It should be noted that all of these rates fall below the UK poverty line of £115 per week (Bambra 2011).<sup>2</sup>

Alongside sickness benefits, other additional benefits are available for sick and disabled people and are also part of ongoing welfare reform. Disability Living Allowance (DLA) is a tax-free benefit for disabled children and adults to help with extra costs disabled people may face because of their disabilities. DLA is a targeted, flexible benefit paid to around 3.2 million people to assist with care and mobility costs. DLA is a non-means-tested, non-contributory benefit available for disabled people from the age of two to the maximum qualifying age of 64, although it can be continued beyond 64. It is made up of a mobility component to help with costs in getting around and also a care component to help pay for additional costs related to living in a disabling society (Burchardt 1999).

However, despite the increased concern over the amount of people receiving sickness benefits, evidence from the DWP (2011) suggests that fraud levels are, in fact, very low. The latest available figures from the DWP state that the fraud rate for IB is just 0.5 per cent. The fraud rate for DLA is also a mere 0.5 per cent, meaning that 99.5 per cent of claimants are not fraudulent. The figures for official error for both benefits are actually higher than the level of fraud, at 1.7 per cent for IB and 0.8 per cent for DLA. By focusing on this issue

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<sup>2</sup> All figures quoted are correct at the time of writing in September 2012.

as if it were one of the most important features of the system is completely unbalanced and thus manufactures an entirely wrong impression of sick and disabled people.

Whilst on the topic of key terminology, it is important to explore the definition of the term 'disability'. Many debates surround the definition of disability; for example, the definition employed in the Disability Discrimination Act (DDA) is: '*A physical or mental impairment which has a substantial and 'long-term' adverse effect on their ability to carry out normal day-to-day activities*'. Roulstone and Warren (2006: 119) comment that although a general definition, the DDA definition sits '*squarely in a medical model of disability*' and focuses upon what disabled people cannot do. The social model acknowledges that different impairments impact upon people's lives in different ways and that people with similar impairments might be disabled in different ways. This model has been influential in the UK, for instance, in supporting notions of Independent Living, direct payments, mainstreaming and the requirement to make 'reasonable adjustments' under the DDA. For Oliver (1990) many policy approaches tend to view the 'problem' of disability as located in the individual. Institutional problems are neglected, and the problem becomes one of personal pathology. Consequently, the problem is understood in terms of individual impairments, whilst wider labour processes are seen as unchangeable (Lunt and Thornton 1994).

The rise of the social model of disability has provided a significant challenge to the way academics, practitioners, researchers and policy makers conceptualise the 'problem' of disability (Oliver 1990; Swain *et al.* 1993; Barnes *et al.* 1999). The social model of disability offers a new framework and language of identifying, understanding and responding to disability, and is the model that discussion throughout this study will adhere to. The focus has rightly shifted to the social and institutional barriers that impact on people with impairments. Yet despite this, an increased focus upon individual characteristics and the

behaviour of individuals means that the binary between 'deserving' and 'undeserving' has worryingly begun to include disabled people (Grant 2011; Patrick 2011b/c; Warren 2005).

Alongside the failure to properly acknowledge the role of illness, there are confusions created by using the term 'disability' to refer to impairment rather than disabling barriers. This is particularly apparent in the inappropriate use of the term 'disability benefits', leading to the situation where, across the OECD countries *'many people on disability benefits do not claim to have a disability'* (OECD 2003). If the word 'disability' in this context is taken to mean 'impairment' then many of the people whose level of physical or mental ill health has been sufficient to enable them to qualify for 'disability' benefits would not choose to apply this word to their situation. This feeds into the negative reactions against people who do not fit the stereotype of a 'disabled person' (Morris 2011: 8). The terminology of 'sick and disabled people' will be used throughout the thesis. When talking about participants in this study, the term will specifically include people with physical impairment and manifest/known about mental health problems. People with learning difficulties and social learning difficulty such as Asperger's or autism were not represented in the narratives of the participants of this study. The following section outlines the historical context to welfare provision and reform for sick and disabled people in the UK, in particular how a shift towards connecting welfare dependency with sickness and disability has become apparent in recent years.

## **Part One:**

### **Sickness, Disability and Welfare in Britain**

To fully understand where we are now in 2012 in terms of welfare for sick and disabled people, it is essential to look back and briefly outline welfare policies that have had an impact upon sick and disabled people in the UK. Whilst this chapter could not attempt to detail fully the policies in use from 1601 to the present, this section hones in on the most significant changes in policy for sick and disabled people, and which relate most closely to the objectives of this thesis.

#### **A historical perspective of the 'deserving' and 'undeserving' poor**

The Old Poor Law of 1601 ordered the raising of taxes for the '*necessary relief of the lame, impotent, old and blind*' (Turner 2011). Following its inception, those claiming assistance on the basis of impairment have faced popular suspicion that their disabilities or medical conditions were faked. Elizabethan welfare legislation was set against a backdrop of increasing distrust of the sick and disabled. The Tudor formulation of welfare relief for the 'lame, impotent, old and blind' was partly intended to discriminate between 'deserving' and 'undeserving' claims. Davis (1998: 1) remarks that the Old Poor Law also consolidated what disabled people have characterised as the 'administrative model' (Finkelstein 1993: 37) in their dealings with people with physical and other impairments, as it viewed them as a problem that required officials to define, classify, register, administer and control. The Poor Law laid a foundation for future legislation which interpreted sickness and disability as being caused not by the state of society, but by the state of a person's body and/or mind. This interpretation is referred to as the individual or 'medical model' of disability which, in

the absence of a cure, requires intervention under the banner of 'care' (Barnes and Mercer 2010: 19).

After the 1834 Poor Law Amendment Act, the principle of 'less eligibility' or making the prospect of poor relief less attractive than working was adopted, thus creating a distinction between those who were able – and expected - to work and those who were not (Marshall 1985; Stone 1984). Deborah Stone (1984) suggests that the differentiation within the Poor Law Amendment Act between those who were able to work and those who were not was one of the crucial first steps in socially constructing disability. She argues that it became necessary to distinguish between three categories: the 'genuinely disabled person'; 'honest beggars' and those who were illegitimately attempting to portray themselves as falling into those categories (Stone 1984: 29). Whilst the first two categories were seen to need state assistance through no fault of their own, and as such were seen as 'deserving' of such support, it was believed that some people from the third category were pretending to have a disability (Stone 1978) and were thus 'undeserving'.

Indeed, after the Poor Law was amended in 1834, the majority of workhouse inmates were in fact '*physically and mentally disabled, the aged, the orphan and a wide variety of sick*' (Wood 1991: 98-99). As a result, disabled people were socially stigmatised by a system that was designed first and foremost as a deterrent to the able-bodied. The 1834 Act settlement remained largely intact until the period commonly known as the Liberal Reforms, 1906-1914, when a wide variety of legislation was enacted on issues of social security. Most importantly, the Royal Commission on the Poor Law reported, as a majority and minority, in 1909. Whilst the majority report saw poverty as a result of individual failing and argued to maintain the Poor Law, the minority report, written by Sydney and Beatrice Webb, opposed this view, instead believing that poverty was as a

result of structural causes (Vincent 1984). In 1942, William Beveridge identified five 'Giant Evils' in society: squalor; ignorance; want; idleness; and disease, and went on to propose widespread reform to the system of social welfare to address these. Beveridge recommended full employment, managed by the state, combined with insurance provision for unemployment and disability, yet within Beveridge's proposals the principle of 'less eligibility' was still clear. For example, unemployed people could be expected to attend 'a work or training centre' unemployment insurance would not be paid indefinitely, despite Beveridge's proposal that it should. At this time, disability and unemployment were clearly separated; for the first 13 weeks of 'disability due to industrial accident or disease', the recipient would be treated the same as other disabled people. The 1948 National Assistance Act opened with the words, *'The existing poor law shall cease to have effect'*. It was Beveridge's great hope that the prominent role in the British welfare system of a stigmatised and residualist model of social assistance would become a thing of the past (Horton and Gregory 2009: 69).

In 1948, Sickness Benefit (SB) was introduced and offered a benefit with unlimited duration, followed by the introduction of earnings-related SB in 1966. It was not until 1971 that Invalidity Benefit (IVB) was introduced by the Heath Conservative Government for the long-term sick, i.e. beyond 28 weeks. IVB offered a higher level of benefit than SB but without imposing another health test. The screening process at the time relied on a medical assessment, by a personal doctor, of the ability to conduct 'suitable work'. IVB was more generous than the benefits offered to the unemployed, suggesting the long-term sick were seen as 'deserving' of considerable financial support as some kind of compensation for them being seen as disadvantaged in the labour market.

## **The Conservative Governments 1979-1997**

Neo-liberalism has been a central feature of politics in the United Kingdom since the Conservative governments of Margaret Thatcher. In her manifesto of 1979, Thatcher outlined one of the five key tasks as being: *'To support family life, by helping people to become home-owners, raising the standards of their children's education, and concentrating welfare services on the effective support of the old, the sick, the disabled and those who are in real need'*. This extract indicates that 'the sick, the disabled' are in 'real need' and at this time were not included in the 'undeserving' category. Indeed, sick and disabled people were not included in the Review of Social Security in 1986 carried out by Norman Fowler, allowing their status as a 'deserving' group to continue. The Review saw Supplementary Benefit being replaced by Income Support (Walker 1983). Two years later saw the introduction of Incapacity Benefit in 1995 which was paid to people who were assessed as being incapable of work and who meet certain contribution conditions.

Throughout the Thatcher years, IB receipt grew, and was arguably used as a smokescreen to hide growing levels of unemployment; indeed, Craig (1998) comments that this was an attempt to manipulate statistics by appearing to lower rates of poverty and unemployment benefit claims thus lowering the claimant count, especially in deindustrialised areas. At this time, discourses in both policy and the media alike implied that many unemployment benefit claimants were fraudulent 'scroungers', despite little evidence to support this (Moore 1981). Such discourses were accompanied by debates surrounding the predominance of an 'underclass' firstly in the US and then the UK (Murray 1990; Field 1989) and a burgeoning 'dependency culture' (Dean and Taylor-Gooby 1992: 3). However, community care policies emphasised naturalistic solutions to previously institutionalised lives for disabled people (Barnes and Mercer 1996). The White Paper *Caring for People*

(DoH 1989) stated that the overall aim of community care was to promote 'choice and independence' by giving individuals more say in *'how they live their lives and the services they need in order to help them to do so'* (DoH 1989: 4).

Meanwhile, sick and disabled people were exempt from Thatcherite attacks on welfare or 'dole' scroungers. The Disability Discrimination Act (DDA) was introduced by John Major's government in 1995 and signalled a crucial development in the legislative protection of disabled people from discriminatory acts for many (Roulstone 2003). The introduction of IB in 1995 replaced IVB. Whilst previously IVB claimants had only to show that they could not continue to work in their previous occupation, IB introduced the 'all work test' which assessed how well a claimant could do any kind of work. Indeed, the Disability Living Allowance scheme was introduced in 1992 and grew dramatically during the Thatcher and Major years. Most notably, the neo-liberalism of the 1980s and first half the 1990s did not connect welfare dependency and disability in any meaningful sense (Roulstone 2011).

### **The New Labour Governments 1997-2010: things can only get better?**

The idea that IB was an alternative to long-term unemployment or early retirement informed Labour's welfare-to-work policies throughout its period of government, and has been carried forward by the Coalition government. Looking firstly at unemployment, the 'make work pay' agenda, the National Minimum Wage and the Working Family Tax Credit (now Working Tax Credit) were introduced in 1999 to increase the wages available to the lowest paid workers, thereby providing greater financial incentives for those on benefits to return to work. These reforms have been accompanied by the roll-out of two key welfare-to-work programmes. Firstly, New Labour welfare reform relied on programs labelled 'New Deals' to address specific groups of people, such as lone parents, disabled people, and young people, that are regarded as the hardest to serve (Evans and Millar 2006). Whilst the

different New Deals vary in terms of levels of conditionality and the type of support on offer, they tended to mandate a period of more intensive job search followed by participation in work-related activities such as training, education or some form of work experience.

*Reducing Dependency, Increasing Opportunity: Options for the Future of Welfare to Work* that was produced by Freud (2007) (hereafter referred to as the Freud Report) intended to address the 'stock' of long-term unemployed (hidden or apparent), lone parents and those on incapacity benefits. Grover (2007: 537) observes that the Freud Report is more concerned with meeting the 80 per cent employment aspiration than it is with tackling in-work poverty, for it mainly focuses upon ways out-of-work benefits might be developed in order to tackle worklessness among what are described as 'the hard to help' (Freud 2007: 6). 'The hard to help' workless include disabled people, lone parents (hereafter referred to as lone mothers as around 90 per cent are female), black and minority ethnic groups, and those who are described as having few skills (academic qualifications or their vocational equivalents). The Government made a commitment to rights and responsibilities a central feature of policy. In return for more support in obtaining employment, it would seem appropriate for the state to expect more work-related activity from those on benefit. The report therefore recommends maintaining the current regime for the unemployed, introducing stronger conditionality in line with Jobseeker's Allowance for lone parents with progressively younger children, and moving to deliver conditionality for other groups (including people already receiving IB) along the lines of Pathways to Work and the Employment and Support Allowance. These changes should be phased in over the next decade, to take account of the rollout of Pathways to Work, the new Employment and Support Allowance, and the government's childcare strategy. In addition, Freud recommended moving towards a single system of working age benefits, ideally a single

benefit, in order to better support the government's ambition of work for those who can and support for those who cannot.

These policies to tackle worklessness have been underpinned by three key claims. The first concerns the economic assumption that worklessness is a supply-side phenomenon best tackled through a focus on improving the employability of those out of work. As Theodore (2007) explains, proponents of this view focus not on the availability of jobs but on the lack of qualifications, skills and motivation that prevents the workless from accessing employment opportunities (see also Jessop 2002). Explicit within this conception of worklessness is the notion that *'the causes of unemployment are...conceived in individualistic and behavioural terms'* (Peck and Theodore 2000: 729). The logic of this reasoning invites *'calls for supply side interventions towards activating underemployed segments of the labour force through training, job-readiness programming and unemployment benefit reforms that encourage (and increasingly compel) rapid entry into work'* (Theodore 2007: 929). As Grover (2007: 536) terms the construction of worklessness: *'workless people are those who 'won't work', rather than those people for whom there are few jobs to apply for, who face barriers to work, including various and multiple forms of discrimination, and/or who do not consider paid work as being an important part of their identity'*.

The second claim underpinning New Labour's policies on tackling worklessness was a moral discourse on 'rights and responsibilities' that pervaded official statements and policies on welfare reform from the mid-1990s (DSS 1998; DWP 2007; Levitas 2005: 121). Indeed, the Freud Report can be linked to the privatisation of the welfare state. Freud was employed to outline policies he felt were required to meet the government target of an 80 per cent employment rate. The use of private sector job placement services, he argued, would be central to this aim (Freud 2007). The creation of another market through privatisation

would be particularly attractive to the private sector because of the amounts of money to be made.

A second, later phase of welfare-to-work reform saw attention shift onto claimants of sickness benefits with the introduction of Pathways to Work in 2003. This marked a fundamental change in the structure of the benefit system by extending conditional forms of welfare-to-work from jobseekers to the economically inactive. Under the programme, individuals making a new claim for sickness benefits were required to attend 'Work Focused Interviews' (WFIs) to discuss options for returning to employment. Rehabilitative support is made available in the form of Condition Management Programmes whilst a Return to Work Credit of up to £40 a week is available for one year for those who find employment through the scheme (Crisp 2008). These interventions generally tried to overcome the different barriers that people with a disability or chronic illness face when trying to enter employment, including a lack of experience or skills, uncertainty from employers, problems with physical access to work, and concerns over pay, hours and conditions (Gardiner 1997; Goldstone and Meager 2002). For sick and disabled people, such policy interventions typically focused on supply-side measures, which reinforced the medical model of disability (Barnes 2003; Oliver 1990). Supply-side measures in this context *'reinforce, rather than undermine, the traditional assumption that disabled workers are somehow not equal to non-disabled peers'* (Barnes 2003: 66).

From 2006, a succession of Green Papers, White Papers and legislation - too numerous to list here - led to the second welfare-to-work initiative launched by New Labour, the Pathways to Work (PtW) scheme. From 2003 to 2011, PtW intended to offer services *'to target a number of health-related, personal and external barriers to returning to work'* (DWP 2006: 28). In some areas of the country this was to be achieved partly through a

partnership between JCP and NHS organisations (Lindsay and Dutton 2011: 2). PtW involved adopting a 'holistic approach' according to the government, providing intensive support for people receiving sickness benefits (HM Treasury 2005). The content of the overall PtW initiative included compulsory WFIs with JCP advisers or other contracted providers; a one year Return to Work Credit paid at £40 per week tax free for full-time workers earning less than £15,000; voluntary 'Choices' support options; and finally, as part of 'Choices', the Condition Management Programme (CMP) – a 6 to 13 week intervention designed to enable clients to cope with mild to moderate health conditions.

The Welfare Reform Bill 2007 rolled PtW out nationally and also introduced the Employment and Support Allowance (ESA) to partially replace existing benefits. The key differences separating IB and ESA are increased compulsion, together with the addition of time limits for ESA. The 2010 White Paper *Universal Credit: Welfare that Works* argues for a one-year time limit on contributions-based ESA for those in the WRAG (DWP, 2010a). For Patrick (2011c: 12):

*Tools of compulsion and conditionality will be blunt instruments without more emphasis on efforts to provide comprehensive, high-quality back-to-work support alongside measures to tackle disabling discrimination and provide financial support to assist disabled people to work.*

In order to qualify for ESA receipt, people were required to face a Work Capability Assessment (WCA), which acts as the gateway to Employment and Support Allowance, as developed from a 2007 'Independent Report' by David Freud – a report which uncritically accepted the New Labour aim of reducing the number of IB recipients by one million by 2015. Interestingly, Freud is now Minister for Welfare Reform for the Coalition. Growing concerns over the large number of people on sickness benefits because of a health

condition or disability were apparent, with the aim of reducing the number of people receiving sickness benefits by 1 million by 2015 being introduced (Freud 2007). Freud claimed that:

*If you want a recipe for getting people on to IB we've got it: you get more money and you don't get hassled. You can sit there for the rest of your life. And it's ludicrous that the disability tests are done by people's own GPs – they've got a classic conflict of interest and they're frightened of legal action.*

Indeed, the idea of 'deservingness' can be seen in the work of van Oorschot (2000; 2006) who found a hierarchy of 'deservingness' based upon European Values Survey data. The study found that Europeans share a common and fundamental deservingness culture: across countries and social categories there is a consistent pattern that elderly people are seen as most deserving, closely followed by sick and disabled people; unemployed people are seen as less deserving still, and immigrants as least deserving of all. For van Oorschot (2006: 23), sick and disabled people were considered to be the most 'deserving' after the elderly. However, what we are currently witnessing is a systemic change when thinking about sick and disabled people and 'deservingness' - as with unemployability, debates about sickness benefits receipt are being shaped as much by ideological and political factors as by broader economic trends. Sickness benefit recipients started to be increasingly portrayed as feckless, idle cheats who 'neither work nor want' and who need to be coerced out of their 'dependency culture' and into work (Collins *et al.* 2009).

The widespread perception of IB claimants is of older, former industrial workers who became unemployed in the 1980s and 1990s and were shunted on to long-term sickness benefits as a way of keeping them off the unemployment register and giving them a bit more money to eke out their lives (Collins *et al.* 2009: 14-15). The further perception is that

they then 'festered' there and proceeded to raise a generation which was unable to learn about the routines and disciplines of working life. The assumption was that this generation then became problematic in its attitude to employment and reliant on welfare. As such, it started to become expected that sick and disabled people become responsible and take up opportunities for support that was being offered. For the first time, sick and disabled people have started to be included in a discourse within policy and the media that labelled them as 'undeserving', heralding a '*concerted onslaught*' (Roulstone 2011) on sick and disabled people, taking Britain back to the dichotomy of 'deserving' and 'undeserving' as first seen in the 1834 Poor Law Amendment Act. Further, Roulstone (2000: 435) comments how a distinction between real and fictitious disabled people can be likened to the Foucauldian binary division between real and imagined, 'deserving' and 'undeserving' (Foucault 1980). Indeed, as Warren (2005: 307) observes:

*When Aneurin Bevan remarked in 1948 that 'We have finally buried the body of the poor law', he did not imagine that its ghost would continue to haunt British social policy into the 21<sup>st</sup> century.*

New Deal and broader welfare-to-work policies began to blur prior distinctions between the 'deserving' and 'undeserving' which had previously been attached to non-disabled and disabled claimants of working age people respectively (Hyde 2000). The mismatch between being reclassified as fit for work and the lack of sufficient employment alternatives has left some in a 'half-world' between work and validated welfare (Roulstone and Barnes 2005). In many ways, these trends represent what Stone (1984: 118) describes as the 'disability category' - a category '*to keep everyone in the work-based activity distributive system except for the very neediest people*'. For Stone (1984: 21) medicine and the state construct administrative categories including 'sickness' and 'disability' that entitle those so classified to certain '*privileges and exemptions*' such as social aid and being exempt from having to

work. Stone recognises that those who are exempt from the labour market due to health reasons are viewed with suspicion and are liable to be stigmatised and face economic deprivation – assertions reflected in the findings of this thesis.

### **Coalition 2010-present: the end of a 'lifestyle choice'?**

Building upon the foundations laid by New Labour who initially introduced ESA, the Coalition government made it clear that they, too, intended to continue forward with '*radical welfare reform*' (HM Government 2010). The Coalition government share New Labour's commitment to extending conditionality to disabled people, with early indications suggesting they may well be even more strident in the utilisation of a contractual, conditional framework towards the sickness benefit claimant population (Duncan Smith 2010; Wintour *et al.* 2010). Adding conditionality, in the form of compulsory involvement in active labour market programmes is novel in terms of UK sickness absence benefits (Bambra 2008). However, it is in keeping with the reform of other UK benefits (such as the reforms to unemployment benefit of the 1980s and 1990s) and changes to sickness absence benefits elsewhere, such as in Australia or the USA (Stone 1984; Organisation for Economic Cooperation and Development 2003) according to Bambra and Smith (2010). Of course, it must not be forgotten that these proposals were made at a time when '*unemployment [was] probably close to its frictional level*' (Freud 2007: 51) and was considered to be a problem largely solved (Grover 2007). Currently, the economic recession facing the UK and the wider global economy has resulted in rising unemployment levels. Put simply, the labour market is in a very different place to the one that was being enjoyed when the previous Labour government announced welfare reform. In terms of sickness benefits recipients, this means fewer opportunities within the labour market and increased competition for jobs, creating a real danger of long-term sickness benefits recipients being

left at the back of the queue. Yet despite the tough economic climate, there has been no suggestion of a relaxation of the conditions attached to ESA.

Since February 2011, the ESA system has been extended to over 1 million IB recipients with the intention of eventually reassessing and transferring the remainder onto ESA. All existing IB recipients will be subject to the WCA with three possible outcomes: fit for work; ESA - work related activity group; or ESA - support group. If someone is found fit for work, they will be moved onto JSA (paid at a lower rate than IB or ESA and which is means-tested after 6 months) and will have to actively search for work. In April 2011, the DWP published statistics for all completed WCA assessments (October 2008 to November 2010): 64% of people were deemed 'fit for work', whilst 1 in 4 people (26%) were moved into the work-related activity group and the remaining 10% of people were placed in the support group. Interestingly, of people who made a claim for ESA between October 2008 and February 2010 and who were found Fit for Work at assessment, 36% have had an appeal heard by Tribunals Service to date. The DWP state that in 61% of appeals the original decision was upheld; therefore, 39% of appeals are successful (DWP 2011a). Horror stories of individuals with serious health conditions being found fit for work, including those with Parkinson's disease, multiple sclerosis, terminal cancer, bipolar disorder, heart failure, strokes, and severe depression have made their way into the public arena (Citizen's Advice Bureau 2010; Gentleman 2010). Further, there is currently little empirical evidence to suggest that such attempts to restrict entitlements to welfare benefits will have a positive impact on the employment of chronically ill and disabled people (Barr *et al.* 2010).

An independent review of the WCA system has found that *'there are clear and consistent criticisms of the whole system and much negativity surrounding the process'* (Harrington 2010: 9). Further reviews (Harrington 2011; 2012) reinforce this key message. There are two main strands to the recommendations made throughout the Harrington Reviews: to

revise the process of the WCA from the first claimant contact right through to appeal (where necessary); and to review whether the current descriptors accurately capture the true nature of the claimants' case. Harrington made a number of recommendations to the DWP. The first recommendation states that it is essential that all relevant medical and allied evidence about the claimant is available to the DWP Decision Maker at the earliest possible stage in the assessment process. If this can be achieved then Tribunals will be based on Judges and Medical Members considering the same body of evidence as the Decision Maker did. The second recommendation: 'DWP Operations need to find an appropriate balance between better quality decisions that are carefully considered and 'right first time' and the achievement of appropriate benchmarks at a local level.' Such a recommendation could hint at target setting.

The third recommendation is that the DWP should try to get more feedback from tribunals as to why decisions are overturned. This seems reasonable as it could affect change in the decisions made to start with. The fourth recommendation is that the DWP must highlight improvements, and be open about problems. The Government response indicated that they welcome the third independent review of the Work Capability Assessment (WCA). The government response claimed that the recommendations of Professor Harrington's first two reviews, and their response of accepting and implementing them, have already led to significant improvements to the WCA. They also claim to welcome Harrington's observations about the improvements he has identified and accept that there is further to go. They agree with Harrington that the WCA '*remains a valid concept for assessing...eligibility*' and that there is no evidence to suggest that the system is fundamentally unsound – despite the fact that 73 people die per week whilst waiting for their WCA outcome (Disabled People Against Cuts [DPAC 2012]). Equally, they acknowledge that the WCA still attracts criticism, and although the system as a whole is

on the right lines, too many individuals are finding the process more challenging than it should be, and that there is more hard work to be done to consolidate and strengthen the improvements that are emerging. Lastly, Harrington noted that '*considerable disquiet remains, and this cannot be ignored*'. This hints at the importance of disability activists and their protestations about the welfare reform process, and further suggests that the work they are doing is invaluable and '*cannot be ignored*'.

The Government has also pledged to cut DLA by 20 per cent and are replacing DLA with Personal Independence Payments (PIP), which sees the end of the automatic entitlement of people with certain impairments and focuses instead on support for those deemed '*most in need*'. All DLA claimants have already been assessed as eligible for the benefit, although differential levels of award are made depending on levels of 'disability'. Former disabilities minister Maria Miller stated that £600m of DLA was overpaid each year, neglecting to mention that a greater sum is saved by others not receiving what they are due through under-claiming. Between 2013 and 2016 everyone aged 16 to 64 receiving DLA will be reassessed to see whether they are entitled to the new PIP. People entitled to PIP will have their claims transferred over and their DLA will stop (DWP 2011b), with the DWP publishing estimates (DWP 2012) which demonstrate at least 500,000 disabled people will lose help.

Another inclusion in the Welfare Reform Bill was the introduction of a single Work Programme for all benefits recipients which replaced the currently complex array of work programmes for sick and disabled people. The delivery of the Work Programme has been contracted out to organisations in the private and voluntary sectors, marking the consolidation of a trend towards marketisation begun under New Labour (Newman 2011), notably (for people in receipt of disability benefits) in Provider-led Pathways in 2008. A key element of the Work Programme is the 'black box' delivery model, which grants providers free rein to design support that will achieve sustained work targets. Attempts to mitigate

concerns about 'creaming' off job ready people into easy to find (but not necessarily sustainable) work and 'parking' those who seem furthest from the labour market have been made through a new contract and pricing structure (Hudson *et al.* 2011). As a result, the bulk of provider payments are paid whilst sustaining individuals in work and higher sums are awarded for assistance given to 'harder to help' client groups in recognition of the need for greater investment (DWP 2010b). For disabled people with more obvious support needs, a Work Choice programme is being introduced to provide intensive support, which is likely to include CV writing, brokerage and closer working with employers will form the main support activities (DWP 2011b); forms of support that were already available under previous schemes. Yet this is based upon a cagey assumption that work will be available for all of the sick and disabled people the government are trying to activate. Further, Mulheirn (2011) points out that the use of private and voluntary sector organisations to get people into sustained employment is at risk of failure due to over-optimistic assessments of what providers are able to achieve, excessively tight financing and a rapidly deteriorating economic environment.

Grover and Piggott (2009) comment that the way that employment services for getting sick and disabled people into paid work are, on the whole, to be removed from the public sector service, Jobcentre Plus. While tranches of the privatisation of Pathways to Work (PtW) were announced in 2007 (DWP 2007b, 2007c), with 40 per cent of Jobcentre Plus areas being left in the public sector, it was announced in February 2008 that all job placement services for ESA claimants would be privatised, with providers being rewarded for the number of people they place into work and the length of time they stay there (Secretary of State for Work and Pensions, 2007). In this sense, not only are sick and disabled people increasingly defined as unemployed labour, they are also a resource for private sector companies to profit from; they are a commodity to be traded. The

privatisation of placement services that will underpin the ESA regime also points to the fact that there are often vested interests pushing for welfare retrenchment. Central to such concerns is the way in which private sector companies will be paid. MIND (2006, para. 4.4), for instance, is concerned that 'outcome-based contracts will mean contractors focus on getting people off benefit, as opposed to supporting people into suitable employment at a pace that suits them', while the Disability Alliance (2006, para 3.3) is concerned '*about private companies being able to tell disabled people they have to apply for a job or lose their benefit, particularly if the private company has an incentive to do this*'.

The Welfare Reform Act, which received royal assent on 8 March 2012, legislates for far-reaching changes to the benefits and tax credits system. These changes are intended to reduce the underlying demand for welfare support. More immediately, as set out in the March 2012 budget, the government is aiming for welfare cuts of £10 billion by 2016 (HM Treasury 2012). The Welfare Reform Act sets out a variety of short- and longer-term strategies intended to contribute to spending reductions. Eligibility for a range of benefits is being restricted, alongside reductions in the actual levels of specific benefits being paid, while strategies have been designed to incentivise individuals to move off benefits where possible. For example, Child Benefit will be reduced for households where an individual is earning more than £50,000 and will not be available when an individual is earning more than £60,000, while Housing Benefit entitlement will be limited for social housing tenants whose accommodation is deemed larger than they need. An overall cap has also been introduced, limiting the total amount of benefits that can be claimed to no more than the average earnings of a working family - £500 per week for couples and lone parents and £350 per week for single adults. Among measures designed to make the welfare system more efficient, the introduction of a Universal Credit, from 2013, stands out. This will provide a single streamlined payment for people of working age, aimed at improving work

incentives. The government is introducing a range of other changes intended to incentivise employment for those considered capable of work. Around half a million working-age people out of the two million claiming Disability Living Allowance are expected to lose their entitlement after 2013, when it is replaced by a more rigorously tested Personal Independence Payment.

These proposed changes have significant implications for sick and disabled people given their greater reliance on out-of-work benefits and housing benefits than non-disabled people. Indeed, the severity of the treatment of some benefits recipients raises issues relevant to human rights and possible contraventions of the Human Rights Act. As well as having equality implications under the Equality Act (see information on High Court challenge, below) the reality of the WCA experience may compromise disabled people's human rights, as outlined in the Human Rights Act, the European Convention on Human Rights and/or the United Nations Convention on the Rights of Persons with Disabilities (the latter having been ratified by the UK Government in 2009). The UK is bound by the Human Rights Act 1998, in particular Article 8 which guarantees the right to independent living and article 9 which guarantees the right to free association. Furthermore, under the CRPD (United Nation Convention of the Rights of Persons with Disabilities), the UK recognised under article 19 'the equal right of all persons with disabilities to live in the community, with choices equal to others'. Under these articles, all disabled people have these rights, and narrowing support given to uphold these rights could be considered to infringe sick and disabled peoples' human rights. The reforms will focus on those 'that need the greatest help'. Disabled people fall into broadly five categories: the sensory impaired, the mobility impaired, those with mental health or learning difficulties, those with a hidden disability and those with a combination of the above (The access group). As previously stated, to achieve a target of 20% cuts under PIP assessments, a substantial number of disabled

people who currently receive DLA will have to lose that support. These proposals could limit support to only some of these categories. Under the Equality 2010 Act, it is illegal to treat one group of disabled people less favourably than another. If removal of DLA from sick and disabled people with so-called 'lesser needs' removes or limits those choices, the UK Government will be in breach of their human rights obligations.

What's more, harsher welfare regimes in the absence of greater employment opportunities will simply lead to movement on to less generous benefits (typically JSA), an important policy consideration where genuine extra costs are no longer met. Similarly, entry into low paid work without additional cost benefit entitlement may increase levels of in-work poverty for some disabled people. The combination of increased conditionality and the privatisation of job placement services is particularly worrying for Piggott and Grover (2009: 167) for it is at odds with the government's concern with the social exclusion of sick and disabled people. They suggest that the retrenchment of benefits for sick and disabled people is aimed at the creation of a pool of labour that can be traded between privatised job placement services and employers and, in this sense, the ESA can be interpreted as creating a group of disadvantaged people through which the private sector can profit. Evidence suggests that people in the mainstream JSA population can be trapped in the low-pay, no-pay cycle – in other words, moving in and out of paid employment and benefit receipt – which could act as a barrier for people leaving ESA (Webster *et al.* 2004; Shildrick *et al.* 2010). Williams (2010: 197) points out that if people with long-term, fluctuating conditions find themselves seeking work, job insecurity and precariousness are unlikely to be beneficial in either economic or health terms (Benach *et al.* 2002; Quinlan and Bohle 2009). Therefore, the presumption that work – any work – is a positive outcome for the individual as a good citizen and for society ignores the reality of precarious work characterised by insecurity, such as zero hours contracts and temporary agency work.

Indeed, Scambler argues that norms of shame and blame in social structures has been illustrated with reference to the British government's 'welfare-to-work' programmes directed at those with chronic disorders or disabilities (Scambler 2006: 293–4). Inherently rooted in the premise that the relatively low employment rates amongst these groups contribute to the evils of poverty and social exclusion, these programmes were designed to facilitate the transition from out-of-work benefit receipt to paid employment. The strategies on offer were: education, training and work placements; vocational counselling and support services; in-work benefits; incentives for employers; and the improvement of physical accessibility. Certainly, for Bamba and Smith (2010: 77) the work of Stone (1984) is useful when thinking about ongoing welfare reform for sickness benefits recipients, with the dawn of *'a potentially disturbing political discourse that dictates that certain types of illness or disability are less deserving of unconditional public support than others'*. Grover and Piggott (2010) warn that effectively, the new welfare regime will result in 'social sorting', in the sense that ESA sorts people who are sick and/or who have impairments into subgroups of claimants dependent upon medicalised perceptions of their sickness and/or impairment. Alongside this, poor health and disability may make it difficult for some individuals to secure jobs in an apparently more competitive labour market with employers demanding more 'flexibility' (Houston and Lindsay 2010). It is also noteworthy that the Disability Discrimination Act (1995) and its amendment made little major difference in the employment gap between disabled and non-disabled people (OECD 2003; Pearson and Prinz 2005; Bamba and Pope 2006). Indeed, for Roulstone (2011) the low level of placement in sustained jobs characterises the New Labour era from early New Deal (Arthur *et al.* 1999) through to Pathways to Work.

A more critical point would view the new welfare discourses as similar to those commonly stated during the Thatcherite era that the fundamental problem of welfare is that the poor are too well off. The Secretary of State for Work and Pensions, Iain Duncan-Smith has made clear the intention to make work pay and to disincentivise out-of-work benefits. Critics have tended to view the rhetoric of the ending of the tragic waste of disabled worklessness as simply a smokescreen to save money and redefine the disability category regardless of the altered economic position of those moved out of the more generous sickness benefits (Roulstone 2011). Recent government reforms are being presented in terms of the 'personalisation' of service to individual customers, and individually tailored advice and support for benefits recipients to enter the labour market (Gregg 2008). For Williams (2010: 191) talk of 'personalised conditionality and support' lacks an awareness of the wider and social historical context of sickness and disability. Indeed, thinking in terms of 'deserving' and 'undeserving', for Warren (2005: 310) the 'deserving poor' are those who are *'prepared to modify their lives, behaviour and aspirations in line with the directives of government'*. Grover and Piggott (2012: 10) counter that personalisation needs to be understood as being framed by unequal power relationships. The UK's government sets the parameters of what is expected of the individual, even if they expect the individual to do something that otherwise they would choose not to do. Hence, rather than being a more empowering version of personalisation related to rights and inclusion, the UK has a rather oppressive version of it.

The Coalition government defend their policy stance with commitments to reduce poverty which is linked to worklessness. Ellison (2010) observes that the Coalition government has taken a more ameliorative approach towards poverty and social injustice than their previous Conservative counterparts. For example, Cameron has suggested (2009: 2) that he perceives New Labour as failing to reduce poverty and tackle associated social ills such as

crime, poor education and welfare dependency because the Labour government relied too heavily on state action and insufficiently on 'social action'. Instead, the importance of the third sector and the Big Society are perceived as the key drivers of change under Cameron's Coalition. The state is present as an 'enforcer' of social and economic discipline, ensuring that all those who can work should do so and that those who do not contribute to society and community are suitably penalised (Ellison 2010). Again, this reinforces further the dichotomy between active, 'deserving' citizens – in other words, hard working tax-payers – and the inactive and 'undeserving' benefits recipients who are viewed as being in all ways non-contributory to society.

### **Welfare reform in a wider context**

Currently, welfare reform is not just affecting sick and disabled people in the UK. This section will briefly examine the situation of other EU countries, alongside the case of countries such as Australia and the US. As is the case in the UK context, Switzerland is also in the process of introducing new responsibilities for persons with health conditions that could lead them to taking up sickness benefits (OECD 2008). Under a reform adopted in 2008, people are now obliged (as the legislation states) to participate in '*measures designed to reduce the costs for society arising from their disability*' (OECD 2008: 10); obligations are listed explicitly, together with sanctions for non-compliance. Similarly, in Luxembourg, people with partial work capacity are now obliged to enrol in training and reintegration measures. Nevertheless, available evidence suggests that reforms activating existing recipients can be successful – even though the context of a recession and rising unemployment may not be the ideal time to implement such change. Sweden has recently implemented reforms for long-term sickness benefits recipients, with permanent sickness recipients earning up to around EUR 4,000 per year before their benefit starts to reduce

progressively. Most importantly, they can cease work and resume their sickness benefit at any time without a new reassessment. This policy may also support those whose ability to cope with incapacity improves over time, and it is especially likely to suit persons with episodic health conditions. Reform of this type is particularly well-suited in the current economic climate; it gives recipients a safe means of trying to re-enter the labour market without having to fear failing in the attempt and having to endure another long and drawn-out assessment process to regain benefit entitlement.

Harris *et al.* (2012) describe how in the United States neoliberal welfare reforms began in 1996 with the Personal Responsibility and Work Opportunity Reconciliation Act, which instituted a five-year limit on social assistance benefits and placed work requirements on beneficiaries. Yet at the time, the reforms did not have a significant impact on sick and disabled people, and there is no mandatory national workfare program for the sick and disabled in the United States. From 1999, sick and disabled people were encouraged through a voluntary programme to seek work. The Ticket to Work and Work Incentives Improvement Act represented the most extensive employment program for sick and disabled people in the US, because all people who receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) are eligible for the program. The scheme incorporated sustained access to healthcare during the move into employment alongside the provision of employment preparation and placement services that people can voluntarily choose to participate in by redeeming a 'ticket' provided by the government (Harris *et al.* 2012: 6).

In Australia sickness benefits for sick and disabled people have undergone similar trends to those that have been occurring in the UK, with increased conditionality, sanctioning and upheaval (Grover and Soldatic 2012). Fundamentally, Grover and Soldatic (2012) note that for sick and disabled people, a process of 'reclassification' to restrict the access to sickness

benefits has occurred in both the UK and Australia, with the intention that such benefits are only applicable to a newly-defined 'truly' disabled group of people. Therefore, as this section has shown, welfare reform is not only affecting sickness benefits recipients in the UK and can be witnessed across the globe.

### **Research evidence**

Debates on health and employment are not always based on clear understandings of the relationships between economic, social and individual factors. It can be argued that the social and contextual aspects of the relationship between health and employment are crucial, as they offer a conception of health as socially embedded. The following section seeks to address a contentious question at the heart of the IB debate of whether the large numbers of IB recipients are due to hidden unemployment or ill health.

### ***Hidden unemployment?***

The perception that those receiving IB are individuals with health problems who lost jobs in the industrial upheaval in 1980s and 1990s and, finding themselves unable to find work, were legitimately diverted onto sickness benefits, is at the heart of Beatty and colleagues' popular thesis. Beatty *et al.* (2000) have argued, for example, that regional differences in employment rates conceal forms of 'hidden unemployment'. This concentration of 'hidden unemployment' in former industrial areas suggests that some regional economies have not fully recovered from the fallout of deindustrialisation, a conclusion also reached by a number of other researchers (see Turok and Edge 1999; Webster 2006; Theodore 2007). This is not to imply that the health problems of sickness benefit claimants are not 'real' – rather, these people are the 'hidden unemployed' because if labour demand was high, their health would not interfere with their ability to get a job (Alcock *et al.* 2003: 120; 126).

Beatty and Fothergill have developed their theory somewhat to reflect changes in the pattern of sickness benefits. While the original 'hidden unemployed' were men made redundant from heavy industry, more recently they are both men and women who lost their jobs specifically for health reasons (Beatty and Fothergill 2007: 17). It is no longer accurate to picture sickness benefits claimants as men with musculoskeletal problems who used to work in heavy industry and were made redundant (Kemp and Davidson 2008). Yet women recipients are still concentrated in the same areas as men receiving sickness benefits (Beatty and Fothergill 2005: 849; Beatty *et al.* 2009: 964). Beatty *et al.* argue that the most plausible explanation is a continuing lack of jobs: in these areas the supply of workers outstrips demand, the gender segmentation in the labour market declines with successive cohorts, and we therefore have competition between genders (Beatty *et al.* 2009). Beatty and Fothergill have estimated that 40% of IB claimants can be considered the 'hidden unemployed', based on the crude assumption that if there was full employment, levels of IB receipt would be the same as in the South East in 1991 (Beatty and Fothergill 2005). Yet incapacity is associated with unemployment but not the availability of jobs; in both cases, this suggests a problem of a mismatch between supply and demand rather than a shortage of labour demand *per se* (Baumberg 2011: 51).

### ***Ill health as an explanation***

Beatty and Fothergill's estimates still suggest that the majority of claimants are not the hidden unemployed. Indeed, their survey of over 3,500 people receiving IB found that 70% lost their last job due to ill-health, for 70% their health limited work ability, and over 90% said ill-health was the main barrier to work (Beatty and Fothergill 2010). For example, surveys have consistently found that IB claimants tend to have left their previous employment due to sickness, and see health problems as a key barrier to work (Beatty and

Fothergill 2002; 2005; Beatty *et al.* 2010; Green and Shuttleworth 2010). Similarly, Kemp and Davidson (2010) found that they had twice as many health conditions affecting their everyday activities as other 'work-ready' benefit recipients. A strong factor behind the limited success of active labour market policies for sick and disabled people is that they focus almost exclusively on employment. Little attention is paid to the chronic health needs of this population, who, after all, are on sickness benefits as a result of ill health or disabilities.

In *Working for a Healthier Tomorrow*, Dame Carol Black (2008) identified the sheer scale of the numbers of people on incapacity benefits represents as an 'historical failure of healthcare and employment support to address the needs of the working age population in Britain'. The report noted that Pathways to Work has had limited effect for those whose main health condition was a mental illness. Finally, the importance of work retention was highlighted by Black (2008). Rehabilitation services and employer adjustments can be critical in enabling someone to return to and stay in work, not just addressing the specific health barriers to an individual's employment, but also providing a source of information for the patient on the types of work which may be most suitable. As such, there is a need for a national commitment to occupational health, which engages with employers to target sickness in the workplace and invests in condition-management services for benefit claimants (Lindsay and Houston 2011).

Much of the descriptive part of the review covers incapacity to work as a result of ill health. Many people with health conditions or long term disabilities can work and want to work, but they are dissuaded from doing so by societal expectations and sometimes by overprotective doctors. The notion that work is good for you has only recently been evaluated in detail. A key message from Black (2008) was concerned with getting sick

employees back to work as soon as possible is not just of economic benefit to the government - it is a positive health promoting measure for patients that all doctors should adopt. Accordingly, the main measure was that sick notes should be replaced by 'fit notes'.

Given the importance of income maintenance during times of ill health, and the links between unemployment and health (Black 2008), the reforms to long-term sickness absence benefits in the UK have potentially important ramifications for public health. There is clear epidemiological evidence from the Whitehall cohort studies to suggest that medically certified sickness absence reflects actual morbidity and mortality (Marmot *et al.* 1995, Kivimaki *et al.* 2003; Vahtera *et al.* 2004). What's more, recent population-level studies found a strong relationship between IB claims and mortality (Bambra and Norman 2006; Norman and Bambra 2007). Nevertheless, despite the absence of any direct evidence (Bambra 2006) a popular perception remains that IB is a disincentive to work, particularly in political and media debates about worklessness. Norman and Bambra (2007) recognise that IB may hide unemployment, yet their estimates using census data on economic activity suggest that '*previous assertions about the relationship between IB and unemployment may have been overzealous*' (2007: 333). Nonetheless, it is far from clear if the current approach to welfare reform, characterised by coercion, conditionality and the stigmatisation of certain recipients, is best placed to facilitate return to work or, indeed, the acquisition of suitable (as opposed to any) employment (Bambra and Smith 2010: 79).

As stated in the Introduction, this thesis is attached to a wider project which is evaluating an intervention aimed at improving the health of people receiving IB long-term. Quantitative evidence from the control group shows that people receiving IB in County Durham and South Tyneside contend with multiple health problems (Warren *et al.* 2012). For example, musculoskeletal problems were the largest category of self-reported health problems with almost half (49.55%) of participants identifying this as their primary health

problem. In February 2010, the comparable national figure was 22.48% (DWP 2010). Mental health was the primary health issue for around a quarter (23.87%) compared to a national average of over twice that number at almost 50%. Other primary problems reported included: digestive/gastric issues (10.36%), cardiovascular problems (9.46%) and respiratory problems (2.25%) all of which represent figures higher than the UK national averages. Comparison with the national figures would suggest that those with mental health issues are under-represented in the sample and those with musculo-skeletal conditions are over-represented. This could be a result of the sampling frame, suggesting that people with mental health issues were less likely to attend the non-compulsory IB Choices events, and this led to them being under-represented in the survey.

### **Place and health**

The importance of place has been alluded to previously in this review; however, the following section will discuss more explicitly the importance of place and the narratives within it. The relationship between health and geographical place has been widely discussed in the academic literature and beyond by geographers and sociologists amongst others. The following section provides a brief overview of available literature relating to the importance of place on health, as this topic will be examined in greater detail in Chapter Five – *Social Networks, Community and Identity*.

A growing body of research has emerged which focuses on the contributions of contextual and compositional effects in public health research (Duncan *et al.* 1993; Duncan *et al.* 1998; Diez-Roux 1998; Diez-Roux *et al.* 2000). The origins of these effects may be due to what are frequently called compositional attributes (Duncan *et al.* 1998; Macintyre *et al.* 1993; 2002; Duncan *et al.* 1996; Duncan *et al.* 1999). These attributes are understood to be those of persons living in certain types of areas (Diez-Roux 2000). Compositional factors most

frequently examined are indicators of socio-economic status such as individuals' social class, housing tenure, employment status, educational status, marital status, and so on. Compositional and contextual explanations have often been discussed as competing explanations, and much of the debate on place and health inequalities has been focused upon these two notions. Macintyre *et al.* (2002) point to a collective explanation that draws on the importance of shared norms, values and traditions.

However, Bernard *et al.* (2007) argue that such a polarised debate regarding this framing of effects constitutes an oversimplification. Privileging one explanation over another can be problematic. Such an approach suggests that there is a specific cause or a hierarchy of causes and therefore that adequate explanation requires the identification and isolation of the cause(s). Instead, a complex interaction of many factors leads to high levels of IB receipt: the social, the economic, the environment, and also individuals themselves - the compositional, the contextual and beyond. In other words, attention should also be paid to the elements which make up an area's history and culture (Warren *et al.* forthcoming 2013).

There are interesting questions to be raised in relation to why illness and IB receipt seem to be elevated in North East England, and how they may relate to long-term processes in the labour market. County Durham is a region replete with a coal mining legacy that relates to wider, long-term processes in the economy and regional labour market. Easington district in Durham covers the towns of Peterlee and Seaham and a number of smaller settlements including Blackhall, Horden, Murton and Easington itself, most of which are former pit villages. Easington has the highest IB rate in England, and has consistently vied with Merthyr Tydfil in South Wales for the unwelcome position of the district with the highest rate of IB receipt in the whole of the UK. As of February 2011, in Easington 13.6% of the

population were receiving sickness benefits. Beatty and Fothergill (2011: 20) estimate that in Easington alone, 4,200 will be moved off sickness benefits, of whom 2,000 could lose their benefits altogether. For County Durham as a whole, of the 31,270 receiving sickness benefits, an estimated 7,500 will be removed from benefits entirely.

Research into the relationship between health and place runs the risk of conceptualising places merely as containers of people and things. Experiences of 'place' are configured through material and social circumstances and the interaction of these sets of conditions can independently affect health (Kelaher *et al.* 2010). Blaxter has suggested that *'accounts of health and illness are accounts of social identity, and it is unreasonable to expect people to devalue that identity by labelling their own 'inequality''* (Blaxter 1997: 747). Bush and colleagues extend Goffman's (1963) notion of stigma beyond the individual to space and place, and illustrate how an area can gain a 'spoiled identity', or be 'discredited' with reference to several sources of stigma, including technological stigma, air pollution or 'dirt' stigma, health stigma, and social stigma (Bush *et al.* 2001: 53). Furthermore, they argue that people living within a 'stigmatised place' can be discredited with the *'same characteristics as those attributed to the place where they live'* (Bush *et al.* 2001: 52). Cattell has also observed that stigma appeared to have been internalised by some residents on one of the deprived estates that she studied (Cattell 2001) and Airey (2003) has argued that neighbourhood reputation can lead to psychosocial stress through the experience of shame, despite attempts to resist being 'tarred with the same brush'.

## **Part Two:**

### **Stigma, Health and Self Identity**

Part One of this chapter illustrated how government policy has distinguished between 'deserving' and 'undeserving' in relation to sick and disabled people. Yet it is not only policy that makes that distinction. In recent years, the media have taken a more vitriolic stance towards sick and disabled people, often branding them deeply offensive terms such as 'scum', 'feckless', and 'work-shy' (Garthwaite 2011). The first part of this section examines how media responses to firstly the unemployed, then more recently towards sick and disabled people, have evolved in recent years, taking into account the negative impact such discourse can have upon the lives of people who are chronically ill and disabled.

The second part of this section focuses upon the relationship between stigma and health. At present, available literature in health and illness narrative research focuses upon the interplay between identity and work, including those in paid work and those seeking paid work. This section poses the question of the importance of the relationship between identity, illness *and* welfare receipt. Whilst previous literature in the field of qualitative health sociology has explored the concept of self, identity formation and illness, what is notably absent from such discussions is a consideration of the experience of people with health problems who are also claiming sickness benefits – a key concern this thesis interrogates.

#### **Bad news? Sick and disabled people in the media**

Reading the newspaper, you might be inclined to imagine that sick and disabled people are in fact malingerers, cheats and fraudsters, out to get over-generous benefits that they are not genuinely entitled to. Poverty and benefits are often discussed in relation to crime,

antisocial behaviour, or fraud, creating the impression that benefits and crime are one and the same. Indeed, Chris Grayling commented on the *'truly alarming discovery'* that a quarter of sickness benefits recipients have a criminal record according to a report by the Ministry of Justice and DWP (2011). Yet as Sue Marsh (2012) points out, the figures show that a full 48% of these offenders got only a fine or a caution. 'Summary motoring or non-motoring offences' accounted for 46% of the total - petty misdemeanours such as parking and speeding fines, or minor drunk-and-disorderly behaviour, which are not tried by a judge. Marsh concludes that in fact sickness benefit claimants are exactly as likely as anyone else to commit a crime; however, such a fact fails to make a good headline. Without doubt, the 'idle, thieving bastards' thesis identified by Bagguley and Mann (1992) almost two decades ago is alive and well today – a discourse identifying people who did not want to work, posed a threat to private property through their criminal conduct and would have children without adequate role models to follow: *'In popular language they [were portrayed as] ...idle thieving bastards'* (1992: 118) deliberately living an alternative, threatening lifestyle in contradiction to the functional norms of society as a whole. This is entirely similar to the current discussions of sickness benefits recipients who are depicted as essentially thieving from the good, honest hard-working taxpayers in society.

For McKendrick *et al.* (2008) recent decades have seen characteristic moral distinctions of the relative 'deservingness' of welfare users (Norris 1978). Alongside this, exaggerated concerns about fraud and 'scrounging' (Taylor-Gooby 1983; 1985) and a belief that entitlement should be conditional on a work ethic (Deacon 1978) have become increasingly popular. In their seminal study of the media portrayal of poverty in *Images of Welfare* (1982) Peter Golding and Sue Middleton investigated media content, the production of welfare news and its relationship to public attitudes to welfare and public understanding of poverty. As unemployment grew in the 1970s, so did the numbers on social assistance. By

1974, the number of unemployed with insurance also having to claim Supplementary Allowance stood at 73,000, up from 19,000 in 1948. And they were joined by increasing numbers of unemployed without any insurance, some 228,000 in 1974 (up from 34,000 in 1948) (Lowe 1999). The mid-1970s became rife with 'scroungerphobia' hysteria in the media (Horton and Gregory 2009) resulting in outrage that continued to grow towards the unemployed themselves, with the anger directed no longer at just the fraudulent, but at all of those considered to be a drain on public resources – all of those perceived not to be contributing. Some years later, Bagguley and Mann (1992) also reported on the depictions of the underclass in the early 1990s and noted how the term permeated the media, popular opinion and political debates. Indeed, the ideological beliefs that fuel contempt for welfare recipients are deeply rooted in age-old debates about the causes of poverty and public assistance (for example, Katz 1989; Piven and Cloward 1993). In the United States, the poor have long been perceived as dependent/passive 'takers', lacking both initiative and morality. Framing techniques that present poverty as an individual problem rather than a societal issue rooted in economic and political inequality further reinforce the perceived un-deservingness of the poor.

The account of media representations of welfare told by Golding and Middleton (1982) remains as true some 40 years later. Just as they and others found then, today many newspapers headlines continue to vilify the 'work-shy', 'cheats', 'scroungers' and 'lazy' benefit recipients, creating crude characterisations of sick and disabled people who receive them (Garthwaite 2011). Additionally, Quarmby (2012: 70) comments how coverage of welfare reform people categorised sick and disabled people as either victims – unable to speak for themselves and wholly dependent – or villains – sick and disabled people who do not deserve state help who were falsely claiming benefits. For example, a headline in *The Daily Mail* laments the 'State-funded idleness: 1.5m are spending fifth Christmas in a row

on sick benefits' (28 December 2010). Others include: 'A benefits cheat who claimed she needed crutches to walk framed herself with her holiday snaps - zooming down a WATER SLIDE in a bikini' in *The Sun* (23 August 2011) and '£33,000 benefits cheat who had SEVEN jobs while claiming he was wheelchair-bound' *Daily Mail* (24 August 2011). Similarly, the *Daily Express* reports that '500,000 benefit scroungers will be made to seek work' (17 September 2011). *The Sun* newspaper even waged a war on benefits cheats and asked the public to contact them with their details, to which the public apparently 'bombarded us with calls and emails to name and shame fiddling scroungers' (13 August 2010). These headlines are amongst many others that depict benefit recipients as the enemy in a battle against fairness and responsibility – a battle that the Coalition government say was not won in the past by previous governments, but one that is being tackled now with the claim that 'we are all in this together'. More recently, the benefits system and people on benefits featured heavily in the analysis of the causes and consequences of the riots in London, with the headline: 'Too sick to work' but not too sick to riot: One in eight defendants were on incapacity or disability benefit' featuring in the *Daily Mail* (25th October 2011). Clearly, sick and disabled people are becoming the focus of increased targeting and suspicion.

There has been a significant increase in the use of pejorative language to describe sick and disabled people, including suggestions that life on IB had become a 'lifestyle choice'. The use of terms such as 'scrounger', 'cheat' and 'skiver' was found in 18% of tabloid articles in 2010/11 compared to 12% in 2004/5. There were 54 occurrences of these words in 2004/5 compared to 142 in 2010/11 (Briant *et al.* 2011). These changes reinforced the idea of disabled claimants as 'undeserving'. Articles focusing on sickness benefit and fraud increased from 2.8% in 2005/5 to 6.1% in 2010/11. When the focus groups were asked to describe a typical story in the newspapers on sickness benefit fraud was the most popular theme mentioned (Briant *et al.* 2011). This strength of fraud as a tabloid theme conflicts

with the reality of marginal levels of sickness benefit fraud, and focuses public perceptions of responsibility for IB levels on recipients rather than problems in lack of labour market demand, economic policies or discrimination, creating a wider individualisation of sick and disabled people. What's more, there has been a reduction in the proportion of articles which describe disabled people in sympathetic and 'deserving' terms, and stories that document the 'real life' experiences of living as a disabled person have also decreased. Some groups are particularly less likely to receive sympathetic treatment: for example, people with mental health conditions and other 'hidden' impairments were more likely to be presented as 'undeserving'.

A comparable discourse is evident not only in political debates and the mass media, but also when considering public opinion. Polls show unsurprising support for welfare reform plans, signalling the public's negative view towards benefits and people who receive them. For example, an IPSOS Mori poll carried out for the BBC published in October 2011 revealed that although a resounding 92% of British people wanted a benefits system providing a safety net for all, 63% doubted the UK benefits system works effectively, 72% wanted politicians to do more to cut the benefits bill and 84% wanted to see stricter testing for sickness benefits. The focus on 'fairness for taxpayers' has fostered the notion that disabled people are a separate group who don't contribute. Indeed, Taylor-Gooby and Martin (2008) identify declining sympathy for the poor in the British Social Attitudes survey of 2008, including in terms of support for the government having a responsibility to reduce differences in income, for redistribution of income from the better off to the less well off, and for government spending more on welfare benefits to help the poor. However, there is a worrying paradox here – the UK is witnessing increasing inequality, yet decreasing sympathy for those living in poverty, including benefits recipients (Taylor-Gooby 2012).

Interestingly, the media has undergone profound changes in recent years, with a wider range of communication modes being used and more opportunities being afforded for participatory journalism. Beresford (2012) comments how increasingly service users are blogging, podcasting, tweeting and communicating within their own Facebook groups. More and more they are both a physical and virtual presence, from flash mobs to pickets and demonstrations, signalling new kinds of activism and collective action. Examples of such activity include Black Triangle, Carer Watch, the Broken of Britain, Diary of A Benefits Scrounger, and the Hardest Hit Campaign. Alongside developing their own campaigns, service users and disabled people are a visible presence in broader struggles and demonstrations - whether against increasing student fees or among the tents of the Occupy movement.

Taking *Responsible Reform*, also known as *The Spartacus Report*, as an example of how activism can help to influence and shape future policy, a report financed and undertaken by sick and disabled people themselves, analysed over 500 group responses made to the Government's consultation on DLA reform and found that (in contrast to the Government's claims of broad support for the measures) 74% opposed the plans. Overwhelmingly, participants objected to plans to make people wait longer before they could access support (98%), opposed scrapping the lowest rate of DLA which allows many sick and disabled people to stay in work (92%), and resented the proposals to end use of DLA as a qualification for other benefits (99%). Indeed, it is possible that public opinion may begin to soften slightly amidst recent revelations of the '*impersonal and mechanistic*' medical tests faced by IB recipients. Horror stories of terminally ill people being deemed 'fit for work' may shock the public into thinking twice before making the assumption that the majority of sickness benefit recipients are simply 'unwilling'. Instead, perhaps the public will begin to see that being unable does not necessarily translate into 'unwilling'.

In August 2012 London hosted the Paralympic Games. Much media and government rhetoric talk surrounded the Games legacy of the Paralympics in changing attitudes towards disabled people. David Cameron captured these sentiments of hope at the games' opening ceremony noting the promise for: *'Eyes are being opened, attitudes hopefully shifted'*. However, there is also the danger of sick and disabled benefits recipients being further marginalised and portrayed as 'villains' as opposed to the 'heroes' of the Paralympic Games. The sight of elite Paralympic athletes on the world stage could place further pressure on all disabled people to defend themselves against charges of being scroungers. Roulstone (2012) notes how whilst disabled people may be some distance from the heroic image of a medal winner mounting a podium, disabled people are heroic in contending with the daily obstacles of the built environment, the shifting of the 'welfare category' in a way that severely disadvantages welfare recipients.

Furthermore, the Paralympics were sponsored by Atos; ironic given they are responsible for the WCA test which has caused untold distress for many sick and disabled benefits recipients, and have also secured the contract to carry out the PIP assessments which will replace DLA. Interestingly, Paralympians have spoken in the media about their own concerns relating to the DLA reforms (Butler and Pring 2012). Lady Tanni Grey-Thompson warned in May that the DLA cuts could affect the development of top athletes and prevent working-age disabled adults from engaging not just in sport but in society as a whole. Ade Adepitan, the Paralympic wheelchair medallist who is a Channel 4 presenter for the Games, said: *'Without DLA I would not have been able to do what I did or be a top athlete'*. Other Paralympians who have voiced their concerns at the proposals including Natasha Baker, an equestrian who said:

*Disability Living Allowance enables disabled people another life. If they have DLA they might be able to afford the petrol to go to work...it allows us to be independent. I love my independence. I hate relying on other people to do everything for me. I drive and probably would not be able to afford the petrol if I didn't have the DLA. I have a Motability car. I have support from lottery fund but definitely, getting around would be a hell of a lot harder without DLA.*

This quotation is strikingly similar to the narratives of the sick and disabled benefits recipients in this study, and represents the importance of DLA for all disabled people – not just those who are unemployed.

As has been shown, the media can create a distorted picture of welfare recipients – mythology is consequently important when thinking about sickness, disability and benefit receipt. This thesis aims to expose these mythologies surrounding sick and disabled people and in doing so, challenge the fallacies of welfare reforms. As Dorling (2010: 256) argues, ‘that people end up at the bottom’ because they are ‘undeserving’ has become the ‘homogenising myth of our time.’ Part of the objective of this thesis was to make the experiences of sick and disabled people visible. In doing so, this research has provided evidence to declare that much of the way that the poor and workless are described is false. In other words, much that claims to speak of the poor and workless are myths (also see Shildrick *et al.* 2012). Indeed, such myths find great support among the poor and the workless themselves, as they, too, reject the stigma and shame of these labels, pointing to ‘others’ who they imagine better fit the bill (MacDonald and Marsh 2005; Shildrick and MacDonald 2013, forthcoming). This is a great myth indeed.

Of course, myths usually have a purpose. They can distract attention, cover up realities and justify actions. Following Byrne (2005) and Standing (2011), it is easy to understand

contemporary mythologies of the workless and the welfare dependent as a cover for the new, more punitive and 'active' turn in government welfare policy described in this chapter. These are policies that punish the poor, that feed the workless into poor work and that do nothing to tackle the most significant form of social exclusion in contemporary society, the low-pay, no-pay cycle. The welfare reforms discussed in this chapter – with their emphasis on greater conditionality and sanctions to hasten the move from welfare to work – are being instituted in economically inauspicious times. This thesis aims to confront these mythologies surrounding sick and disabled people and in doing so, challenge the fallacies of welfare reforms. Exposing the myth of 'the welfare scrounger' is the first step towards better-informed debate and policy.

### **Stigma: identity, illness and welfare receipt**

Stigma is typically a social process, experienced or anticipated, characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group (Weiss *et al.* 2006: 280). This judgement is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgement is in some essential way medically unwarranted. In addition to its application to persons or a group, the discriminatory social judgement may also be applied to the disease or designated health problem itself; a good example of this would be schizophrenia and other types of mental illness. Other forms of stigma, which result from adverse social judgements about enduring features of identity apart from health-related conditions (*e.g.* race, ethnicity, sexual preferences), may also affect health; these are also matters of interest that concern questions of health-related stigma (Weiss *et al.* 2006: 280). Erving Goffman's work on stigma dramaturgical treatment of the concept in '*Stigma: Notes on the Management of Spoiled Identity*' is where many

commentators have turned for illumination on the subject. Here, Goffman (1963: 2-3) outlines his interpretation of stigma and its occurrence:

*While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind-in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap.*

For Scambler (2006: 442), while Goffman's contribution retains its theoretical insight and subtlety, it is possible to move beyond what Goffman was saying - Scambler asserts that Goffman was not wrong, he just did not ask all of the questions that he could have asked. Some of these questions have been posed by disability theorists and sociologists approaching stigma with a primary interest in social structure or political economy while individuals perform to maintain face through lines in 'front regions' (e.g. hospital clinics), in the absence of an audience they can stop performing, behaving in a manner that contradicts their performance, in 'back regions' (e.g. in the hospital canteen or at home). Therefore, what is notably absent from Goffman's account of the structure of interaction is the causal input of social structures like class, command, gender, ethnicity and so on (Scambler 2006). A useful refinement of the concept of stigma comes from the work of Scambler and Hopkins (1986) on epilepsy. By making the distinction between enacted stigma (experienced from others) and felt stigma (self-maintained) they point out that it may well be the latter rather than the former that causes disruption in patients' lives (Scambler 2004). Schneider and Conrad (1980) show how this sense of felt stigma can have

its origins in the 'stigma coaching' of others, like over-protective family members and well intentioned doctors.

Link and Phelan (2001: 363) draw on disability as well as sociological studies to define stigma '*as the co-occurrence of its components - labelling, stereotyping, separation, status loss, and discrimination*', critically adding that for stigmatisation to occur power must be exercised. Indeed, as Charmaz (1983: 181) points out: '*Although not all chronically ill persons suffer the visible impairments readily resulting in stigmatized identities, many suffer discreditation related to their decreased and now marginal participation in the normal*'. Equally, just as there can be a stigma attached to ill health and disability, the act of claiming benefits themselves can also be a deeply stigmatising experience for people. Inadequate amounts of money, coupled with having to be constantly investigated and prove oneself mean that the act of being a recipient carries with it a certain level of stigma.

At present, available literature in health and illness research focuses upon the connection between identity and work, including those in paid work and those seeking paid work. But what about the importance of the relationship between identity, illness and welfare receipt? Of course, much previous literature in the field of qualitative health sociology has explored the concept of self, identity formation and illness (see, for example, Parsons 1951; Charmaz, 1990; 1991; 1994; 1999; 2002; Anspach 1979; Bury 1982; Schneider and Conrad 1981; Conrad 1987, amongst others). This paucity of research on the interplay between identity, illness and welfare receipt is perhaps surprising given that the experience of being a recipient would appear integral to a range of issues which have long been the subject of sociological investigation, including a 'loss of self' and social isolation (Charmaz 1983); biographical disruption (Bury 1982); relationships with others (Anderson and Bury 1988); and the work of illness (Corbin and Strauss 1985).

Going back to the 1950s, the 'sick role' thesis outlined by Talcott Parsons and was established as a frame for sociological research on sickness behaviour, according to Conrad (1990: 1259). Parsons outlined a model that drew upon four chief characteristics. First, the sick person is exempt from carrying out normal social roles. The more severe the illness, the more one is freed from normal social roles. Everyone in society experiences this; for example, a minor chest cold allows one to be excused from small obligations such as attending a social gathering. By contrast, a major heart attack allows considerable time away from work and social obligations. Second, people in the sick role are not directly responsible for their situation. Third, the sick person needs to try to get well, which is based upon the premise that the sick role is a temporary stage of deviance that should not be prolonged. Finally, in the sick role the sick person or patient must seek competent help and cooperate with medical care to get well. To achieve the sick role is to achieve recognition of one's suffering and is also a social license to be exempt from particular duties for a given period of time. This exemption requires legitimation by and to the various persons and arenas involved. The sick individual is not expected to get well by an act of decision alone, but is exempted from responsibility for his or her condition and must be looked after. In return, he or she is expected to display a visible attempt to get well, including a desire to cooperate with those seen as appropriate and competent (Parsons 1951).

The sick role concept has been frequently discussed and criticised since its emergence and is seen as particularly inappropriate for chronic illness. The concept is largely based on an acute medical model of sickness (Crossley 1998) where sickness is characteristically time-constricted, responsive to treatment, and related to physical rather than mental health (Segall 1976). In this acute model, the doctor-patient relationship is central, but for long-term illnesses, and particularly for chronic illnesses such as back pain where doctors have

little biomedical insight to offer, the doctor - patient relationship is seen as far less important (Glenton 2003). Further, Charmaz (2010: 14) notes that in contrast to the sick role, chronic illness refers to health that will not recover. As such, the sick role as outlined by Parsons over 60 years ago does not tally with long-term sickness benefits receipt that is being discussed in this thesis. For instance, Williams (2010) argues that the concept of getting better and thus exiting the sick role, one of Parson's key principles, can be seen as being breached by those who remain on IB for some time.

*'Discourses provide us with conceptual repertoires with which we can represent ourselves and others'* according to Burr (1995: 141) and in this way they have implications for identity. As Burr (1995) argues, we are an 'end-product' of the combinations of various discourses available to us, although assorted configurations of the 'self' are offered across different discourses. Much of the sociological work on chronic illness has adopted a biographical approach. For example, Bury (1991) conceptualised the career of the sufferer as passing through three key stages: onset; explanation and legitimisation; and finally adaptation. For Bury (1982; 1991) the onset of chronic illness is associated with 'biographical disruption', i.e. the person experiencing the onset chronic illness not only suffers pain but also experiences the disruption of work and family relationships and future plans. This can lead in turn to 'loss of self', a sense of diminished identity and a feeling of being stigmatised (Charmaz 1983; 1987). Chronic illness as a threat to self and identity is a prominent theme in the literature, and there have been previous attempts to understand the experiences of chronically ill and disabled people within a theoretical framework of identity (for example, Anspach 1979; Bury 1982; Schneider and Conrad 1981; Conrad 1987; Charmaz 1983; Charmaz 1987). As Adams *et al.* (1997) observed in their study of identity and asthma, participants who had successfully reconciled the social identity of 'asthmatic' with both their other social identities and with their personal identities did not experience

a diminished self and in return, for such participants being an asthmatic was, as they explained, 'just a part of me'.

Furthermore, perhaps it should be pointed out that participants' narratives may inevitably centre on their illness and suffering, which often are accepted without questions or challenges (Hsieh 2004). An interviewee is granted creative license, a captive audience, and legitimacy and significance of his or her role and identity. In addition, a researcher often is expected to respond to these personal narratives with neutrality, demonstrating minimal emotions and reactions. In everyday life, however, a story is told with approvals, challenges, and even social sanctions from its audience (Goffman 1961; Maines 1991). Whereas an illness identity may still be salient, a patient may strategically construct his or her illness experiences and other identities to meet different communicative goals such as empowerment or help seeking. As such, a story of sickness can take on life of its own. Frank (1995) views some stories as over determined: the person views illness as pivotal at every interval in his or her life and attributes every misfortune to it. Yet, when researchers get close to the phenomena, we find that chronic illness does start a chain of misfortunes. Illness combines with and complicates additional disadvantages in other stories.

Therefore, the construction of identity amongst IB recipients is likely to be multi-faceted; constructed, accepted, managed or rejected in varying ways by different people. Whilst little attempts have been made to explore the relationship between sickness benefits receipt and self identity, research by Wainwright *et al.* (2011) is a notable exception. In their qualitative study of 12 long-term IB recipients, they found that life on IB often brings with it damage to self identity, diminishing their sense of competence and resilience (2011: 144). However, Wainwright and colleagues do not consider the potential positive influence on self identity that long-term IB receipt may have; something this study will develop

further. In *Welfare Fraud and Welfare Stigma*, Yaniv (1998: 2) argues that welfare-related stigma is largely self-afflicted, emanating from one's own recognition that he or she is engaging in an action he or she views as self-demeaning. Stigma does not just stem from a sense of personal failure, but also a fear of what others might say, and the embarrassment caused when they say it. In a review of the benefits system Walker (1994: 6) also suggested: *'there is stigma by association when, by applying for benefits, people join a group they have previously despised'*. Therefore, it is important to discover how long-term IB recipients construct and maintain a sense of identity, and whether this includes 'biographical disruption' and a 'loss of self'.

### **Implications of stigma**

Worryingly, there is strong evidence that the way someone feels they are perceived or treated in society has an impact on their life, with one of the well-documented effects being on an individual's health. For example, a London Health Observatory (LHO) report describes a range of health problems associated with being unemployed (including higher rates of mental health problems, higher rates of life-limiting illnesses, and higher rates of premature mortality), and attributes these partly to 'social exclusion, isolation, and stigma' (LHO, 2010). Link and Phelan (2006: 528) show that:

*An insidious form of discrimination occurs when stigmatised individuals realise that a negative label has been applied to them and that other people are likely to view them as less trustworthy and intelligent, and more dangerous and incompetent.*

In addition to tabloid terms such as 'scrounger', language used by politicians has been frequently repeated in the press. For instance, in 2004 Tony Blair spoke of people 'languishing on benefits' (Tempest 14 October 2004), which was then picked up and repeated 5 times in 2004-5. The reference to 'sick note culture' by Alan Johnson (DWP 15

March 2005) and the variation 'sick note society' were popular as noted above. In 2005, the Child Poverty Action Group (CPAG) urged the government 'not to utilise language which appears to criticise recipients of benefits' which it argues engineers the tabloid frenzy over IB recipients (CPAG October 2005). The data demonstrates pejorative language of this kind was still commonly used by the government and picked up by the media in 2010-11 (Briant *et al.* 2011). More recently, an alliance of 50 charities, the 'Disability Benefits Consortium' put pressure on the government regarding their portrayal of disabled people, which they argue is '*a partial picture [that] feeds the tabloid media's negative narrative on 'benefits scroungers'*'. They assert that '*these releases in turn have an impact on the public - and therefore employers' - perception of disability and disabled people'* (Boffey 24th July 2011).

There may be an even greater problem emerging: the focus on fraud in sickness benefits by the government and in the mass media could be fuelling the growth of hate crimes against disabled people. Opinion polling for the charity Scope (2011) carried out in September 2011 found that 47 per cent of disabled people believe that public attitudes towards them have got worse over the past year. Two-thirds of disabled people say that they have experienced aggression, hostility or name calling. Two statistics in the poll suggest that the growing emphasis on fraudulent claims for sickness benefits may have something to do with this - 65% thought others did not believe that they were disabled, and 73% said they felt others presumed they did not work. Scope's polling of disabled people shows that two-thirds said they had experienced recent hostility or taunts, up from 41% four months before. In the last poll almost half said attitudes towards them had deteriorated in the past year. Some disabled people say the climate is so hostile they avoid going out, or avoid using facilities such as designated parking bays if they 'don't look disabled' as shown by some of the remarks by individual disabled people in Scope's (2011) report:

*"I have been called scrounger, parasite, and a waste of space. My personal assistant was spat at for helping me recently in a local shop."*

*"I've been called names in the street and told to "stop faking and get a f\*\*\*ing job" while struggling to transfer to my wheelchair from the car."*

*"I take a wheelchair with me most places and I am treated so much differently in a wheelchair. When I do get out of the wheelchair and walk a little way, I have been accused of faking it and being lazy. Because on the outside I look healthy and 'normal' people expect me to be healthy and normal."*

However, the UK is not alone in this worrying trend that sees sick and disabled welfare recipients being vilified. In the US, welfare recipients are among one of the most hated and stereotyped groups in contemporary society according to Wilthorn (1996). Underscoring the extent of this devaluation, Fiske *et al.* (1999) found that welfare recipients were the only group out of 17 stereotyped groups studied (for example, migrant workers, ethnic minorities, the rich) that participants both disliked and disrespected. The ideological beliefs that fuel contempt for welfare recipients are deeply rooted in age-old debates about the causes of poverty and public assistance. In the United States, welfare recipients have long been perceived as dependent/passive 'takers', lacking both initiative and morality (see Katz 1989; Piven and Cloward 1993). Further, the belief that a reliance on public assistance signifies failure (Tropman 1989) is dominant, yet research shows that welfare recipients themselves are highly aware of this perception (Dodson 1998; Seccombe 1999; Seccombe *et al.* 1998).

## Chapter Summary

Part One of this chapter began with a context to sickness benefits receipt in the UK, including a history of sickness and welfare from the Old Poor Law 1601 to date. It is clear that notions of 'deserving' and 'undeserving' have recently re-emerged in policy responses to unemployed sick and disabled people; a dichotomy that is also being represented in the mass media and when considering public opinion. The chapter also considered possible explanations for high levels of IB receipt, which led to a particular focus upon the history and local labour market of County Durham. As the research objectives were to uncover the health and illness narratives of long-term IB recipients, Part Two of the chapter focused more specifically upon stigma, health and identity, including a consideration of the relationship between the mass media, public opinion and people receiving sickness benefits. Finally, Part Two discussed the relationship between stigma, health and identity in the current literature, tying this into the aims and objectives of the thesis. Whilst research that investigates the relationship between illness, stigma and identity, it is clear that a consideration of welfare receipt alongside these concepts is largely absent from current discussions. As such, a key research question of the thesis explicitly asks how long-term sickness benefits recipients feel about receiving welfare benefits, and specifically how they feel about receiving them at a time of drastic change and upheaval that is being very publicly played out in the media on a daily basis.

Overall, the chapter suggests an interplay between government rhetoric, the mass media and public opinion. All of the aforementioned appear to be colliding together to reinforce the 'deserving'/'undeserving' dichotomy – which, in turn, impacts upon sick and disabled people in the form of stigma and shame. It seems likely that recent sickness benefits reforms have been significantly shaped by other factors, such as political priorities and

responses to public and media concerns, rather than actual research evidence (Bambra and Smith 2010: 79). Indeed, there is some evidence that policy can lead opinion; for example, by presenting unemployed people as active or by stressing training and the pursuit of paid work. In much of the data presented there are clear trends in attitudes with a break after 1997 reflecting expectations of or assumptions about the impact of the policies of the new government (Taylor-Gooby 2005: 16). This chapter suggests that the way in which language is employed by the government when talking about sickness benefits is important when considering wider repercussions within the media and the public alike – utilising a language of ‘shirkers and scroungers’ is not in the least bit helpful, and only serves to encourage frustration and anger amongst the ‘hard working tax payers’ in society. Therefore, it is important to consider how long-term sickness benefits recipients experience not only health and illness, but also how ongoing welfare reform, characterised by a more ‘active’ framing of welfare and media disgust, impacts upon the health and welfare related stigma felt by those receiving sickness benefits long-term.

## **CHAPTER THREE**

### **METHODS**

#### **Introduction**

The first part of this chapter begins with an explanation of the research design and process. Research questions underpinning the study will be discussed, locating the PhD within the wider context of an NHS funded research project. This will be followed by an exploration of access and sampling used in the study. The first section will detail the qualitative methods that were employed, resulting in semi-structured interviews with 18 key professional stakeholders who had experience of working with long-term IB recipients, alongside 25 in-depth interviews with IB recipients themselves. Furthermore, coding and data analysis will be explored, underpinned by an approach based upon the epistemological framework of grounded theory. Lastly, the section will reflect upon ethical considerations.

The second part of the chapter section focuses upon reflexivity throughout the research process. This section discusses the practicalities of doing research with long-term IB recipients, firstly reflecting upon how participants feel about the interview process, from becoming involved to dissemination, alongside a consideration of how myself as a researcher has experienced the research journey. The remainder of this chapter seeks to locate the chronic health and disability narratives of sickness benefit recipients within a wider framework that considers not only the relationship between the researcher and the researched, but also issues of the performance of both parties in the research process. In doing so, the emotional aspect of being involved with carrying out and also participating in

qualitative health research will be debated, including risk and its place within the research process. Throughout all discussions, ethical considerations will be reflected upon.

## Part One: Research Design and Process

### Research design

#### *Aims and research questions*

The research sought to explore the relationship between long-term IB receipt and stigma in areas of North East England with the highest levels of IB take up. A central concern underpinning the study was the construction and reconstruction of health and illness narratives for those receiving sickness benefits. Alongside this, the research was interested to uncover how identity could be affected by the onset of illness or a recurrence or worsening of existing health problems that led to the receipt of IB. As the literature review indicated, identity for IB recipients can only be considered amidst wider political, societal and media representations of IB recipients is a key aim of the research. As such, the study aimed to situate the qualitative, lived experience of receiving IB against populist images of IB recipients in order to explore how these two standpoints can differ, and how this may produce a tension upon the health and illness narratives of those receiving IB long-term. Below, the key research questions of the study are outlined:

- What are the health and illness narratives of long-term IB recipients?
- What is the relationship between IB receipt and stigma in the narratives of IB recipients?
- How do people receiving IB construct their identity amidst political, public and media constructs of welfare 'scroungers'?
- How do people receiving long-term IB respond to welfare reform and the shift from a 'passive' to a more 'active' framing of ill health?

## **Wider research context**

It should be clearly noted here that this PhD research is situated within a wider project '*Evaluating the impact of case management on the health of long-term Incapacity Benefit recipients in the North East of England*', a three year programme funded by County Durham Primary Care Trust (PCT). The project is evaluating an intervention fundamentally aimed at improving the health of IB recipients in order to move them closer towards education, training or employment in the future. Under the programme, those receiving IB are referred by their GP (or self-referred) to a case manager who in turn facilitates access to a variety of supplementary health, social and vocational interventions (such as social prescribing, condition management, vocational guidance, counselling, etc). The central element of the research involves an evaluation of this intervention. Through a mixed methods approach, the evaluation assesses the impacts of the programme by comparing trends in health and employment/benefit status of IB recipients between intervention and non-intervention groups. Alongside this, quantitative data analysis, including economic evaluation and contextual analysis of place effects will be carried out. Lastly, qualitative interviews with samples of programme users have been undertaken to understand the experiences of IB recipients involved in the intervention.

As a complement to this, the thesis has focused upon exploring the narratives and experiences of those in the control group who have not undergone the intervention, but who are receiving IB long-term. The control group is made up of people who are long-term IB recipients in County Durham and South Tyneside. Importantly, it should be pointed out how the PhD project is distinct and separate from the wider project. In order to achieve this, it was decided that the intervention group that are the subject of the evaluation would not be included in the qualitative interviews I would undertake. Instead, the focus of the

PhD research has remained solely upon qualitative interviews with the control group cohort, thus ensuring a clear and distinct separation between both elements of the research.

## **Access and sampling**

### **Access**

The research involved two separate groups of participants. Firstly, professional stakeholders who were interviewed between August 2010 and March 2011; and secondly, IB recipients who were interviewed between March 2011 and August 2011. Both sets of participants were recruited via Jobcentre Plus Choices events between September 2009 and June 2010. Corden and Nice (2006: ix) summarise the concept behind Choices events as follows:

*The Choices package of interventions is a range of new and existing provision available at Jobcentre Plus and offered to people taking part in Pathways to Work Work Focused Interviews. New support in the package includes the Condition Management Programme, Return to Work Credit and enhanced In-Work Support. The package also includes easier access to existing support such as the Adviser Discretionary Fund (ADF), and programmes such as the New Deal for Disabled People (NDDP), Work Preparation and Work Based Learning for Adults (WBLA).*

Initial contact with the stakeholders was forged when myself and colleagues attended the Choices events which tended to be held weekly in different venues across County Durham and South Tyneside, in venues such as local colleges, community centres, and leisure centres. The events were intended to be informal, and those who came along could have coffee and biscuits and peruse the various providers' stalls as they wished. Jobcentre Plus

told us that there was no compulsion for IB recipients to attend, and the events were not mandatory and therefore non attendance would not impact in any way upon someone's benefits.

Typically, a range of approximately 10 stakeholders came to the events from organisations such as the NHS, local colleges, CMP, Groundworks, Royal British Light Infantry (RBLI), Shaw Trust, DISC, and a variety of local organisations that could help with issues ranging from health and wellbeing, retraining and transport to work. They would set up stalls with advertising materials, often giving away free items such as pens, notebooks, and chocolates to tempt people over to their stalls. With our Durham University stall, we advertised the study we were recruiting to, outlining what it would involve and what benefits we could offer potential participants. We also participated in the trend that other stakeholders set of offering pens and chocolates to potential participants. However, what other stakeholders were not offering was 'Love to Shop' High Street vouchers. As a thank you for taking part in the survey, we offered participants an initial £10 in vouchers for completing the first survey, followed by a further £20 in vouchers upon completion of a further three, shorter interviews administered over the telephone in order to track what was happening with peoples' health over time.

In total, 229 people were recruited to the wider project between September 2009 and June 2010. The 'Choices' events offered a consistent sampling frame as all of those eligible within a given postcode area (IB receipt > 3 years) were invited to the event. Of the 8858 individuals invited to the events 1429 attended (16.1%). Of these 1429, 229 (16.0%) participated in our survey (Warren *et al.* 2012). In terms of gender, the cohort was 50% male and 50% female with a mean age of 49. The average time spent on IB was 9 years. The majority of people in the cohort had previously worked in semi skilled (32%) or unskilled (33%) jobs. 50% of the cohort reported musculoskeletal health issues as primary problem,

whilst mental health was the primary health issue for 24%. 80% had seen a health professional in the 30 days prior to interview. In terms of co-morbidity, almost 60% had 3 health problems or more. We attended events between September 2009 and June 2010 until the events came to an end in June 2010; hence, no further participants were recruited to our control group as we were keen not to alter the sampling frame we had employed. Having discussed how recruitment to the wider project evolved, this chapter now outlines the sampling frame employed in this PhD study and situates this within a wider discussion of the principles and practicalities of adopting an approach based upon grounded theory.

### **Grounded theory and sampling**

Originating from sociology, specifically from symbolic interactionism, grounded theory is underpinned by the notion that meaning is negotiated and understood through interactions with others in social processes (Blumer 1986; Dey 1999). These social processes have structures, implied or explicit codes of conduct, and procedures that circumscribe how interactions unfold and shape the meaning that comes from them. The goal of grounded theory is to develop an explanatory theory of basic social processes, studied in the environments in which they take place (Glaser and Strauss 1967; Glaser 1978; Glaser 1992). Grounded theory examines the 'six Cs' of social processes – causes; contexts; contingencies; consequences; co-variances; and conditions to understand the patterns and relationships among these elements (Strauss and Corbin 1998). Within this approach knowledge of social realities is achieved through careful observation of behaviour.

Grounded theory relies on theoretical sampling, which involves recruiting participants with differing experiences of the phenomenon so as to explore multiple dimensions of the social processes under study. The researcher continues to add individuals to the sample until

theoretical saturation is reached; that is, when the complete range of constructs that make up the theory is fully represented by the data. Although it is impossible to predict what sample size will saturate a given theory, typical grounded theory studies report sample sizes ranging from 10 to 60 persons (Starks and Brown-Trinidad 2007: 1375). In qualitative research, sample selection has a profound effect on the ultimate quality of the research (Coyne 1997: 623). According to Patton (2002), there are many examples of different strategies that have been used for drawing qualitative samples. Some key features of qualitative samples outlined by Patton (2002) are listed below:

- *The method of drawing samples is not based on theories of the statistical probability of selection, but on other, purposive or theoretical sampling criteria;*
- *Samples are small, are studied intensively, and each one typically generates a large amount of information;*
- *Samples are usually not wholly pre-specified, and instead selection is sequential (by a rolling process, inter-leafed with coding and analysis);*
- *Sample selection is conceptually driven, either by the theoretical framework which underpins the research question from the outset, or by an evolving theory which is derived inductively from the data as the research proceeds;*
- *Qualitative research should be reflexive and explicit about the rationale for case selection, because there are ethical and theoretical implications arising from the choices which are made to include particular cases and exclude others;*
- *Qualitative samples are designed to make possible analytic generalisations (applied to wider theory on the basis of how selected cases 'fit' with general constructs), but not statistical generalisations (applied to wider populations on the basis of representative statistical samples).*

The above features suggested by Patton (2002) were largely incorporated into my sampling frame, particularly the idea that '*Qualitative research should be reflexive and explicit about the rationale for case selection, because there are ethical and theoretical implications arising from the choices which are made to include particular cases and exclude others*'. As Sixsmith *et al.* (2003: 582) remark, the primary aim of theoretical sampling is to '*recruit participants into the research as long as each person's thoughts and experiences add to theoretical or conceptual insight*', which continues until a saturation point is reached. This method ensures that a varied sample is gained rather than a representative sample, as it must be recognised that through qualitative inquiry the importance of individual's experiences, rather than generalisable claims, is paramount. Morse (2001) has argued that in qualitative research sample size depends upon five things: the scope of the study; the nature of the topic; the quality of the data; the study design; and the use of shadowed data (when participants speak of others' experience as well as their own). The concept or the experience under study is the unit of analysis; given that an individual person can generate hundreds or thousands of concepts, large samples are not necessarily needed to generate rich data sets. The exact number of individuals needed, and the number of interviews per individual, depends on the goals and purpose of the study.

The foundations of this research project are, indeed, rooted within the realms of grounded theory. Yet whilst grounded theory assumes a lack of prior knowledge before embarking upon a research endeavour, this was not the case for this research project. As described, I already had *a priori* knowledge of certain characteristics of potential participants; therefore, a 'pure' theoretical sampling frame could not be achieved. Instead, a sample based upon the notional underpinnings of theoretical sampling was employed. Certainly, according to Coyne (1997: 629) researchers have a problem with the esoteric terminology used to describe grounded theory and suggests that a more accurate term for theoretical

sampling could be '*analysis driven purposeful sampling*'; this is a term which fits more accurately when describing how I have drawn on theoretical sampling. Whilst hardcore grounded theory followers would not agree with this approach, other commentators believe it is entirely feasible and even preferential to a pure grounded theory approach. For example, Bulmer (1979: 6671) states that Glaser and Strauss' '*tabula rasa view of inquiry is open to serious doubt*'. He accuses them of espousing pure induction since they propose reading the literature in the relevant fields after having developed a set of categories. Additionally, authors such as Kenen *et al.* (2003) and Wilson and Luker (2006) indicate that they, too, employ certain features of grounded theory, but not all of them. Ultimately, the key aim of the research process was to explore the lived experience of long-term sickness benefits recipients; Charmaz (1990: 1162) explains that when researching chronic illness, the researcher constructs theory from the data. By starting with data from the lived experience of the research participants, the researcher can from the beginning attend to how they construct their worlds. In turn, the lived experience shapes the researcher's approach to data collection and analysis; the approach I have employed throughout this study.

### **Sampling in action**

With the first phase of fieldwork with stakeholders, I began by employing a theoretical sampling frame, which gradually led to the inclusion of snowball sampling. Snowball sampling is a form of sampling whereby one subject gives the researcher the name of another subject, who in turn provides the name of a third, etc (Vogt 1999). Snowball sampling can be seen as taking advantage of the social networks of identified participants to provide a researcher with an ever-expanding set of potential contacts (Thomson 1997). This process is based on the assumption that a 'bond' or 'link' exists between the initial sample and others in the same target population, allowing a series of referrals to be made

within a circle of acquaintance (Berg 1988). Snowball sampling can be applied as an 'informal' method to reach a target population. If the aim of a study is primarily explorative, qualitative and descriptive, then snowball sampling offers practical advantages (Hendricks *et al.* 1992). In total, of the 18 interviews that took place, only 4 participants were recruited via snowball sampling. The remaining 14 were recruited following initial meetings at the Choices events, where I had already explained the aims and objectives of the research to potential participants.

Deciding which participants to include in the second phase of research was also underpinned by the approaches discussed at length above. However, in contrast to other qualitative research based upon grounded theory, in most instances I had already spent time getting to know participants when completing health questionnaires with them as part of the wider evaluation project. Questionnaires could take almost one hour to complete as once people began talking, often they would digress from the questions being asked and begin telling me their wider narratives. These encounters allowed me to make notes of who could be a useful person to interview for the study. Not only that, I had begun to form a relationship with potential participants; they already felt like they could begin to trust me enough to reveal personal information, and seemed to enjoy having someone to talk to. Therefore, I am aware that I was in a privileged position compared to some qualitative researchers who do not get the opportunity to build a relationship prior to the qualitative interview process. This is particularly important given that IB recipients are often referred to as a 'hard to reach' group. Conducting questionnaires with people meant that they had already told me a lot of personal characteristics and information. For example, I knew their marital status; who they lived with, if anybody; previous work history; when they began claiming IB; their health problems; and their perspectives about returning to work.

As I was interested in difference and variation rather than generalisability, this information allowed me to seek out people who had varying experiences. I was able to identify people who had spent 3 years on IB and those who had spent 30 years plus receiving it, alongside people who had started receiving IB due to an accident that led to health problems, as opposed to people who had battled health problems throughout their lives. In the majority of cases, when I began the process of getting back in contact with people to see if they would still be interested in taking part in a qualitative interview with me, people were keen to do so and some people even commented that they had been looking forward to me getting back in touch. Overall, I believe this initial contact with people at the 'Choices' events provided me with a greater legitimacy that allowed me to begin the qualitative interview process. The following section fully explores the qualitative methodology employed in this study.

#### **Qualitative methods: semi-structured interviews**

The technique of interviewing is one of the most common methodological tools of social science in order to gain insights into the worlds, beliefs, values and opinions of those you are interested in studying (Kvale 1996). The aims of qualitative research interviews are purportedly to gain access to the experiences, feelings, and social worlds of participants (Fossey *et al.* 2002). Interviews are designed to produce data, which are useful or relevant in terms of the research question, and the type of interview and the processes involved are determined by the philosophical perspective, which underpins the research design (Robinson and Thorne 1988).

As this research was interested in the biographical narratives of long-term IB recipients, it is essential to reflect upon the literature surrounding how a narrative approach can fit into

grounded theory based approaches to social research. The processes of getting ill, being ill, getting better (or getting worse), and coping (or failing to cope) with illness, can all be thought of as enacted narratives within the wider narratives (stories) of people's lives. For Sandelowski (1991: 162):

*Generally, narratives are understood as stories that include a temporal ordering of events and an effort to make something of those events. This suggests that narratives are stories organised to allow the individual to make sense of, or impose order on, a set of related experiences'.*

In other words, although all people carry around with them their biography, those biographies are not always organised into a coherent story. It must be kept in mind, however, that stories are told to audiences. Certainly, for Singer *et al.* (2001: 593) '*narration allows the storyteller to construct himself or herself, social others, and social events in meaningful ways*'. Or, people tell stories because someone asked them to tell a story – as is the case in social research.

Riessman (2005: 2) offers several typologies when considering narrative analysis. They are: thematic analysis; structural analysis; interactional analysis; and performative analysis. With thematic analysis, emphasis is on the content of a text, what is said more than how it is said. As grounded theorists do, this approach would involve collecting many stories and inductively creating conceptual groupings from the data. A typology of narratives organised by theme is the typical representational strategy, with case studies or vignettes providing illustration. Next, the typology of performative analysis goes beyond the spoken word and, as the stage metaphor implies, storytelling is seen as performance – by a 'self' with a past. Variation exists in the performative approach, ranging from dramaturgic to narrative as praxis – a form of social action. Consequently, researchers may analyse different features,

such as characters and their positioning in a story; settings, including the conditions of performance, and setting of the story performed. Performative analysis is emergent in narrative studies, although the dramaturgic view originated with Goffman (1959: 1967), and researchers are experimenting with it in studies of identities –when thinking about vested presentations of ‘self’ (Riessman 1990; 2003).

Within this study, I have adopted a stance drawing on aspects of thematic analysis and performative analysis; while I am interested in collecting stories and creating conceptual groupings from the data, I am also keen not to disregard how participants present themselves in the telling of their story, from the casting stage of the research – the sampling phase – to the final act of disengaging from the field and the end of the research process. However, it is important to point out that it cannot be assumed that interviews reveal the objective ‘truth’ (Holstein and Gulbriun 1995). Participants will inevitably relay a version of events they want to purport; they choose what to divulge and what not to divulge; it would be naive to assume otherwise. This discussion will be fully explored in part two of this chapter.

### ***Phase One – key stakeholders***

Qualitative interviews with key professional stakeholders who had experience of working with IB recipients formed this phase of the fieldwork. In total, 18 professional stakeholders were interviewed for the study, including professionals involved with the administration of state benefits and the provision of retraining and rehabilitation schemes. For example, participants were professionals from agencies such as JCP, CMP, the NHS and a local PCT, alongside various local and national organisations and charities aimed at supporting people who were receiving long-term sickness benefits. A flexible topic guide prompted interviewees to discuss their role of working alongside people who are receiving benefits

due to health conditions or disabilities. They were also asked their perspectives on the barriers faced by the people they engaged with and their own barriers in working with this group, alongside their perceptions of sickness benefits recipients and lastly, ongoing welfare reform. Interviews were conducted face-to-face and largely took place in the stakeholders' place of work in private rooms away from other staff or clients. Interviews were digitally recorded with prior permission from interviewees and typically lasted between 45 minutes to 60 minutes. Data were then transcribed verbatim and fully anonymised before thematic analysis was undertaken.

Participants were ensured that all information given would be treated with anonymity and confidentiality. Anonymity is a basic process of removing the identity of the individuals by using pseudonyms. Confidentiality, on the other hand, is an active process to remove not only the name, but also any identifying features of participants (Henn *et al.* 2006: 85). This entailed the withdrawal of easily identifiable information about the stakeholders or IB recipients; as a result, any potentially implicating information has been removed; consequently, all participants' names have been anonymised and it has been ensured that individual participants cannot be identified. All quotations cited here are in participants' own words.

I sought to include a range of stakeholders, from front line staff up to Chief Executive level, in order to gain a wide and varied understanding of working with long-term IB recipients. Below, Table One provides a complete list of participants' pseudonyms, their organisation and their role within that organisation.

**Table One: Stakeholders**

<b>PSEUDONYM</b>	<b>ORGANISATION</b>	<b>JOB ROLE</b>
Alan	NHS based organisation	Case manager
Billy	Training college for unemployed adults with disabilities	Marketing manager
Steve	Jobcentre Plus	Incapacity Benefit Personal Advisor
Jeff	Local charity	Job broker
Jim	Disability training college	Counsellor
Jenny	Disability charity	Personal advisor
Michael	CMP	Occupational therapist
Rob	CMP	Registered nurse
Helen	CMP	Occupational therapist
Jacqui	Jobcentre Plus	Customer engagement manager
Christine	Jobcentre Plus	Area manager
Caroline	Local social enterprise	Chief executive
Emily	NHS based organisation	Core manager
Lianne	NHS	Self employed GP
Johnny	Primary Care Trust	Public health
Sarah	Environmental regeneration charity	Employment adviser
Anthony	RBLI	Personal advisor
Tanya	Jobcentre Plus	Incapacity Benefit Personal Advisor

Chapter Eight of the thesis provides a comprehensive empirical account of the interviews with the stakeholders.

### ***Phase Two – IB recipients***

The second phase of fieldwork involved interviews with long-term IB recipients. I was interested in finding out their health and illness narratives – what they felt was important

in their stories, and why. In total, 25 chronically ill and disabled people were interviewed between March 2011 and August 2011. Participants were chosen in order to reflect a wide range of different situations and backgrounds; I was keen to include variation by way of age, gender, employment history, length of time spent on IB, educational background, household status – i.e. if they lived alone or with others, and differing health conditions, including how and why people had made the transition to receiving IB. The age range of the sample varied greatly – the youngest participant was 32, and the oldest was 65, and had recently retired. Of the 25 people I spoke to, 15 were female and ten were male. In terms of marital status, most participants (19) were either married or had been married and were now divorced. Interestingly, a massive range existed between the lengths of time people had spent on IB – some had only just been receiving it for three years, whilst some people had been on IB for over 20 years.

The following table, Table Two, outlines the IB recipients who were involved in the research, detailing their pseudonym, length of time spent on IB and general health problems.

**Table Two: IB participants**

<b>NAME AND AGE</b>	<b>LENGTH OF TIME ON IB</b>	<b>HEALTH CONCERNS</b>
Fred, 53	8 ½ years	Arthritis, collapsed discs, degeneration in shoulder, diabetes
Laura, 57	4 years	Mental health problems, hip problems
Sarah, 54	15 years	Reynaud's, mental health problems, underactive thyroid
Jacqui, 50	5 years	Back pain, mental health problems
Angie, 50	7 years	Physical health problems, mental health problems
Caroline, 46	5 years	Undiagnosed, but epileptic-like symptoms
Diane, 59	5 years	Multiple sclerosis (MS)
Shaun, 46	13 years	Broken back, depression
Mick, 45	5 years	Osteoarthritis, depression
Julie, 56	16 years	Depression, gall bladder problems, mobility issues
Kevin, 56	5 years	Heart problems, depression
George, 65	12 years	Heart problems, arthritis
Sandra, 52	13 years	Mental health problems, neck and back problems
Linda, 54	11 years	Shoulder and hand problems, depression
Lisa, 45	13 years	Back problems, depression
Kirsty, 33	3 years	Neck, arm and back problems, depression
Martin, 54	5 years	Knee and leg problems, alcohol issues
Tom, 59	9 years	Neck and arm problems
Marian, 45	11 years	Arthritis, mental health problems
Terry, 53	12 years	Bipolar disorder
Alice, 54	26 years	Diabetes, polycystic kidneys, rheumatism

Joan, 52	16 years	Osteo-arthritis, rheumatoid arthritis, fibromyalgia
Ray, 53	6 years	Alcohol issues, anxiety, depression
Sue, 50	20 years	Diabetes, heart problems, mobility issues, depression

The majority of interviews took place in participants' own homes. This decision was reached for two reasons; firstly, given the nature of the research often participants are experiencing debilitating health problems which limit their mobility. Interviewing people in their homes ensured that they did not have to worry about meeting me elsewhere. Secondly, I believe that carrying out interviews in someone's own home enhances the research experience for both the researcher and the researched – for the researcher, they are able to see someone in their own home and make sense of their narrative within the context it is situated. For those being researched, they are likely to feel more comfortable in their own home and therefore might feel more relaxed. Obviously, research in someone's home setting does raise safety issues. Safety procedures were put in place and I always had to 'check in' with a member of staff at the University before and after an interview. Less often, participants were keen to come to the university, perhaps out of curiosity regarding academic and university life, as Clark (2010) explains.

Interview schedules were largely based around a semi-structured style which aimed to uncover biographies through an exploration of various aspects of their lives, with a particular focus upon health, feelings about and experiences of receiving IB, employment trajectories, and hopes for the future. Interviews typically lasted between 45 minutes to over two hours, and were transcribed verbatim and fully anonymised before thematic analysis was undertaken. Participants were offered £10 'Love to Shop' High Street vouchers for giving up their time; a gesture I believe helps to foster mutual respect between the researcher and participants, rather than acting as a bribe in any way to take part in the

research. The vouchers were considered valuable by the majority of participants; for example, some people told me that they used them to buy food at Iceland when they were running low on money, and others such as Julie, who was setting up her own business, used them to buy art supplies. Some people, on the other hand, had to be strongly encouraged into accepting them. In those cases, I told people to just give them away – one person gave them to a ‘Big Issue’ seller, whilst others gave them to family members as gifts. As with the stakeholder interviews, participants were ensured that all information given would be treated with confidentiality. With both phases of qualitative interviewing, a thematic framework for analysis was derived partly from the study objectives and partly by identifying themes from ongoing analysis of transcripts; this will be discussed further in the subsequent coding and data analysis section of this chapter.

### **Coding and Data Analysis**

Data analysis in qualitative research manages words, language, and the meanings these imply (Miles and Huberman 1994). Qualitative data analysis seeks to organise and reduce the data gathered into themes or essences, which, in turn, can be fed into descriptions, models, or theories. Coding in qualitative research is one way of exploring bits of information in the data, and looking for similarities and differences within these bits to categorise and label the data (Padgett 1998; Patton 2002; Tutty *et al.* 1996). Coding is not simply part of data analysis; it is the *‘fundamental analytic process used by the researcher’* (Corbin and Strauss 1990: 12). Grounded theory involves a constant comparison method of coding and analysing data through three stages: open coding (examining, comparing, conceptualising, and categorising data); axial coding (reassembling data into groupings based on relationships and patterns within and among the categories identified in the data); and selective coding (identifying and describing the central phenomenon, or ‘core

category' in the data) (Dey 1999; Strauss and Corbin 1998). Ideally, each interview or observation is coded before the next is conducted so that new information can be incorporated into subsequent encounters. Themes identified through the coding of initial interviews may also be explored in follow-up interviews. As I was not following a pure grounded theory approach, sometimes I did not adhere to these strict guidelines; however, I did always attempt to transcribe and code each interview before the next one was undertaken. This approach is ideal for pointing out areas that have thus far been under researched in a study, and also areas that do not need much further exploration.

In *Discovering Chronic Illness*, Charmaz (1990: 1168) provides a few suggestions for coding. For example, she suggests line by line coding during the initial coding prompts the researcher to study the data, to dispel earlier preconceived assumptions about the data, and to begin viewing the data analytically. However implicitly, the researcher's definitions of reality clearly shape what categories he or she constructs. As such, coding and analysis was carried out alongside the fieldwork, in order to fulfil the following key aims: (i) to identify any emergent new areas of interest/ideas to ask participants about; (ii) to identify if certain types of participant are being overlooked, for example, if there is a paucity of older long-term IB recipients, then I can address this by actively seeking this type of participant; (iii) to identify when a saturation point is likely to have been achieved.

Additionally, computer assisted qualitative data analysis software (CAQDAS) software NVivo 8 was partially employed used to code and analyse the data. I developed the coding framework as I went through the transcripts, rather than trying to impose a pre-developed framework on the data (i.e. the approach was 'bottom-up' rather than 'top-down'). One drawback of this approach was that I continually had to return to earlier transcripts and consider whether new codes could be applied to previously coded sections. I employed NVivo in a fairly basic manner, approaching the coding framework as a tool to aid the

writing-up process rather than exploring the more complex analytical possibilities the programme offers. The coded interview transcripts were explored and presented in a case-by-case format as opposed to issue-by-issue. Presenting the findings via a narrative for each individual was more accessible and easier to navigate through than would be the case for discussions of individual issues.

Alongside the process of data collection, a research journal where notes, thoughts, feelings and ideas could be documented allowed me to be reflexive throughout the research process. Memo writing is the pivotal intermediate step between coding data and writing the first draft of the analysis for Charmaz (1999: 376). Memo writing helps researchers to define and delineate theoretical categories and to focus further data collection. This analytic step is crucial because it keeps researchers in control of their studies. The following list describes the advantages of memo writing. Memo writing helps researchers to:

- *Stop and think about data;*
- *Spark ideas to check out in the field setting;*
- *Avoid forcing data into extant theories;*
- *Treat qualitative codes as categories to analyse;*
- *Clarify categories - define them, state their properties, and delineate their conditions, consequences, connections with other categories;*
- *Develop fresh ideas, create concepts, and find novel relationships;*
- *Discover gaps in data collection;*
- *Link data gathering with data analysis and report writing; and*
- *Build whole sections of papers and chapters.*

All of the above mentioned by Charmaz influenced the decision to begin a research journal where memos are noted and reflected upon. Journal keeping has allowed me a space to

record my initial reactions and decisions and to be able to look back and analyse the factors behind those decision making processes, and to see how my thought processes changed throughout the course of the research. This approach was supported through numerous pieces of literature which argue that personal journals or diaries can be a valuable and relatively simple way for researchers to work through and acknowledge their emotions, and the roles that they play within the research context (Darra 2008; Glaze 2002; Goodrum and Keys 2007; Hewitt-Taylor 2002; Hubbard *et al.* 2001; Smith 1999), and also as a way to manage distress, sadness and release emotions (Goodrum and Keys 2007). Journals can therefore be viewed as an effective tool for reflexivity, as they can lead the researcher to a state of openness where prior assumptions, beliefs and attitudes are recognised and understood (Dowling 2006). In particular, the journal allowed me to discover gaps in the data and developing and clarifying connections - enabling me to '*hear subjects' voices more clearly and understand their tales more completely*' (Charmaz 1999: 379).

### **Ethical considerations**

Morse (2007) asks: '*What should we consider when preparing to conduct qualitative health research?*' Accordingly, participants were provided with information about the study and were fully informed of their right to decide whether to participate, and to withdraw from the research if they wish. The issue of informed consent remains controversial, with debates highlighting differing perspectives and expectations of researchers and participants as to manner, timing, and depth of information required or desired in obtaining consent (Birch *et al.* 2002; Graham *et al.* 2006; Lee and Renzetti 1993).

According to Hewitt (2007: 1151) so-called vulnerable groups such as those with mental health problems have often been denied a voice in qualitative research because of beliefs of *ipso facto* incompetence and no autonomy. This was not the case in this research

project. However, utmost care was taken to ensure informed consent was obtained and documented via a written consent form which was read aloud and fully explained to each participant. Participants were assured that anonymity and confidentiality would be maintained at all times. Ethical approval for the study was granted from the Geography Department at Durham University.

In addition, given the very nature of qualitative inquiry, problems relating to bias can be considered an issue. Researchers are often expected to respond to personal narratives with neutrality, demonstrating minimal emotions and reactions. Every study has biases and particular threats to validity, and all methods have limitations. Research involves multiple interpretations as well as moral and ethical judgments (Marshall 1990; Smith 1990). Every attempt was made to assure validity as much as possible; for example, in order to work through the complex and distressing narratives I was listening to, I always completed my field journal after interviews and ensured I placed the narrative within their wider context. These final points relating to ethics and sharing of information clearly leads onto the second part of the chapter which focuses upon reflexivity throughout the research process.

## Part Two

### Reflexivity in the Research Process

Having provided a discussion of the research design and process of the study, it is important to draw attention to reflexivity and its role within the realm of qualitative health research, and more specifically, within this study. Generally, the term 'reflexivity' is used without defining how it is being used, as if it is something that is commonly understood and accepted as standard methodological practice in qualitative research. Reflexivity is commonly used in qualitative research and has been posited and accepted as a concept that qualitative researchers *'can and should use to legitimize, validate, and question research practices and representations'* (Pillow 2003: 175). One of the most noticeable trends to come out of a use of reflexivity is increased attention to researcher subjectivity in the research process – a focus on how does who I am, who I have been, who I think I am, and how I feel affect data collection and analysis - that is, an acceptance and acknowledgment that *'how knowledge is acquired, organized, and interpreted is relevant to what the claims are'* (Altheide and Johnson 1998).

It is widely recognised that such research entails complex relationships that exist between the researcher and the researched; certainly, the challenges associated with supporting and sustaining these relationships are well articulated. Commentators have focused on the dynamics of power (Hammersley 1995; Crozier 2003), gaining access (Emmel *et al.* 2007; Sixsmith *et al.* 2003), building rapport and trust (Miller and Bell 2002), ethics (Goodwin *et al.* 2003; Mason 2004; Hewitt 2007) and identity (Finch 1984; Letherby 2000). Furthermore, it is often expressed that the researcher must comply with a specific set of ethical guidelines to ensure the safety of not only the research participants, but also of themselves. This part of the chapter seeks to locate the chronic health and disability

narratives of sickness benefit recipients within a wider framework that considers not only the relationship between the researcher and participants, but also issues of the performance of both parties in the research process. In doing so, the emotional aspect of being involved with carrying out and also participating in qualitative health research will be debated. Undertaking sensitive research has the potential to pose significant risks for the psychological and/or physical safety of the researcher. Narratives of sickness and disability by nature include sensitive issues that can often be difficult to speak about for the participant, but also difficult for a researcher to hear. Reflexive personal reflections upon how I felt and my identity are discussed alongside a consideration of participants' experiences.

### **Researcher/researched relationship**

The beginning of the researcher-researched relationship commences when the researcher enters the sampling stage. At this juncture, the researcher wields the power to decide who they recruit as participants, as Clandinin and Connelly (1994) observe. The researcher makes the decision who to 'cast' as participants for the research, thus they are effectively in control of who they decide to include in the research experience (Garthwaite 2009: 114). Although the majority of the reflections in this part of the chapter will relate solely to my experience of interviewing long-term IB recipients, I feel that it is important not to neglect the relations that occur when interviewing professionals such as key IB stakeholders. Whilst I would argue that power relations between myself and the IB recipients I have interviewed is not equal, nor so is the balance of power between myself as a PhD student and the professional stakeholders. In these interviews, it can be argued that the majority of power lies in the hands of the stakeholders. Not only in a position of employment, but they were also keen to stress their often lengthy personal experience of working with IB recipients; thus perhaps making them more of an expert than myself in their opinion. Certainly, similar

sentiments can be found in the work of Wright (2003) and Grant (2011) in their research with welfare-to-work stakeholders.

Fundamentally, the researcher-researched relationship is a constantly developing one. In order to illustrate reflexive practices that are apparent between myself and participants, I am introducing empirical evidence to strengthen and further illustrate my argument. Firstly, certain attitudes are required from the researcher. The minimum essentials would seem to be a non-judgemental attitude towards any information offered by individuals, awareness of how the other person might be feeling, sensitivity to their needs and when they want to talk or would prefer not to. Although rapport is essential between researchers and participants (Goodwin *et al.* 2003; Punch 1994), exploitation of the participants' needs to meet the aims of research is not acceptable, and researchers should be aware of the risk of manipulation through professional identity and skills (Tee and Lathlean 2004).

A clear example of how the researcher-researched relationship can evolve can be seen in Sandra's story. At the beginning of our interview, Sandra expressed her concerns at being able to talk openly about her health and was anxious about being able to reveal personal reflections. I assured her that she should only reveal what she was comfortable with, and at any time I could turn the digital recorder off, or she could cease the interview. However, once Sandra began talking, she completely relaxed and found herself telling me things that she does not tell her own family and even commented that she had not '*spoken to anyone like this since my psychiatrist*'. Sandra was open about her mental health problems, but seemed to shock herself that she was able to talk about it, stating '*I didn't think I'd be able to talk to you like this*'. For Sandra, the interview process was a chance to talk unreservedly and with openness without feeling like she being judged. At the end of the interview, Sandra repeatedly stated how much she had enjoyed the experience and that I should get back in touch with her if I have any further questions. This interaction is of great interest to

me as a researcher and leads me to question why Sandra, amongst others, felt able to open up to me.

Often, participants were reluctant to talk to family and friends about their health problems as they did not want to be seen as moaning, or they did not want to upset anyone else by revealing the extent of their pain or suffering. Having someone to talk to for sometimes up to 3 hours allowed participants the freedom to reveal their stories freely. Perhaps cathartic benefit can occur when participants experience comfort, validation, empowerment and a unique opportunity to confide in someone knowledgeable, interested and caring, alongside the opportunity to work through and express their emotions (Tillmann-Healey and Kiesinger 2001; Orb *et al.* 2000; Howarth 1998; Darra 2008). Participants have noted that it was beneficial to them to not only have the opportunity to talk openly about their experience, but also to feel like it had the possibility of helping others in a similar situation (Rowling 1999). Other researchers have remarked how they, too, were surprised by the way participants shared their stories with strangers (Yee and Andrews 2006; Goode 2000). Other participants also remarked on the way they opened up throughout the interview, as shown in Lisa's story: *'I've rabbited on a lot. I think that's the most I've talked to anyone in ages!'* Feeling like someone was listening to their stories was something that arose regularly throughout the research.

Indeed, feeling 'useful' or 'worth something' was often given as the reason why people decided to take part in the research. For many, being out of the labour market due to health reasons resulted in a loss of self and identity, and a loss of purpose. Taking part in the research was viewed not only as helping me as a researcher, but also as giving people something to do and helping them and was described as therapeutic – something also reflected on by Birch and Miller (2000). Many participants felt that they had never been given the opportunity to talk honestly and openly about what it was like to experience

chronic health and disability and how it affected them. Here, Ray, age 53, who suffers health problems due to his alcoholism, explains why he decided to take part: *'Doing stuff like this, I think if it wasn't for stuff like this I'd be stuck in the house a lot more. It's given us a bit purpose to get out and I'm grateful for that'*.

Several participants also expressed appreciation that someone was giving recognition to their situation and to their lives. Research by Johnson (2009: 35) found that many participants had spent so long trying to fit into what Heidegger refers to as 'the they world' and present themselves as 'normal', that they never had the chance to authentically 'be' and reveal their true experiences. However, it should not be naively assumed that the research process is one sided. As Miczo (2003) observes, it cannot be ignored that the first answer of the interview encounter is going to depend on the motives that led that person to be in the role of interviewee in the first place. Clark's (2008) work on research fatigue emphasises that research encounters are not just negotiated and managed by researchers, but are also actively negotiated, managed and experienced by those who agree to be involved and who have their own perceptions of engagement.

### **Identity and performance**

Having outlined the role of the researcher and the researched, the following section discusses identity formation in greater detail. From the very beginning of the research journey, identity is considered by both parties involved, both implicitly and explicitly. Indeed, Gerson and Horowitz (2002: 202) suggest that: *'to enter a world in which one is not naturally a part, a researcher needs to present an identity that permits relationships to develop'*. As the information sought in the study was often of a sensitive and personal nature, it was imperative that participants felt they were able to talk openly and honestly. I did not want people to perceive me as the supposed 'other', someone from the university

entering their homes and asking personal questions; after all, Crozier (2003: 89) notes how 'wholly intrusive' researching sensitive topics can be. Nevertheless, I was also aware that there is a fine balance between reducing the extent of my 'otherness' and ensuring that I maintained both ethical and professional guidelines. Therefore, although I felt it was important to ensure participants were aware of my professional status, I was equally aware that this may result in me appearing an 'outsider'.

For Goffman (1959: 35) clothing and symbols of professional status are two elements deemed to determine 'personal front' in the performance of an individual. As a result, upon entering people's homes to carry out an interview, I always made sure that I was not too smartly dressed but neither was I too casual. I did not want to appear overly formal and as 'someone from the university'; whilst that is my professional role, I wanted to ensure participants felt comfortable around me. I also felt that it was important to disassociate myself from the place that I had met participants - Jobcentre Plus Choices events - so that the research participants did not feel that they were being 'investigated' in any way and did not feel obliged to give consent or provide different responses because of this perception. As the following extract shows, I was correct to be wary of this, as Terry, 53, expressed concerns over where he thought the information might go:

*They (the Jobcentre) don't realise how it eats away at you and how people worry, they don't give a shit as far as I'm concerned. That's why I wouldn't want any of the information I give to you to go to the Jobcentre, y'know?*

Obviously, I reassured Terry that all of the information given in his interview was fully anonymous and confidential, and I would ensure when publishing the research that he could not be identified.

Goffman (1981) observes that the performance of the interview encounter is fraught with risk for both the interviewee's and the interviewer's identity. In entering people's homes and carrying out interviews, the researcher is bound to act and behave in a certain manner, as they are, after all, a guest in the person's home. As Yee and Andrews (2006: 407) observe, there is a paradox between the role of the researcher as a 'good guest' and a professional researcher. They give the example of being offered refreshments and question whether *'accepting an offer of tea or coffee can demonstrate that the researcher feels relaxed with the family and can be part of establishing a relaxed atmosphere'*. Obviously, when embarking upon the research process the researcher seeks openness and honesty, but should be aware that participants will present a version of themselves that they wish to convey – what Goffman (1959: 30) terms an 'idealized self'. Indeed, in telling their stories, participants are in fact creating a new identity which either confirms an existing self or repositions their identity (Lee and Roth 2004; Snow and Anderson 1987; Snow and McAdam 2000).

Initially, I did not wish to reveal too much of myself in interviews, unless I was specifically asked. Riach (2009: 361) uses the term 'sticky moments', understood as participant induced reflexivity to describe this occurrence. I saw the interview as a space for participants to present their stories; stories which are not often heard or listened to. I felt I would be encroaching on their time and their space if I revealed too much of myself. Yet in some circumstances, it was deemed relevant to disclose more of myself. In the more intimate setting of the home, for example, if a participant asks about the researcher's own experiences, Crozier (2003: 87) notes, *'the failure to answer could be seen as exploitative in the sense that the relationship would be based on taking without giving anything meaningful in return'*. Consequently, when I was specifically asked about myself, in the interests of maintaining rapport and reciprocity I did oblige and answered questions in an

open and frank manner. How participants viewed me as a researcher will unquestionably affect the response they gave me during the interview. I felt that my identity was characterised by me being a 25 year old white PhD student from the North East of England, sometimes carrying out research in an area that I live in and had been brought up in. As a result, I had the same regional accent as they did, I possessed local knowledge of places they mentioned.

Yet despite this common ground, I remained different to them in two fundamental ways – firstly, I was perceivably fit and healthy, and secondly, I was without any direct personal experience of benefits receipt, unlike them. However, difference between researcher and participant is not necessarily negative and Vincent and Warren (2001) warn that too much researcher and participant symmetry could lead to assumptions on either side and misunderstandings can arise from either party on the basis of shared assumptions. Although I do not personally suffer from any health problems myself, sometimes I could relate to certain situations regarding health issues that are significant to me. In those instances, I chose to reveal my own experiences as I felt it would have been dishonest if I had kept this to myself. Upon doing so, participants would openly reveal more about their narratives and seemed genuinely interested that I, too, had experienced the issues they were narrating.

Commentators have often questioned the ethics of a non-disabled researcher doing research with disabled people (Barnes and Mercer 1997; Stone and Priestley 2006; Priestley 1997). On occasions, participants attempted to seek similarities between themselves and my experiences, perhaps in an attempt to break down the ‘us’ and ‘them’ discourse created about sick and disabled people in populist discourse, as the quotation from Jacqui, 50, illustrates:

*I'm setting up a business making costumes, you're doing a PhD - you're wanting to do something with your life and that's what I want to do.*

In his seminal work on performance and presentation of the self, Goffman (1959) remarks that *'the individual will have to act so that he intentionally or unintentionally expresses himself [sic], and the others will in turn have to be impressed in some way by him'* (1959: 2). Here, Jacqui wants to illustrate that she is different to other people on IB in that she is setting up her own business, thus distancing herself from a 'spoiled identity' (Goffman 1963: 3). Other participants, such as Sue, 50, were keen to present themselves as good hosts. When I arrived at Sue's home, she had baked a range of homemade cakes for my arrival – despite telling me in the interview of her difficulties preparing the tea for her husband. This performance further hints at the dramaturgical notion of performance as suggested by Goffman (1959: 123) of front and back regions:

*One of the most interesting times to observe impression management is the moment when a performer leaves the back region and enters the place where the audience is to be found...one can detect a wonderful putting on and taking off of character.*

Here, Sue was 'putting on' the character of good host, despite the fact that she struggles to perform daily tasks she was keen to present herself to me in a positive way.

### **Risk and the research journey: emotions, power, and trust**

Undertaking sensitive research has the potential to pose significant risks for the psychological and/or physical safety of the researcher. Qualitative researchers working on sensitive topics are undertaking research interviews with participants regarding intimate and often distressing aspects of their lives. For Malacrida (2007) there is a paucity of

research regarding the impact of emotional topics on researchers themselves, despite an abundance of literature focusing upon the potential emotional effects of qualitative research on research participants (Corbin and Morse 2003; Grinyer 2004).

### ***Emotions***

Emotions become involved in qualitative research from the outset – after all, a researcher should feel a certain level of passion and connection to the topic they are researching from the very beginning of the research process. The following section explores how emotion and identity featured within the study, and how these factors can impact upon the outcome of qualitative research. Internalising sensitive and distressing information can present a real risk for the emotional wellbeing of researchers.

Often, I would finish an interview and experience a myriad of emotions – drained, distressed, upset, privileged, guilty, angry, and lucky, amongst many others. Participants would tell me about their daily life, their health and illness experiences, and significant traumatic events that they feel have shaped them as people. I did regularly feel like participants saw me as something of a counsellor, although I am not trained for that role. I did not offer advice to participants other than to suggest they talk to a doctor, counsellor or someone close to them if they wanted to discuss anything further. Indeed, some interviewees expressed concern for my emotions and often apologised for ‘burdening’ me with their stories of battling chronic health conditions and disabilities. For example, Lisa, 54, comments: *‘I have really poured everything out to you haven’t I, I’m sorry...I just don’t want you to think I’m burdening you with all of this’*. In order to avoid becoming overwhelmed, I attempted to space my interviews so that I had time to process each individual story before attempting to move on to the next. By pacing interviews I was able to reflect on what I had been hearing and provide a place for validation of my emotional

reactions to these stories (Beale *et al.* 2004; Hubbard *et al.* 2001). It is also a way for me to have enough time to be able to process and 'let go' of information (Dickson-Swift *et al.* 2008; 2007; 2006) given that doing research of this kind does evoke emotional responses (Bourne 1998).

Arguably, researchers should undertake no more than two interviews per day to ensure that burnout or exhaustion does not occur (Wilkes 1999). I made a point of limiting the number of interviews that I did each week predominantly for the purpose of giving myself a rest period, as I knew that trying to push too many interviews into a day or a week would result in a greater emotional impact. It also allowed me the opportunity to keep up with my transcription so that I could work with my data while the interview was still fresh in my mind. Further to this, I also found it really important to make sure that I had some 'down time' where I could just relax and do mindless activities, an approach also recommended by Johnson (2009). All of these things meant that I felt better equipped to handle the emotional aspects of this research project and reassured me that if I needed help, or someone to talk to, everything was organised and accessible. Johnson and Macleod Clarke (2003) remark that having to deal with the unexpected during the research process, such as in my experience of revelations of an interviewee revealing severe depression, can generate feelings of anxiety and concern. The extract below from Shaun's interview highlights the emotional nature of revelations in the interview process:

*To sum my life up, it's not worth living. It's not that I've given up, it's just I can't do anything. I'm in so much pain and it doesn't show on me face but I'm that used to putting up with pain. I dunno what life holds now y'know?*

These feelings of concern can '*be experienced at a more intense level if the research topic is highly sensitive*' (Johnson and Macleod Clarke 2003: 425) as can be the case when a

researcher delves into narratives concerning health and illness whose ultimate subject matter might be hidden from view.

It is inevitable that exploring health and illness narratives evoke sympathy from the researcher. Whilst health and illness narratives can be shown through quotations from the transcript, the experience of interviewing people face-to-face and witnessing how their voice, expressions, and emotions change as they relay their story cannot really be replicated through transcribed text. Kirsty's interview was a pivotal moment for me in thinking about reflexivity in the research process. Kirsty, 33, was a prison officer for ten years until a chance accident at work – a heavy door fell on her neck in her workplace of a young offender's institution - that meant her future prospects of working were, according to her, 'very restricted'. I could not avoid the thought that Kirsty was only seven years older than me, yet in one split second her life had completely changed. Kirsty said of the accident:

*(Laughs) Of all the things that can happen in a prison, a door fell off and hit me on the head. I pushed it open and the top hinge failed. It swivelled on the bottom hinge and fell onto me and I took the full weight on my head and it snapped my neck back. That's what caused the damage to my spine so it's a bit ironic. Of all the brave things that could happen to me in a prison – a door fell on my head.*

Although the transcript tells the tale, researcher encounters are embodied and situated events, and significant details are lost if we take away and preserve only the words people actually said (Warr 2004: 579). For example, when Kirsty spoke of previously being given shopping vouchers to commend her excellent performance at work, the cruel irony of me offering her shopping vouchers to participate in the research because I wanted to hear about her experiences of health and illness was a sharp and unavoidable contrast. At that

moment, I felt uncomfortable, frustrated for her, I felt like an intruder and I also felt frightened that something like that could happen to anyone - it could happen to me.

The previous point, however, does lead on to questions of portraying narratives without prejudice. Another factor the disability studies community suggests should be avoiding in writing up research is any portrayal of 'pity' (Barnes 2001). Yet evoking feelings of pity and sympathy might be unavoidable when looking at the narratives of long-term IB recipients. The narratives tell stories of chronic pain, disruption, loss of self and a struggle to reconcile an identity that was once shaped by something other than illness. Whilst Barnes (2001) and other disability rights scholars see such views as having the potential to make the lives of disabled people tragic, portraying the realities of living on IB for the people who receive it crucial in order to avoid people receiving such benefits from being branded as simply another group of the unemployed. A moral obligation then exists for the researcher to ensure that there is sound justification for the investigation and research method, which extends beyond intrusive curiosity and achieves more than the '*telling of sad stories*' (Thorne and Darbyshire 2005).

### ***Power***

Certainly, carrying out research in people's homes raises issues of power which can shift throughout the research process (Bravo-Moreno 2003). Although the researcher exercises control in deciding who and where to recruit, the participant holds power in respect of whether or not they consent to participate. Following consent, the researcher acquires data, evidencing a multifaceted balancing act between the researcher and the researched from the outset. This is echoed by Karnieli-Miller *et al.* (2009: 282) who remark:

*The researcher, who is in possession of the information about the study, and the participants, who own the knowledge and experience needed to perform the study,*

*can use their respective powers to negotiate the level of information provided about the study.*

For Stone and Priestley (1996: 700), when thinking about non-disabled researchers, they argue that the inherent power relationship between researcher and researched is accentuated by the unequal power relationship which exists between disabled people and non-disabled people in the wider world. Yet they also recognise that the researcher is required to bow in several directions: to research councils and to academic peers, to disabled people and their organisations. In this sense, the researcher both acts and is acted upon within these power relationships. Yet, the power balance can shift over the course of the research process. I have been left outside on doorsteps ringing the doorbell, stood in freezing cold weather, pushing hastily scribbled notes through doors in the hope that participants have simply forgotten that I was coming rather than silently withdrawing their initial consent to be interviewed.

Another area where power becomes important is the power that the research can have, or indeed fail to have, following the study's completion. Unfortunately, as researchers are all too aware, change is not an inevitable outcome of the research process, as suggested by Clark (2008). This sentiment is echoed by Fine *et al.* (2000) who noted that the participants of their study who were receiving welfare benefits regarded the researchers as being in a position to take their stories and issues to policymakers in a way that they could not do themselves. Again, this elucidates a further strand of the power debate, as the participants perceive themselves as powerless as opposed to the researchers who can use their powerful status to give the participants a voice.

## **Trust**

Johnson and Macleod Clarke (2003: 422) comment that in depth qualitative interviewing can encourage participants to 'develop a relationship founded on trust, which invariably involves them in a role relationship beyond that of the more conventional participant and interviewer role'. There is a genuine risk that participants may feel obligated to respond in a certain manner (Johnson and Plant 1996). Further, just as there is a protocol for embarking upon a research project, there is also a protocol for leaving the field. The intricacies of generating a sample and building trust and rapport as part of the performance inherent in the researcher-researched relationship have been well articulated in this chapter, yet disengaging from the field and knowing when to finalise the relations that have been created can be equally complex.

Emmel *et al.* (2007) comment that while researchers have identified strategies to maintain trust during research, the potential for these trust relationships to break down when data collection is complete is recognised as a particular difficulty. Researchers translate and interpret the private lives of participants and produce public representation of their lives in academic work; Lofland and Lofland (1995: 62) remark that a researcher may '*want to leave open the possibility of a return*' to re-interview participants in the future; an avenue I would certainly wish to explore with participants in this study. Standing (1998) suggests that the researcher continues to hold power in the researcher-participant relationship once the researcher leaves the field. Ortiz (2004: 480) warns of the dangers of over rapport and makes the point that in the process of a researcher disengaging from the field, the very skills and techniques that were important for gathering data made it difficult for him to know when and how to leave the field, referring to his subsequent 'guilt' at dissolving the relationships developed for fieldwork. Commentators have noted that the researcher

should leave the field without having caused harm to any participant, thus leaving their lives the same as it was before they entered it. For instance, Stake (1995: 60) advises that *'the researcher should leave the site having made no one less able to carry out their responsibilities'*.

### **Chapter Summary**

The chapter began by outlining the theoretical considerations that underpin the research design and process of the study. Building on academic discussion around issues such as research design and process, research methods, access, sampling, and coding, Part One demonstrated that the research is loosely based upon an approach rooted in grounded theory. Qualitative research as a method when researching health and illness was discussed, before details of the qualitative fieldwork undertaken for the study were provided. Finally, ethical considerations were outlined, including a consideration of informed consent and anonymity. Health and illness narratives are inherently complex and multifaceted, evoking both the researcher and participants to occupy certain roles and behave in certain ways at different points in the performance.

Consequently, the second part of this chapter demonstrated how the researcher-researched relationship is a constantly evolving continuum in which the performance of both parties is highly significant at each stage of the research process. Reflexive contemplation at each stage of the research process is required in order to ensure that the intricate narratives and performances of the researched are analysed and represented in a considered manner, and do not simply represent only the researcher's voice. It is important to retain awareness of power shifts and of performance by both the researcher and the researched whilst negotiating the difficulties of accessing participants' lived experiences. In retaining such awareness, a researcher can fulfil their ethical obligations to the participant,

and also remain accountable not only as researchers, but also as individuals exploring intricate health and illness narratives. Overall, it is hoped that this chapter not only justifies the methodological rationale behind the research, but also makes clear the practicalities of how the data was collected.

## CHAPTER FOUR

### BECOMING INCAPACITATED? EXPLORING NARRATIVES OF IDENTITY AND STIGMA

*Mick, 45:*

*“Not only was I worried about me house, I was worried about the impact it would have on me family and me children - it was horrendous. Just worried sick about the future - oh it was awful, it was. I mean another side of it was the social aspect of it as well as me wage and everything. Me work colleagues they were good friends of mine for 20 years, I played football, ran two five-a-side teams and I was playing football up until me knee collapsed and the social side of it hit us a lot more than I expected. Oh I was in tears and everything obviously worrying about the future, and some of the lads have stayed in touch but your relationship changes away from work and I can’t physically do the things I used to do. Every now and then they’ll take us for a drink but I can’t drink much now anyway cos I’m on painkillers and things, me mobility is affected now - stairs and everything, I can’t do the pub crawl like I used to and being on crutches permanently is hard work. And that’s another thing it took two years to heal so two years upstairs I wasn’t allowed to move at all and that was a nightmare that like and the pain...for two months I just couldn’t move, I had to be immobile while the graft took root and it was months afterwards up to 6 months before I was reasonably mobile on these crutches. But yeah I got secondary depression me GP said and I don’t want to go down the route saying ‘Oh I was depressed’ and all that but I was looking back cos I was worrying about the future, it’s a change in life and your identity as well. It’s funny how many people I’ve talked to who’ve lost their jobs and your identity just goes overnight. I went from being a Nissan worker, hopefully becoming a supervisor I was on that career path, I was in charge of a team at the time y’know things was looking good and the social side of it was as well and then suddenly...I mean I had a brilliant sickness record, fantastic attendance record then you felt as if you were devalued, disempowered all these big words and I remember coming home from that meeting, coming up the path in tears.”*

## **Introduction**

This chapter is the first of four chapters that presents the narratives of long-term IB recipients. As the above extract from Mick's interview indicates, the transition from being healthy and in paid employment to becoming 'incapacitated' and receiving sickness benefits can clearly be a deeply traumatic and painful process. It is not simply about health, either – the change encompasses family, friends, status, identity – it signifies a complete change. This chapter focuses upon how people perceived and managed becoming 'incapacitated' – beginning with how the transition happened in the first place. Next, the chapter examines the key changes that people identified as occurring when they began receiving IB, with an emphasis on identity formation and reformation, alongside a consideration of how stigma features in the narratives.

## **Becoming incapacitated?**

Sociological accounts have moved on from the functionalist perspective of Parson's sick role in the 1950s with its emphasis on acute illness, to understanding illness as an often long-term social process characterised by degeneration and change (Nettleton 2006). Bury's (1982) description of the onset of rheumatoid arthritis as a form of 'biographical disruption' represented an explicit attempt to develop a new theoretical account, offering both explanatory and predictive power in understanding chronic illness. There is now a rich literature describing the biographical impact of illness: the processes that are a consequence of the changes brought about by illness; and the subsequent adaptive processes, including biographical reconstruction (Williams 1984). This section will focus upon participants' health trajectories within their narratives, showing that the onset of health conditions could occur at different stages in the life course: before entering the labour market; gradually, usually whilst working; or suddenly, usually whilst working. What is evident is that participants experienced the trajectory in different ways – for some,

leaving the labour market to begin claiming IB was a welcome relief, whilst for others it evoked feelings of shame, guilt and isolation. For some people, it was an opportunity to pursue a different career path, learn new skills or take up a hobby that they had always wanted to try. Overall, whilst this chapter will illustrate that the transition of becoming ill or indeed becoming more ill is a massive shift in people's biographies, it is not necessarily always a negative shift and positive identities can emerge. Such identities can then challenge stereotypical views of sick and disabled benefits recipients as idle and non-contributory to society.

### ***Growing up with health problems***

Of the 25 participants, only two reported growing up with health problems. Gillian, 52, spoke of how her health problems began when she was younger and needed a lump removed from the back of her foot – something which she believes led to her arthritis that she now suffers with. Gillian has been receiving IB for around 16 years; prior to this, her only job was as a housekeeper at the post office for a period of nine years whilst at the same time caring for her brother who is *'so severely disabled he couldn't even sit up'*. Currently, Gillian also cares for her 27 year old niece who has cerebral palsy. Going back to work is ruled out as an option for Gillian – she told me the doctors say there's *'no chance'* of that happening. Sue, 50, is the other participant in the sample who has grown up with health problems. She told me how her mother had heart problems and was advised not to get pregnant but she did, and Sue believes her own health conditions stem from her mother having a heart operation whilst pregnant with her. Sue has had problems with her legs but it did not stop her from working. However, when Sue was 30 she had an accident whilst working at a high street pharmaceutical store, falling down the stairs with a tray of coffees. Sue says of the accident:

*I got an Industrial Accident Allowance at the time but I just never got back to work, I couldn't put me weight on me foot and then I started seeing specialists who did an MRI scan and everything and it showed I'd damaged me spine. They also said spondylosis had set in and I could have had an operation but his advice was he would have sent us somewhere else to have it cos it was too near a nerve and I said 'Would it be better just to leave it?' and he said he thought so cos there was a 50/50 chance...he said things would get worse but he couldn't tell us how long or anything and as I say this is going back 20 odd year and it has gradually got worse to the stage that now I cannot do what I used to be able to do. I have good days, bad days, good nights and bad nights.*

None of the other 23 interviewees reported growing up with health problems. More often, health problems crept into people's lives over time. Whilst some attributed this to the effects of their particular form of work, for others conditions such as arthritis, musculoskeletal problems and mental health issues began to build up which finally resulted in them having to exit the labour market and begin receiving IB. The following section explores these narratives in greater depth.

### ***Health problems whilst working***

Leaving the labour market due to health problems that set in gradually was a common theme for many interviewees. Laura, 57, has been receiving IB for four years after leaving her job as a secondary school science teacher due to mental health problems. A teacher at the same comprehensive school for almost 32 years, following a thyroid operation, Laura returned to work to find she was facing numerous problems which eventually led to her having a nervous breakdown:

*What was happening with me I was doing my own job, part of the head of department's job and I was heavily involved in assessment and coursework. Originally there were four of us doing that and two of those staff had nervous breakdowns so basically to cut a long story short I was being torn between one place and another. Then I had flu and I wasn't very well and again I was only off a week and they were ringing me up constantly. I wasn't particularly well but I went back and that week I was involved in interviews, I had a health and safety course and when I went back on the Friday of that week basically I was told by another member of staff that I wasn't doing me job properly and that I couldn't go home that night until she'd talked to me. And the next week I went in and had all this abuse thrown at me and at this point I totally flipped, I couldn't stop crying, I couldn't stop shaking. I wasn't sleeping anyway and I was coming up in blotches all over me and I went to see the doctor who said I couldn't go back cos I was physically and mentally exhausted.*

For some time following this, Laura could not bring herself to drive past the old school where she had worked, let alone think about heading back to work.

Others such as Terry believe that working led to the onset of their health problems. Terry had been a salesman, a crane driver and a factory worker before he began receiving IB. Terry told me how his bipolar disorder is exacerbated by stress, and for him '*jobs equal stress*' so he views working as having a negative impact upon his health. Honey (2004: 360) reports that in general, mental illness tended to reduce the benefits and increase the drawbacks of employment. Some participants said that the effects of their mental illness restricted their choice of jobs, so that the jobs they felt able to do were undesirable to them – similar to Terry's case presented here. Terry was diagnosed with bipolar disorder

ten years ago, but suffered with the symptoms since his teens yet the condition remained undiagnosed:

*Oh it was horrible, I got no treatment. Then we moved from Richmond to County Durham and I went to see the doctor and this time Miranda had kept a diary of what was going on and the doctor had a look at it and prescribed bipolar disorder and gave me Lithium and anti-psychotic medication. I also take an anti-depressant as well and I've never looked back, that cured me - well I'd say so, y'know? See when I had a diagnosis my life changed for the better, when I wasn't diagnosed it was terrible y'know. It just shows you how you can slip through the system.*

Whilst Goffman's classic work *Asylums* (1961) warns of the potential risk to self identity posed by being labelled as mentally ill, Terry suggests that being diagnosed with a severe mental illness was, in fact, a positive experience for him. For Terry, the diagnosis of bipolar disorder answered many questions – it explained his previous behaviour where he described how he would 'get manic and go to India, just decide I'd take £1,000 and go to India. I went about 5 times just travelled round India...now I know why'.

### **Accidents at work**

A number of people I interviewed had experienced accidents at work which led to a sudden health problem or a worsening of an existing problem, as Sue's story showed in the previous section. For me, speaking to Kirsty, 33, was an extremely powerful reminder of how a freak accident can change someone's life immeasurably. As noted earlier, Kirsty was a prison officer for ten years until a chance accident at work – a heavy door fell on her neck in her workplace of a young offender's institution. Following the accident, Kirsty described how her employers were not fully supportive:

*It's been hell, I'll not lie. Being medically retired from the prison service is hard work, thankfully there are a lot of procedures in place to protect staff but...you've got two sides to it. You've got the management side who are just wanting to get rid of a...of a dead limb basically, y'know I was costly and of no use to them. As soon as occupational health heard what was wrong with me I wasn't allowed back in the gates, I was actually escorted out of the prison - that was really hard. So there was no way I was ever going to go back and they were just wanting to do it as quickly as possible. My union were trying to protect my interests and I ended up being sacked before I was retired so the accident was August '06, I was sacked May '08 for medical inefficiency and it wasn't till the October '08 I actually won my case.*

Above, Kirsty describes how she won her case for unfair dismissal against her employers and was eventually awarded her Industrial Injuries benefit.

Shaun, 54, had an accident aged 31 on the building site he was working on, which left him with broken vertebrae in his back:

*What happened with the accident, they asked me to move a Land Rover gear box and I tried to move it but it would hardly move, we were half lifting, half dragging it. It was that heavy but anyway I don't know if he buckled or what but I ended up with the full force of it and it shattered the vertebrae in me back. I remember dropping to me knees and something didn't feel right, and I tried to stand up and passed out.*

Linda, 54, had worked in factories all of her life until she had to leave due to health problems which were exacerbated by an accident at work:

*I trapped me hand in a machine and rove me shoulder so that place has a lot to do with what's wrong with me I reckon. I can't blame me hip on that apart from the fact I was on me feet all day but me hands certainly, it was all that stapling.*

As these extracts show, working in often physically demanding jobs could lead to a worsening of existing health problems or the onset of new ones, whether that derives from an accident or the nature of the job itself, as is the case for Linda. Of those who had an accident at work, only Kirsty pursued legal action. Kirsty said:

*After nearly 5 years of making sure the union had copies of everything it becomes almost like a full time job, especially last year when the court case was still going on. It really does become like a full time job, having to send things off time and time again cos they say they haven't received it and now you're sitting there thinking 'What can I do today, I don't have to go and use a photocopier, I don't have to go and make a dozen phone calls' it's brilliant (laughs) it did take a few weeks of getting used to but yeah, all done and dusted now.*

For Kirsty, having the case 'done and dusted' meant she experienced reduced stress and could now fully focus on trying to improve her health and seeking work.

### **Being ill**

I was interested to find out how the daily reality of being ill played a part in people's narratives. Many described a daily routine filled with feeling guilt, boredom, restlessness and frustration at not being able to do the things they used to be able to do. Yet on the other hand, in some instances becoming ill allowed, or indeed encouraged, people to pursue a different career path or a hobby they had previously not had the chance to take up.

***'Every day is the same': transitions to ill health***

An overarching theme that emerged from the narratives was one of a life 'before illness' and a life 'after illness'. A deep sense of longing for the person they once were permeated the narratives. Becoming ill did not just result in losing a job: it could mean losing a wife, home, friends, independence, confidence and a sense of self. Certain 'critical incidents' can occur that can cause a person to question who they are or '*force a person to recognise that 'I'm not the same as I was, or I used to be'*' (Strauss 1969: 93). Angie, 50, was involved in a car accident just after New Year's Day in which a car collided with her vehicle head on. Describing the period of time following the accident, Angie says:

*Me seatbelt went through my stomach, I lost two thirds of my bowels, my appendix, gall bladder, and all my stomach had burst out. I was in a coma and they thought I wasn't going to make it. I got a blood clot and blood poisoning in my stomach and I was in hospital for like a couple of months. I couldn't manage on me own so I stayed with my partner Billy for 2 years and basically I was just a cabbage I didn't move, I had a stoma bag on so of course Billy was having to change my bag, did all that washed us and stuff and that was for 2 years and I got to the point where I was like 'I can't live like this'. I just lived in jogging bottoms and a massive big t-shirt, I never got me hair done or put make up on and I hadn't been like that before. Before the accident I had a really good life, I had the two lasses, me mam was there, y'know just I loved to work.*

Laura, 53, spoke of how she battled suicidal feelings following her mental breakdown at work as a teacher:

*I can understand how people do physical damage to themselves, I can understand why they do it cos you feel generally worthless and just self destructive...I wouldn't*

*say I was totally suicidal but there were times when I was thinking 'I don't want to do this anymore, I just don't see the point, I don't want to go out'. I just wanted to stay in bed and hide and not talk to anybody cos you just feel worthless.*

Angie, 50, told me about her attempt at suicide following her car accident:

*That day when I was going to do something stupid, I started walking towards the viaduct and I thought I either do it or I pull meself back y'know? I was just totally hopeless. I couldn't look after me grandsons anymore cos I didn't have the strength to lift them, just the whole thing of it and I hated the fact that you had to go and beg for Incapacity and DLA, it's horrible it really, really is.*

Additionally, others narrated stories of extreme suffering and pain. When asked to describe living on IB, Shaun says:

*I had another partner she was lovely but I had to break that up cos I was holding her back. I've been on me own for three years, yeah I'm bored and I'm lonely but I'm scared. I'm scared of falling out the shower, I've got scars all over where I've done that. Because of this I've lost me home, me family, me business, I lost the ability to be a bricklayer...and here's me now years later on me own, too scared to have a shower.*

As Charmaz (1991: 49) found, people who live with chronic illness have good days and bad days, and good days and bad days 'reveal images of self'. On a bad day, when symptoms are more intrusive, people are more aware of changes in themselves and begin to feel that they have less control, which can negatively affect their personal competence and overall sense of self. On a good day, when they have more control, they are able to feel more like their usual selves. For some people who were already dealing with juggling work and

chronic illness, leaving work was viewed as a positive step. For Jacqui, 50, initially leaving work to begin receiving IB was somewhat of a relief:

*In the beginning for me health I was quite grateful [that she had left work] but now it's just monotonous isn't it, every day is the same. I get up and take me tablets and that's my life and that's not my way, I am very independent so I've never really took to it. Like some people might be like 'I'm on it and that's it' but I can't settle.*

Others such as Linda told how the thought of having to claim IB did not actually bother them. Instead, the boredom and daily monotony is what had an impact:

*I think I would have loved it if I could do more than what I can do. It's just the sitting in the house by yourself all day playing on flaming computer games, looking for something to do, phoning people. There's not a great lot to do especially when your kids are grown up, I play with me cat well when he's not in bed all day, do a bit washing, that's it and over the day I get things ready to make the tea on a night time. Peel some taties, have a cup of tea, think what I can make for dinner on the night time and that's it, that's all I do. I do nothing. The doctor says I run the house and that's enough to do but I don't see it like that, I feel guilty.*

Indeed, Jahoda *et al.* (1972: 66) lament how '*leisure proves to be a tragic gift*' following an exit from the labour market. For other people in the study, a narrative of 'I'm sick but there are other people who are sicker' was dominant in their narrative. Deborah, 54, who was diagnosed with multiple sclerosis (MS) 11 years ago and has been receiving IB for 5 years, said:

*You have to be positive, you could think 'I've got MS so I'll sit here and be a cabbage' but I'm one of the lucky ones I suppose. With MS you can lose the ability*

*to walk, your speech, you can go completely gaga and have to go into a wheelchair and need 24 hour care y'know, not be able to wash yourself or talk.*

A similar sentiment of 'There are people worse off than me' can be found in Laura's interview. Laura, 57, says:

*I do feel sorry and a bit of a fraud as I say for people who are much more incapacitated than I am. I know a lot of my problems are nerves but I did go through phases of feeling very guilty about it, thinking 'I shouldn't really be having this' but then it was pointed out to me that I've paid in and I'm entitled for it so I've just done as I'm told.*

#### ***A lifestyle choice?***

In direct contrast to much media opinion and indeed the growing opinion of the Coalition government, for the majority of people in this study, being on IB was certainly not a choice. Poverty and insecurity was a harsh and unavoidable reality for some, particularly in the case of people who were living alone and managing on IB as their sole income. The extract from Shaun's interview below indicates this perfectly:

*It's a case of having to make me money last and stretch it out but I've lost so much through this. Living on benefits might work for 2 people but it's not like that for me on me own. I mean at £6,000 a year that is not enough for someone to live on when they've been severely injured like me. £86 a week is not enough. Yes I get me rent paid but every penny counts to me. It's difficult, I've got bank loans as well from the life before I broke me back. I mean sometimes I go three days without nothing to eat and even then I'll only have one meal a day. And that's genuine. I live on water.*

Yet Shaun's experience was unfortunately not an isolated example. Ray, 53, an alcoholic who suffers from mental and physical health problems and lives alone, says:

*Being on Incapacity, you can't afford little luxuries anymore. I used to like having steak for me tea, I can't afford that now so it might be beans on toast or something like that. When you're working you can treat yourself to things like that, but now it's just getting by, day to day.*

Yet having a partner did not necessarily safeguard people from the threat of financial hardship. For example, Sandra and her family also had to face the financial reality of being on IB:

*I can't help out much with the household bills and we've had some really bad times a few years ago. At the time we couldn't pay our bills and we got in so much debt, we couldn't pay the bills I mean we managed the mortgage cos I sold my car and my jewellery, I got about £800 for it which Chris had bought me all over the years but it paid the mortgage until we got back on our feet and when our daughter bought that little car she said I could use it. I mean...saying we didn't have enough money for a pint of milk and we're living here but it was true...my sister was wonderful, she'd send £50 down in a card and she's even slipped me £300 when she's come up to see us. I must owe her about £2,000 and she says don't worry about paying it back but I do want to.*

Kevin and Jennifer, a married couple both receiving IB, spoke to me about how they both depend on IB for their joint income. Kevin, 56, a former Army recruit and taxi driver, says:

*Actually going from work to sitting around the house it's horrendous, all you can do especially when you're disabled is just sit. I try and go shopping to keep meself busy*

*but you can't do that every day cos we don't have enough money coming in for a start. The biggest difference is of course lack of money cos when you've both been working and then you're on the system it's not as good as a wage.*

Jennifer, Kevin's wife, says:

*That's why they've got us that (mobility scooter) cos it's not doing his health any good but I mean me son and his wife have been really good, but I don't want to be a burden to them. But I need to have something to do otherwise I'd go crazy so I do a bit of light dusting. I mean it kills us cos I'm in this house 24/7 and it's because I suffer with panic attacks as well. Terrible. If I go somewhere and it gets packed he has to get me out so if we go down the town it's early on a morning. But yeah I deal with a lot but we just get on with it don't we, some days I go upstairs and have a good cry cos I'm that frustrated at not being able to do what I used to do.*

These extracts all illustrate that receiving IB is far from the cosy, comfortable lifestyle of benefit receipt we are so often portrayed by the government and the media. Constantly presenting the public with these assumptions results in further stigmatisation and prejudice against sick and disabled people, further marginalising them. What's more, welfare reform means that there is a risk of people's health status changing overnight, despite no actual change in their circumstances. For example, following a WCA, someone can be found 'fit for work' even though their health has not altered, thus creating further obstacles for sickness benefits recipients to face when we consider stigma and identity. This notion will be further interrogated in Chapter Seven.

## **(Re) constructing narratives of identity and stigma**

Showing resilience and resourcefulness, participants used various means by which to negotiate identity. Emerging as significant themes, these resources and strategies were employed to strategically protect and preserve identity - constructing new dimensions of self; validating their illness; and pursuing aspirations are described and discussed below. Although separated for analytical purposes, they are not mutually exclusive.

### ***Constructing new dimensions of self***

It is important to reiterate that the categories of 'sick' and 'disabled' are not synonymous. If someone is registered disabled, it does not automatically mean they are sick, or that they, too, receive sickness benefits. Indeed, as David Gibbs (2005: 196) argues: *'it seems absurd to expect that one concept, like 'incapacity', could cover both'* [disability and illness]. There are 3.2 million people receiving DLA and 1.2 million of these claim sickness benefits (HM Treasury 2009). People can receive DLA and be employed simultaneously. Roulstone and Prideaux (2012: 156) note that in the late 1990s, a moral panic became attached to the growing numbers in receipt of DLA. This could be linked to research evidence (Beatty *et al.* 2009) that was beginning to point to a growing overlap of IB and DLA recipients - 1.25 million adults by 2008. Although the UK benefits system had never outlawed this mixing of activity and inactivity benefits, suspicions were often raised in the welfare system where these were straddled and work or IB was combined with DLA. Notably, official research conducted for the DWP established that those claiming sickness benefits and DLA were older claimants likely to be further away from the labour market (Roulstone and Prideaux 2012: 163). Clearly, therefore, sickness and disability can and should be understood as separate yet overlapping categories, and for the people in this study, an acceptance or

rejection of a disabled identity was a key theme in the narratives. For example, Kirsty, age 33, found it difficult negotiating a disabled identity following her accident at work:

*I found it very difficult to accept that I had a disability cos I've always been fiercely independent, I've never kind of asked for help before it wasn't in my nature and to have to ask it was tough but trying to quantify being disabled was difficult, it was something to get your head round and I still don't think of myself as disabled, I'll still call it an injury rather than a disability but I suppose one day I might have to.*

What separates disability from sickness in the narratives presented here is whether sickness or injury was viewed as having permanence. Clearly, Kirsty was keen to reject a disabled identity and disassociate herself from the 'undesired differentness' (Goffman 1963) she believed came with being disabled – a loss of independence, reliance on others for help, and ultimately a permanence to her condition.

Certainly, according to Goffman (1963: 41), the pressure of idealized conduct is most clearly seen in marginalised people, who are viewed as 'discredited'. Goffman (1963: 47) further explains that the emphasis on idealized, normative identity and conduct limits the ability of the 'discredited' individual to achieve full acceptance by the population that he or she is forced to be engaged in – as is the case for Kirsty and others here. Indeed, Beauchamp-Pryor (2011) remarks that during the twentieth century the medical profession dominated the lives of disabled people. Disability was viewed as a personal tragedy, reflecting deeply held assumptions about 'normality' and 'abnormality', in terms of the worthiness and worthlessness of disabled peoples' lives. Terminology and the labels that society gives disabled people affect not only the way disabled people are perceived, but also how they perceive themselves (Zola 1993). The following extract demonstrates how

Kirsty was labelled '20% disabled' following an Industrial Injuries Disablement Benefit assessment:

*You go through the same medical then they decide what percentage disabled you are. They class me as 20% disabled because it's only one arm and my neck that's affected, they don't look at how much of your life is affected. Disability Living Allowance looks at how much your life is affected by your health, where Industrial Injuries looks at how much of your body is affected if you like so I'm classed as 20% disabled on that...when you think about it, it is weird because it's something that does severely restrict me day in, day out but to be told I'm 20% disabled...but at the time I was actually really annoyed I was disabled at all.*

The dominance of a distinctly medicalised view of disability is strikingly apparent here as Kirsty is struggling with the administrative label of being classed '20% disabled'. Mick's experience was similar to Kirsty's in that initially, he was expecting to recover. When asked if he saw himself as disabled, Mick said:

*It's a good question I see meself as I was but with sort of a painful condition but not as a disabled person even though I am, sounds mad but your identity from being an able bodied person, running around cracking jokes and being a normal member of society to suddenly you've got something wrong with ya it does take a lot to contend with, it does. And I know when I meet people, professionals or just new friends or whatever straightaway they ask what's wrong and I think 'I wish I'd put it on a laminated card or something' saying exactly what happened cos invariably they think it's short term, they think it's a broken leg or something. They're just asking out of politeness or curiosity but you have to say 'I'm permanently disabled, on crutches blah blah blah end of story' and that's sort of...it's not irritating but*

*again your identity they perceive you as a fit and able bodied person but no, I'm permanently on crutches.*

Many participants had a distinctly medicalised view of disability, which included a wheelchair, guide dogs, white sticks and missing limbs. Caroline, 46, told me that she suffers epileptic-style fits but was as yet undiagnosed. She believes that the medics she has dealt with did not believe she was genuine: *'I get the impression that they thought I was pretending to be ill'*. As Charmaz (1983) remarks, when the patient does not display any external signs of illness and tests do not show abnormal results, a caregiver, for example, a doctor, may regard the patient as someone who is simulating illness or is mentally ill. Caroline says:

*To somebody who doesn't know me, I just look like a normal person...someone who's in a wheelchair or who's been injured in some way y'know if they've only got one arm or one leg, if someone is blind they've got a guide dog or white stick you can tell they're not well. Other people might think well what's wrong with her for her to get that (IB).*

This enacted stigma felt by Caroline led to her not revealing to anyone that she claimed IB, as she felt wary that others, too, would discredit her. What is further important to note that stigma often implies a separation of 'us' from 'them'. This separation easily leads to the belief that 'they' are fundamentally different from 'us' and that 'they' even are the thing they are labelled. 'They' become fundamentally different from those who do not share a negative label, so that 'they' appear to be a completely different sort of people. For example, it is common to say someone is a 'schizophrenic' instead of saying 'a person with schizophrenia'. For physical illness, things are often handled differently and people usually say a person has arthritis. The person afflicted with arthritis remains one of 'us' and

has an attribute, while the 'schizophrenic' becomes one of 'them' and is the label we affix to the person. In this way, language can be a powerful source and sign of stigmatisation (Rusch *et al.* 2005: 530). For example, Sandra comments:

*I don't see myself as disabled, I'm not in a wheelchair I have two arms, I have two legs and I can see, and that's another thing I feel guilty about - I'm on Incapacity Benefit cos of the problems I have, not cos I'm disabled. Because I've got limbs and I'm not strapped up people think there's nothing wrong with her. Like people with mental health problems I always thought 'Deal with it' until I fell down with it.*

Marian, 45, suffers from arthritis and mental health problems following a nervous breakdown, spoke of what disability meant to her:

*I've never really thought of meself as disabled, I class it more as an irritant but I know I'm registered disabled. But to me disabled means that I've got me legs amputated or you're permanently in a wheelchair cos you're paralysed and no disrespect to those people but I can still get around most of the time.*

Other such as Sue and Martin did identify themselves as being disabled. Their decision to accept the label was explained by the fact that they are no longer to do 'normal everyday things' for Sue and for Martin, the acceptance of a blue badge for his car. Sue said: '*Yeah I probably do see meself as being disabled cos you're not doing normal everyday things that other people who are perfectly alright do*'. The following extract from Martin's interview illustrates his feelings:

KG: *We spoke before about being disabled - do you view yourself as being disabled?*

MC: *This is a hard one, I have a blue badge...the answer to the question is yes but I see people worse off than I am, I can still hobble around, I'm not confined to bed but*

*yes that was a hard one when the disability badge arrived in the post it was like 'This is it now'.*

The dominant discourse in the narratives failed to recognise disability as a desired differentness, which can be core to an individual's identity (Wendell 1996). Indeed, the only time the identity of 'disabled' was accepted was in instances where people had to class themselves as disabled for official reasons; for example, when claiming for certain benefits or applying for a disabled badge for car parking. As Kirsty states below:

*I really don't like referring to myself as disabled I must admit, I don't but I am and y'know when it comes to official things I will use it but in every day conversation I always refer to it as an injury. But that implies it'll get better and then you have to go into the whole spiel of when people question you.*

What is most worrying here is that people feel they need to present themselves as 'disabled' in order to guarantee they will receive ESA following their WCA. Accepting a new identity and label of 'disabled' was something that was particularly hard for most participants, yet there was an underlying opinion that portraying a disabled identity would be beneficial when it came to undergoing a medical assessment. In turn, this could have a negative effect on a person's future chances of seeking employment or training, as they have had to accept the label of 'disabled' for a certain length of time. This is further illustrated by Jacqui's comment on referring to being on IB:

*I don't think you have any freedom mentally from it, you're claiming that and it just makes you feel more disabled than you actually are.*

As Finkelstein (1991) has pointed out, the dominant form of oppression of disabled people shifted from the medical 'cure or care' model to an administrative model which focuses on maintaining dependency upon able-bodied people to 'administer' the solutions. Clearly, for

many participants in this study, the social model of disability was not something they were familiar with. Instead, a deeply medicalised view of disability was apparent in the narratives, perhaps reflecting their exposure to power relations; for instance, Kirsty's experience following her assessment reinforces a medicalised view of disability that assigns a certain percentage to her disability.

Particularly for people who had experienced an accident at work or elsewhere, such as Angle, Kirsty or Tony, coming to terms with the fact that their health would not just return to 'normal' was a huge barrier to contend with. Just as there was an avoidance of accepting the term 'disabled', the stigma of being on IB could be so overwhelming that people refused to admit they were receiving it. In some cases, interviewees refused to reveal their 'claimant identity' to close family and friends, and would even avoid social situations to avoid being asked the dreaded question: 'What do you do?' For Sarah, a 52 year old who has battled with mental health problems all her life and is now dealing with a range of physical health problems such as arthritis and Reynaud's syndrome, being on IB is highly stigmatising:

*I make any excuse to not to go a party, not that I'm invited to many but at church it might be someone's Golden wedding anniversary and if I go and there's people I don't know and they ask me what I do, what do you think I say? I say 'I'm a piece of shit' What else do they want me to say? I say 'I'm one of the dregs of society, I'm one of the ones wasting your tax'.*

Similar findings were reported by de Wolfe (2012: 9) in her study of people with myalgic encephalomyelitis (ME) who were receiving sickness benefits. Nine of her 23 participants also reported concealing their status as claimant from friends and neighbours. Sometimes this was related to being a claimant, sometimes due to the fact they were not working (as

opposed to being a claimant *per se*), and sometimes as a result of the belief that, as ME patients, they would be particularly liable to be regarded as scroungers.

Sandra's story is another clear example of the stigma experienced as a result of being on IB. Sandra had a car accident 20 years ago which led to back problems which have caused her pain ever since, and she also suffers from severe depression. Previously a factory worker, she also worked in pubs on an evening as she enjoyed working. Sandra has claimed IB for 13 years but nobody other than her husband and the relevant authorities know about it. Her two adult daughters, 21 and 25, do not know, nor does her sister. Sandra says:

*She'll (her sister) say 'You must be able to get this' and I'll just sort of change the subject cos I am so ashamed, I really am ashamed. I mean when I went down to the Jobcentre thing that took a lot of guts, I thought what if I know somebody, what if somebody sees me? To be honest it's like a rope around your neck, it's horrible that I'm not earning my own money - it's dreadful.*

Asbring and Narvanen (2002) studied women with chronic fatigue syndrome (CFS) and fibromyalgia and found that they, too, concealed their sick identity and shied away from friends, family and others who may have previously reacted negatively towards them.

However, concealing a sick identity can be problematic when thinking about welfare reform. People may fail to sustain this display at benefits assessments, and, to their detriment, slip into a more customary mode of being able to manage (Donnison and Whitehead 2009: 22). For example, Angie, 50, does voluntary work following a car accident she was involved in which left her with a variety of physical and mental health problems. Angie says of being on IB:

*I wouldn't tell anybody, people don't ask so you just don't say, do you? No, no I don't say. The people who have to know it, know it but anybody else, no way. I do me voluntary work, and see even that isn't that terrible, if people say 'What are you doing with yourself?' I say I work for the charity, I didn't realise I do that until now telling you about it but yeah that's what I say, I don't say 'I'm on Incapacity'. I wouldn't say that, I would never mention DLA or Incapacity. And what has it go to do with anybody? I didn't ask to be in the accident, I would have rather have the life I had before.*

In *Asylums* (1961: 123) Goffman terms this transition the 'prepatient phase' whereby individuals are coming to terms with the reality of their changing circumstances, indicative of the narratives of Sarah, Sandra and Angie above:

*Coupled with the person's disintegrative re-evaluation of himself will be the new, almost equally pervasive circumstance of attempting to conceal from others what he takes to be the new fundamental facts about himself and attempting to discover whether others, too, have discovered them.*

Clearly, stigma and shame were strongly linked to receiving IB and experiencing illness in participants' narratives. Controlling information means deciding not only which people can be given information about the illness but also how much and what information they are given.

However, identity could also be perceived in a more positive, uplifting way. Gradually, Mick was able to adjust his identity and begin to present himself as a foster carer instead:

*When I first came out of work me self esteem was low and I started studying and it gradually built up. But I remember feeling conscious when the other students were*

*introducing themselves and it would come to my turn and I'd say 'I've recently lost me job, on benefits' but now first and foremost I'd say 'I'm a foster carer'. That's another part of the identity and introducing meself as a foster carer it's a brilliant thing we're doing and something to be proud of. I feel more confident now about projecting me identity and yeah I do get a bit down who wouldn't so I suppose I do suffer a bit with me self esteem and its crazy I'm nearly 45 year old but things like that do affect ya it's funny yeah.*

For Laura, following her nervous breakdown which led to her leaving her teaching job, being on IB did not result in a negative identity:

*I think maybe if somebody has had a less meaningful job without making that sound superior, I would say that if you'd had a less meaningful job then maybe I could understand that but after teaching for 30 odd years I do actually feel as if I have achieved something. I'd kind of say I'm a retired teacher...well maybe semi-retired, until I actually get my pension I'd say semi-retired.*

Instead of a negative, discredited identity, Terry identifies as a 'survivor' when speaking about his experiences of bipolar disorder:

*The way I look at it I'm a survivor y'know? Many a bloke would have ended up in jail, or dead. I was a drunk as well y'know, I used to drink a lot but I don't drink now, I don't touch the stuff.*

For Terry, finally being diagnosed with bipolar disorder actually made him feel 'relieved' as he finally had a name for the condition he'd battled since he was a teenager. Here, the positive consequences of receiving a diagnosis often outweigh the negative ones (Cooper 1997). This was the case especially with those who had felt themselves being stigmatised to

a great extent, even if it can be difficult to erase a stigma that has already become integrated into the identity (Woodward *et al.* 1995).

### ***Validating illness***

'Looking ill' and appearing to be genuine was a theme that was littered throughout the interviews; perhaps unsurprising given the continued questioning of sick and disabled people from the media, the government and the wider public. Mick spoke of how 'visually' it was important for him to prove his condition was in fact genuine:

*I worried if they'd think I was genuine, I remember one of the awards nights and I showed them me scar on me knee and I felt that was important. I know it sounds crazy but I'm not in a wheelchair or anything so to show them that scar visually I dunno in me own mind that was important and I'm well known in the community as well and it does bother us wondering if people think I'm genuine or not - it's crazy.*

Importantly, for Kirsty having physical proof of illness or disability meant the distinction between feeling stigmatised or not:

*There is the stigma and I think if you've got a hearing dog, a stick, if you've got something people can see that stigma is taken away, it's the invisible problems where people just assume you're lying. But there's a lot of us who are genuine and we get tarred with the same brush.*

On the other hand, sometimes participants would choose to disguise visible manifestations of ill health. For example, Shaun spoke of how he would hide his walking stick because he did not want his neighbours to judge him for using a stick yet being able to drive his car:

*No matter how much pain I'm in I always walk to the car unaided, I keep all my sticks in the car because I don't want people to see my sticks and think 'Oh, what's the matter with him?'*

Additionally, several participants felt guilty about engaging in activities that were perceived as 'enjoying themselves', wishing to behave in ways congruent to being ill. This is hardly surprising given the onslaught sick and disabled people can face in the media for daring to attend a theme park or use a water slide, for example. Fluctuating conditions may allow for behaviour such as this, as people report having good days and bad days so may have felt able to go on a rare family day out on a good day.

Other identities were taken on, such as carer, mother or even member of staff, which took their mind off their illness, made them feel 'needed' and motivated them to keep going. This allowed them to suspend their illness identity temporarily, but once these roles disappeared they returned to an ill state, a finding also found by Millward *et al.* (2005). This can be linked to the varying stigma towards physical and mental health problems. In research on healthcare practitioners attitudes towards mental health problems, clear messages that they had 'better' or 'more constructive' things to do with the scarce healthcare resources of time and money, such as looking after someone who is 'really sick', 'more deserving', who has not 'brought it on themselves' (Bailey 1994; Happell 2005; Thornicroft 2007). For Byrne, stigma seems to exist in every area of life for people with mental illness and represents a major barrier to effective rehabilitation and reintegration of these patients. A qualitative study of women with chronic fatigue syndrome (CFS) and fibromyalgia revealed that they felt stigmatised by others who tended to doubt the truthfulness and accuracy of their reported symptoms, question their morality or character, and ascribe their symptoms to psychological causes (Asbring and Narvanen 2002). Further,

Looper *et al.* (2004) argue that increased disability may lead to perceived stigma to the degree that it interferes with social interactions or makes the illness apparent to others.

Chronic illness can have various potentials for stigma depending on the character of the illness and on how people generally regard the illness in question. The potential for stigma increases from short-term acute conditions, such as influenza, to long-term illness, such as multiple sclerosis and mental illness (Field 1976). Stigma has been studied in relation to mental illness (Wahl 1999), various chronic conditions such as HIV/AIDS (Bunting 1996), epilepsy (Scambler and Hopkins 1986; Schneider and Conrad 1980), diabetes (Hopper 1981), and stroke (Hyman 1971). Participants in this study talked about the stigma of living with a health problem. For example, Sue, 50, spoke to me about going for a day out at a nature reserve with her husband. She said:

*I had to keep stopping all the time, and people are looking at you and it's like – yes, I've got a problem but you don't have to keep staring at me like I'm a moron, and that makes me think I don't want to go out. Why should people look at me and think - 'Look at her, she can't do much'?*

Kirsty described the enacted stigma she experienced at having to persuade her GP to take her pain seriously, which left her with immense frustration:

*It took a long time to get referred to see a pain specialist cos my GP kept thinking it was whiplash and saying it would ease. It wasn't till I had a bit of a meltdown with her and said 'Look I'm sick of people telling me I shouldn't be in pain, please just see why I am rather than telling me it shouldn't be happening'. With chronic pain they question you - if I was missing a leg not a problem cos they can see it but with chronic pain, it's subjective.*

Indeed, Newton *et al.* (2010) observe that the experience of being disbelieved is stigmatising. Episodes of stigma that have occurred can be described as enacted stigma, whereas an experienced stigma originates from the feeling of shame that accompanies having a certain deviancy and the fear of being exposed to enacted stigma (Scambler 1984). Below, Fred, who used to be in the Army and has 'worked all of his life' until polyarthritis set in throughout every joint in his body, speaks about the stigma he feels due to being on IB. For Fred, stigma is related to a particular moment in time; that is, whilst in the Army his sergeant used to describe sick people as 'lazy':

*God, definitely it does pray on you, he used to call us lazy, the sick parade. I think people maybe of my generation there is a definite stigma attached to being on Incapacity. Because of the stigma from the Army, I shouldn't be down sick. It's that damn mindset and I've spent the last twenty odd years trying to break it. If you are on it, you're a scrounger. It doesn't matter if you've worked for the past 20 years then – bang! – it's scrounger and this flaming stigma, people find out you're on Incapacity Benefit and you just get looked at as through they're scraping you off the bottom of your shoe.*

Overall, it is evident that a high level of stigma, shame and fear are present throughout interviewees' narratives. Yet the transition onto IB was not always experienced as being so problematic. The following section highlights how pursuing aspirations can represent a positive identity shift for long-term IB recipients.

### ***Pursuing aspirations***

Negotiating illness does not necessarily result in only negative 'biographical disruption'. Some studies (Ware and Kleinman 1992; Ware 1998; 1999) have focused on the social consequences of the illnesses and the strategies developed while coping with them.

According to Ware and Kleinman (1992), illness can be a catalyst for change in social life. Fifty per cent of their sample declared the illness experience, although painful, to be ultimately positive. For Asbring (2001: 317) approximately 80% of the women in this study described new insights in terms of illness gains. Nearly half of the sample explicitly stated that their illness experiences had even had positive aspects, such as increased self-respect and personal integrity. They had in some regard transcended their illness experience and created a new and more favourable identity than before. This sentiment can be found in the narratives presented here. For example, for Tony, 59, who had a motorbike accident which led to him leaving his long-term job on the oil rigs, being positive was the only way he could cope:

*When I came out of hospital I just basically started from scratch again just building myself up. And now I've got the Rav 4, I've got me bike back, I've got me own little place even though I don't own it it's still my own little place, I've got a new partner, I've learned how to play the saxophone so yeah life's good. You can sit on your backside and whinge all the time or you can get up and do something about it.*

As Mick's story has shown throughout this chapter, creating a new identity as not only a foster carer but also forging a new career as a social worker were key aspirations for him:

*Thinking about a new career, I'd done manual work but I couldn't do that anymore. We'd started fostering in 2005 a year before I left me job and we've had some great social workers and some terrible ones and I thought 'I could do that'. I mean I did me level one course and I got a distinction I was like 'Wow I can do it' cos I'd never studied since leaving school. I was so proud I was literally in tears but I think I'm gonna get a 2:2 which for me is absolutely phenomenal, but I dunno I aspire to better meself, I don't want this to stop us in me tracks.*

Indeed for Jacqui, having to leave work following an accident meant that she was able to pursue a new career as a self employed children's costume designer. When asked about her hopes for the future, Jacqui says:

*I'll be rich put it that way. If I can get this back sorted out there's no doubt about that, I'll be living quite happily. I'll definitely be in a better place than I am now. I have goals and I have dreams but in five years time you won't be coming to visit me here, I'll be in a new house, the lot.*

Clearly, for Tony, Mick and Jacqui, becoming 'incapacitated' allowed them to evaluate their lives and follow different goals and aspirations. So why did some people narrate a positive identity whilst others did not? There are no common themes in the chronic health conditions – Tony had a motorbike accident, Mick suffers osteo-arthritis and Jacqui injured her back at work. Perhaps it can be linked to wanting to provide the best for their families – this was certainly a defining reason for Mick who stated: *'I didn't wanna give up and I feel strongly that I'm a role model to me children as well and I didn't wanna be sitting around watching Jeremy Kyle'*. In Jacqui's case, she spoke of wanting to contribute to the household for her husband and for her own self worth. Finally, for Tony, the adoption of a positive identity could be attributed to the fact that he feels he now has a second chance following his accident therefore he is resistant to sitting on his backside and whinging, as he put it.

### **Chapter Summary**

As the research objectives outlined, it was important to uncover the day-to-day lived reality of being a long-term IB recipient; something that is largely absent from current academic literature. This chapter has explored how people perceived and managed becoming 'incapacitated' – beginning with how the transition first occurred. The transition onto IB

was made in three ways – people had grown up with health problem; people had become ill gradually, usually whilst working; and finally, people who had experienced a sudden accident or illness, again usually whilst working. Next, the chapter examined the key changes that people identified as occurring when they began receiving IB, with an emphasis on identity formation and reformation, alongside a consideration of how stigma features in the narratives.

An overarching theme that emerged from the narratives was one of a life ‘before illness’ and a life ‘after illness’. Becoming ill did not just result in losing a job: it could mean losing a wife, home, friends, independence, confidence, identity and a sense of self. The findings show that many people described a daily routine filled with feeling guilt, boredom, restlessness and frustration at not being able to do the things they used to be able to do. Yet on the other hand, in some instances becoming ill or more ill and departing from the labour market allowed, or indeed encouraged, people to pursue a different career path or a hobby they had previously not had the chance to take up. The chapter illustrated how participants negotiated changes to their identity in varying ways- constructing new dimensions of self; validating their illness; and pursuing aspirations. Health and illness narratives revealed severe hardship; particularly for people who were living alone and only had IB as their sole income. Crucially, the chapter highlighted that government rhetoric and media portrayal of IB recipients as happily living a cosy, comfortable lifestyle is a myth for IB recipients in this study. In line with other research, the study has shown that a life lived on benefits is a relentless struggle (Shildrick *et al.* 2012; Shildrick *et al.* 2010).

Overall, in most cases, dealing with stigma was a daily consideration in the health and illness narratives of participants. This stigma is tied into an endemic media and government rhetoric that regards sick and disabled people as suspicious, untrustworthy and faking it. What this chapter has highlighted is that long-term sickness benefits recipients are not

solely defined by their illness or disability; the term 'incapacity' masks a whole range of realities; for example, pursuing new aspirations and goals allowed some participants to evade the negative connotations attached to being on IB for many participants. Instead, new identities were created that included learning new leisure skills, following different career paths and accepting their new identity.

## CHAPTER FIVE

### SOCIAL NETWORKS, COMMUNITY AND IDENTITY

Kirsty, 33:

*"I used to have neighbours coming in checking on me, making me a cup of tea and it's mortifying, it's really hard to deal with. I used to get really angry and frustrated about it and not want any help at all. I used to just stay upstairs with a bottle of water and a kind of readymade...like a few packets of crisps and a sandwich and that would just tide me over during the day until he was home. I just used to live upstairs when I was having bad days. But I've got a good support group with my friends which is important I think, without them I'd probably go barmy. It was quite surprising when I allowed people to help me, I was amazed at how much people help you out cos at first I wouldn't have any help. I didn't want to let my accident change my ways cos I used to walk up to the supermarket and come back with 5 or 6 bags of shopping in one go, so rather than accept a lift I'd spend all day going up and down, getting two or three items at a time just out of pure stubbornness - there was no way on earth I was allowing it to affect me. But then I put my hands up and said I couldn't do it anymore and I was overwhelmed by how much my friends were willing to give."*

## **Introduction**

This chapter focuses upon the importance of social networks, community and identity in the narratives of the long-term IB recipients in the study. This chapter will show how important social networks are – beginning with the social side of employment and its relevance in the narratives. This discussion will be followed by a consideration of how family, friends, and also medical professionals and practitioners play a key role in the narratives of IB recipients. In one way or another, all participants spoke of the importance of friends and family within their narratives whether this was in a positive or negative way. In addition to these relationships, many indicated that the role of professionals, such as GPs or Jobcentre Plus staff, was also considered to be important in shaping people's experiences of illness and IB receipt. Finally, the chapter focuses upon the importance of place. As Chapter Two demonstrated, the County Durham and South Tyneside areas are renowned for their high numbers of IB recipients when compared to the rest of the UK. The chapter will highlight how place can impact upon participants; for example, in terms of proximity to social networks, job opportunities, transport, and lastly how stigma can be linked to living in particular areas.

### ***Missing 'the craic': the social side of working***

The following section explores the importance of social networks for IB recipients beginning with a discussion of the significance of work as a way of providing a social identity in their narratives. The social aspect of work was described as being incredibly important for participants, and something that was hugely missed following their transition onto long-term sickness benefits. Jennifer, 56, said: *'I would love to work, it's like you if it happened to you you'd think 'I'm stuck what am I gonna do?' I bet when you have holidays you get frustrated and want to be back at work. Its social, socialising and we haven't got*

*that no more*'. Talking about the importance of work to her, Linda was enthusiastic about how 'the craic' of working in a factory was appealing to her:

*It was very important, I loved it. The girls, the craic, we had a hell of a laugh. Music on all day, singing, dancing, carrying on it was one big laugh from start to finish. There's nothing like working in a factory I loved it, it was a blast. As long as you got your work done it didn't matter what you were doing, as long as you kept that line going. I loved it.*

Angie's interview revealed a similar sentiment. For her, work was important due to the social aspect that came with it:

*I loved to work. I worked in the doctors we were all friends I had meals out, things like that. You know what it's like, you work. We used to go to London together things like that and you lose everything, you lose your friends, you lose your job which I loved me job, I love people working with people and I just loved it all I really did.*

The seminal work of Jahoda *et al.* (1972) must be mentioned here. They studied Marienthal in Austria, a prime site for the study of unemployment in 1930. Marienthal was a town that had depended almost entirely on one factory to the extent that its closure was followed by almost total unemployment in the town (Jahoda *et al.* 1972: 3, 20). The Marienthal study stands as a landmark piece of research by going beyond describing the conditions of the town's inhabitants and developing social-psychological theories of response to unemployment that were premised on a theory of human nature. Unemployment meant a state of deficit in relation to a set of 'enduring human needs' that are provided for by paid work (Jahoda 1982: 60). Unemployment takes away shared experience; a structured

experience of time; collective purpose; status and identity; and required regular activity. The problem with unemployment is not the lack of resources as such, but the deprivation of the legitimate means by which resources are secured by employed people and the demoralizing effect this has on people *'in terms of a series of lacunae associated with a state of non-working'* (Walters, 2000: 85).

Whilst work was viewed as important for many participants, for others it was not a main priority. The key reasons behind this were linked to wider concerns regarding health and the physical or psychological limitations their health placed upon them. Terry, who is diagnosed with bipolar disorder, says: *'I couldn't handle a job, I couldn't take one on...it wouldn't be fair on an employer and it wouldn't be fair on me, y'know'*. Laura, who had worked as a teacher for all of her working life, implied that although she had considered returning to employment, she was worried how the stress could affect her:

*I have thought about it, I have actually thought about it about going back to teaching but then I don't know. So I dunno, I've thought about it, I've thought about doing invigilation and things like that. But I don't know whether I want to go back to a full time job, I'm actually frightened if I went back to that it would make me ill again. I'm in a position where I don't really need to work and I've told the doctor and he advised me just to stay as I am cos I do have these momentary flips and the assessment said I should just stay as I am so basically I'm doing as I'm told now. I've also had about three interviews from the Jobcentre and they actually said there wasn't anything they could do for me anyway.*

Although Sue described how work was important to her, what was infinitely more important was being able to complete simply daily tasks that she used to take for granted. She said:

*I would love to be in the situation where I could do something for a job but I couldn't sit for long y'know what I mean, I couldn't stand for long periods so I honestly don't know what I could do. Me own grandbairns come and I cannot do things with them, me granddaughter will sit on me knee and have a cuddle and I'll read to her but me husband will do loopy things with them like chase them around and I just think it would be lovely to do things like that, let alone work y'know?*

This point by Sue leads on clearly to the significance of friends and family within peoples' narratives.

### **Friends and family**

The importance of friends and family was a common theme throughout the narratives. Whilst for some, the support of those in their social networks was crucial in terms of their daily coping, for others friends and family were not an important part of their narratives, as was the case in the research of Gallant *et al.* (2007) on family and friends in relation to chronic illness management. In certain circumstances, friends and family were shut out by participants who wished to keep their health and illness narratives to themselves, sometimes in an attempt to spare their loved ones the true extent of their suffering. The following section explores the importance of friends and family in terms of caring responsibilities and how these social networks can alter with the onset of health problems or disability. How this impacts upon social identity for long-term sickness benefits recipients will also be reflected upon.

### ***Caring and being cared for***

On the whole, participants did not speak of caring responsibilities for others. Two notable exceptions were Joan who cared for her niece, and Jennifer and Kevin who were married

and both disabled. Joan described how caring for her niece was difficult given her health problems of arthritis and fibromyalgia:

*I look after Gemma as well she has cerebral palsy and her sight's going now, she's been with me ten year, she's me sister's daughter we've applied to put an extension on the back of the house for when her eyes do go. It's hard having to try and keep meself right as well as looking after Gemma, but she's got support workers they're brilliant and we just take every day as it comes.*

Jennifer and Kevin both found themselves out of the labour market and on long-term sickness benefits. The following extract shows their frustrations at their situation and how it affected their relationship:

*KM: I looked forward to working cos I loved work, I'm a people person and me and her sitting in the same room for too long we end up arguing. Being stuck in here all the time it causes friction and thats the biggest downfall of both of us being disabled*

*KG: What's it been like for you both having to deal with health problems?*

*JM: It's so frustrating cos right up until I was 40 I used to cycle all over on me mountain bike, we used to walk all over but since it started it's just been a slippery slope cos like him I'd love to go out and work and have a life again, meet people. You used to get invited to things, girls nights out but I haven't got none of that no more, y'know the social side, that's why I get so depressed and so angry at times y'know but I would love to go out there. I can't understand how anyone can sit in the house and not want to work and with just having him to talk to, you get fed up of each other. You've said everything, done everything and you need a break from each other*

*KM: Most of the things we do, we do together anyway so we've got things to talk about in that way. But basically our life is boring cos we don't have anything to talk about.*

Various commentators have discussed how families can experience emotional strain when family members face illness or disability. This strain can be a result of physical demands, uncertainty, fear, altered roles and lifestyles, and financial concerns, together with the need to provide support (Ell 1996; Thompson and Pitts 1992). Alongside the upheaval of trying to adjust to life with a chronic illness or disability, participants spoke of how their relationships with friends and family altered. Increasingly, participants became more dependent upon those in their social networks which caused strain and embarrassment for those suffering with their health problems. The idea that a reliance on others was somehow diminishing one's own independence, and therefore identity was found in Jacqui's narrative. She said:

*It's the independence isn't it, I don't like depending on anybody. I know it's a unit when you get married but I'd like to put something into it. I know you get money from that [IB] but to me it's not money you've earned'.*

As Charmaz (1983: 187) explains: *'When inability to function occurs, the defeat they experience may become more of a burden to the caregivers than the actual physical care. The pathos of the ill person who cannot accept dependency permeates the existence of the caregivers'*. This notion was also present in Sue's story, below:

*The hardest part is getting people to do stuff for us cos I was so independent, I would be the one that done everything for everybody else not the other way round and its took us a long time, like when me friends come round and I say I'll put the kettle on and they're like 'Oh no you sit here we'll do it'.*

## **Bereavement**

Research in disadvantaged communities in Teesside has explored how bereavement was a common experience for research participants, many of whom had suffered multiple bereavements in quick succession (MacDonald and Shildrick 2012; MacDonald and Marsh 2005; Webster *et al*, 2004). Laura spoke of how multiple bereavements in her family were the beginning of her mental health problems and subsequent breakdown that led to her leaving her role as a secondary school teacher:

*I think maybe looking back I'd been stressed and quite depressed for a while but I suppose over a period of about 3, 4 years I had a lot of deaths. My father died suddenly on October 19<sup>th</sup> then about two years later on October 18<sup>th</sup> me mam's uncle died from a heart attack. The year after on October 13<sup>th</sup> my grandfather died from a heart attack so come that week in October I'm paranoid. I was going to a crematorium for a funeral then for a remembrance service. It just seemed to be like a few years of that then my grandmother wasn't well and she died and then I got this problem with my neck. I'm not blaming that to set it off but I think it was a series of events that had gone on and on and I was just doing far too much.*

Similarly, Mick described how something his father said spurred him on to pursue his goals following his exit from Nissan:

*After I left Nissan me mam died of terminal cancer, a difficult time and I remember at the funeral me dad saying 'If he loses his job at Nissan that's him finished' and I remember him saying to people 'That's him finished' and...he's an alcoholic he's got his own problems and things but when I heard him say that I thought 'No, I'm not finished' so that was another spur but it was reinventing the wheel and moving on to something else.*

## Social networks and Identity

Many participants spoke about how their relationships with family and friends had altered following their transition onto sickness benefits, and with this came a change in identity.

When asked about friends and family, Mick said:

*The thing is I do miss socialising a lot, I can't do what I used to do but life goes on, friends come to see me as well, we have a chinwag but that friendship is different. The identity of the friendship has changed cos I can't do the things I used to do with them, the daft things we used to do, play football and we still have the same laughs and things but at work that history of all the daft things that happened, that's sort of slowly evaporating, those stored memories. I've got loads but I'm not creating new ones so I miss that as well y'know. Sort of a little bit of loneliness at times, you'll be getting your violin out soon but it is it's slightly lonely as well do you understand that? Even though I've got friends the visits aren't what they used to be. But I'm a very family orientated person and I still feel very valued as a family member. Identity as well within the family unit, I used to do all sorts of things for the family physically which I can't do now but I still support them mentally.*

Interestingly, Mick spoke about his feelings of a loss of self and identity in relation to his friends – he feels things have changed between them. Yet in relation to his family, although no longer able to physically support them, Mick still feels valued and describes himself as a 'very family orientated person'. However, an equally oft told story was one of friends no longer visiting following the onset of chronic health problems. Shaun said:

*I was losing all me friends cos they felt uncomfortable coming round, they felt bad talking about what they were doing cos I couldn't do anything. I decided I didn't want anything more to do with me sister and it was just horrendous.*

Similarly, Martin described how his friends no longer visited him anymore: *'All our friends the only time we saw them was in the club, but now nobody visits us. But I'm quite content because over the years you just get used to it'.*

Others such as Sue and Sandra chose not to share the full extent of their problems with family and friends as they did not want to reveal the true extent of their pain and suffering, alongside the shame they felt due to claiming benefits. Sue revealed how she felt guilty asking her family to help her out so much:

*I think sometimes rightly or wrongly if I'm saying to the family 'Me hands are bad' I think they must think 'Oh she's off again' and I don't know whether they do but I think they must think I always complain. I dunno I've never actually asked them but I'm sure they must get sick of us saying can you do this, can you do that. They shouldn't have to be doing it. Like asking Catherine [daughter] to put me socks on, fasten me bra or put me knickers on up to here so I can pull them up - it's embarrassing. I know she'll do it but she shouldn't have to and that hurts a bit but yeah you just get on with it.*

Sandra described how friends and family can fail to understand the complexities of sickness and disability – something made even more difficult given the fact that Sandra refuses to disclose her long-term sickness benefits recipient status:

*I bumped into a friend who I hadn't seen for 30 years and she asked if I was working and when I said no she was like 'Oh I wish I could be a lady of leisure, I wish I had nothing to do all day' and I thought you haven't got a clue. It's like my sister she works full time and she was on one day and I said I would love to be earning £300 a week, getting a pay packet, earning money I would love to be in her shoes. But like I*

*say they don't understand why I'm not working, they know I have back problems but nothing more.*

Continuing her narrative, Sandra said of her relationship with a close friend: *'I'm like two people cos even my closest friend doesn't know. She asks if I'm ok and I say I'm fine but inside I'm screaming, it's really hard to cope with sometimes'*. Here, Sandra is actively distancing herself from friends and family members as she feels ashamed and concerned about others' reaction to her illness.

This discussion can be furthered strengthened by looking at a case study example of the Washington Men's Health Group. Originally set up through CMP, every Monday afternoon men with health problems in the Washington area meet up to chat, tend to their allotments, plan what courses they would like to do, arrange day trips and discuss any problems they may be facing, whether that may be in terms of health, benefits or something else unrelated. There is also a Facebook group page for members to join and keep up to date with ongoing activities and meetings. At each group, approximately 8 to 10 men attend each week, sometimes more and sometimes less. Of particular importance here is the geographical work of Gesler (1992; 1993) on the notion of 'therapeutic landscapes'. Based on an understanding of the ways in which environmental, societal and individual factors can work together to preserve health and well being, Gesler suggests that certain environments, in this case allotments, promote mental and physical well being. Gesler's concept suggests that specific landscapes not only provide an identity but can also act as the location of social networks, providing settings for therapeutic activities. This certainly fits into the narratives of the three members of the group I interviewed - Shaun, Fred and Ray –with all of them speaking of the significance the group has had in their lives. Fred was referred to the group through CMP almost five years ago. For Fred, the group not

only allowed him to enjoy social activities such as day trips, it was also a source of information and support:

*They may have experienced something I haven't like with the benefits office and they can advise me and I've actually managed to help two ex-soldiers as well just sitting in the cafe talking to them.*

Ray struggled with alcoholism and for him the group was a way of giving his day 'more purpose' and providing a structure that did not allow him to begin drinking at 3pm:

*Ganning to the men's group and doing stuff like this, I think if it wasn't for stuff like this I'd be stuck in the house a lot more. It's given us a bit purpose to get out. Being at the men's group there's a bit purpose cos you're meeting other people as well cos basically at the minute when I come here I'll start me drinking at 5, half 5 and it's trying to delay that. If I'm in the house not doing nowt I might kick off about 3.*

Yet for Shaun, whilst he attends the group regularly, as the chairman he feels pressure to be the one who helps everyone else with their problems; however, as a result he feels his own concerns are being neglected:

*I've got the support group and I tried to talk to them and they said they see me as the one who sorts problems out. It's me strength that's kept me going all these years and I just feel like I'm running out of strength. They elected us chairman and I didn't even want to be elected, so I feel I've got a responsibility now when really I can't face it.*

Again, this highlights how social interaction with friends and family can have either a positive or a negative consequence. As this section has shown, friends and family play an

important role in the narratives of the long-term IB recipients in this study, whether in a positive or negative way. The following section explores how professionals are important when thinking about social networks.

### ***Professionals***

Whilst relationships between family and friends are clearly significant, the importance of professionals was also a key theme throughout the interviews. On several occasions, it was reported to me that GPs had advised that returning to work was not an option. For example, Shaun says:

*I wanted to get back to work but me doctors advised against it. And they couldn't find any work that I could do so eventually I said I'd go self employed as a guitar teacher but when I came here to get a business plan together they said I would lose me benefits.*

Being told work was not a realistic option for him meant that Shaun gave up the idea of becoming a guitar teacher as he feared losing his benefits. Deborah also spoke of the moment when her GP said she could no longer work:

*The doctor said to me 'I'm sorry you can't work anymore now'. I mean I'd worked 11 and a half years after being diagnosed with MS but when he said that I just sat and cried. When you've done nothing but work all your life it's a shock, it's a shock to the system but there's not much you can do about it.*

Fred reported a similar experience; he spoke of how he was told during a medical that he could no longer work:

*The government dragged us into an office in Durham to give us a full medical and basically said 'You're stuffed, son'...he sat me down and talked to us, I told him what sort of pain I was in just as I have here to you, he stripped us down to me shorts, examined us, told us to get down on me hands and knees which I did. Told me to get up which I struggled to do, few more questions and another examination and basically he said 'You're stuffed, you've got polyarthritis' which means I've got it in every joint and I've been that way ever since. I thought bollocks, now what? You can sit there and cry about it or sit there, accept it and say that's that.*

Others such as Linda tried to convince themselves that their doctor's opinion was the one they should adhere to, despite not fully agreeing with their assertions:

*Dr West always used to say there's too much going on in me life to even think about going back to work cos at the time me mam was very ill, I have the problems with me sister and that was before me hip kicked in really. Sometimes I do feel guilty...the doctor says I run the house and that's enough to do but I don't see it like that.*

Indeed, research by Holmqvist (2009) described how Swedish officials classified jobseekers as occupationally disabled (in order to get access to additional assistance) even on occasions when neither the unemployed nor their doctors would classify them in this way.

However, for Kirsty, dealing with medical professionals proved to be frustrating at times, as the following extract indicates:

*Occasionally you get the ones who don't understand pain, cos the majority of the doctors who do medicals are GPs and if you get one that doesn't understand it gets really quite tough, they almost have a 'Pull yourself together and get on with it' attitude.*

Yet it was not only medical professionals who were cited as having an important role in the narratives. Other professionals such as Jobcentre Plus staff, counsellors and care workers were also highlighted as playing a crucial role. Kirsty described how despite her deep seated desire to work, she feels Jobcentre Plus staff wrote her off as she does not 'tick the boxes':

*It was a case of 'Here's my card, get in touch if you are ready to work' but that was my only contact because it has always been clear that my options for going into work are virtually none, they don't bother with me. I'm always going to fall through the cracks if you like. I'm not going to get back into any form of employment in the near future at all so I can understand there's no point putting any resources into people like me, and I know how high pressured it is trying to get people the right support and I don't tick those boxes so I'll always fall through the net.*

Yet Jacqui described a totally different experience to Kirsty when discussing her views of interaction with Jobcentre plus staff. Jacqui found them to be incredibly helpful, as they secured her funding to set up her own self-employed business from home. She said:

*I think if you really, really want to work they'll just bend over backwards for you. Patricia cuddles me and gives me a kiss when I go and she's my advisor, Janet's the*

*same now and this is the rapport I've got with them, it's so nice to have that relationship.*

Other professionals who were cited as playing a positive role in people's narratives included counsellors, like in Kirsty's experience. Seeing a counsellor really helped her to come to terms with the permanence of her condition:

*I saw a counsellor at the surgery. I got a course of 8 sessions and that was brilliant, she was really good and I think in a way both me and my GP were right I needed a better handle on my pain. But the reason my pain was escalating was because of my mood but talking to the counsellor made a world of difference, having to come to terms with the fact that this is gonna affect my life for good. I know there's not gonna be a second of my life where I won't be in pain and that was overwhelming at first, I mean the repercussions of it are still hitting home now.*

Yet others such as Lisa felt that certain professionals had let her down. Speaking about her engagement in a health improvement service, she said:

*I said to them 'Do us a favour and don't forget about us cos I don't want to be sat at home doing nothing' and a couple of the others said the same but they did, they did forget about us.*

All of these quotations highlight how important the opinion of others can be in the construction and experience of the narratives of long-term IB recipients.

### **Place and community: 'I tend to keep meself to meself'**

The negative health experiences of unemployment are not limited to the unemployed only but also extend to families and the wider community (Novo *et al.* 2001). Therefore, the local communities and neighbourhoods which individuals inhabit are likely to be highly

significant factors in whether people experience a health improvement. Neighbourhoods are vulnerable to being stigmatised with implications for residents' social networks, experiences of social connectedness, and opportunities for developing or accessing social capital. For Warr (2005) there was evidence of people being involved in supportive local bonding networks, but few people were linked in bridging networks that extended outside the neighbourhood. Similarly, MacDonald and Marsh (2005) have noted how the sort of 'bonding social capital' present in close family and social networks can help to ameliorate the adversity of living in conditions of deprivation (e.g. via emotional support and friendship, informal loans of money, informal sharing of child and other forms of care, recommendations and tip offs about jobs, protection from and redress after criminal victimisation. Despite objective indicators that label neighbourhoods as being characterised by multiple deprivation, they can also be places in which high degrees of informal social support amongst residents can be found (Kearns and Parkinson 2001). It has also been argued, however, that whilst crucial supports to 'getting by', this form of bonding social capital can serve to keep people in place, geographically and socially, and limit individual's chances of escaping deprived situations (MacDonald *et al.* 2005).

Research by Warren *et al.* (forthcoming 2013) suggests that social relationships are particularly important for health improvement, especially for younger women. However, the way in which the frequency of talking to neighbours interacted with the other factors produced some seemingly counter intuitive results. The study suggests that contact with neighbours on a weekly basis was something that some of the groups who did not benefit from intervention shared. Why this should be the case is unclear but suggests that some communities have negative social capital. Similarly, Parkes and Kearns (2006) found that participants to the Scottish Household Survey who reported friendly people or good neighbours were more likely to report their health was 'not good'. However, one could also

speculate that the most deprived communities may well be mutually supportive but this may only have a negligible effect on their chances of improving their health.

Solid evidence links informal social networks, social activities, and participation in organisations with better health chances (Wolf and Bruhn 1993; Berkman and Breslaw 1983; Rogers 1996). Informal networks are an important part of this scenario in that social capital also resides in the support that people receive from friends, family and local communities – and, ideally, sick and disabled people’s contribution is enabled and recognised so that these are reciprocal relationships. Coleman defines social capital in terms of its structural, relational and functional elements (Coleman 1990), while for Jacobs (1960) it refers to networks which provide a basis for trust, cooperation and perceptions of safety. Like ‘community’, social capital is a contested and complex concept however. For Putnam (1995) participation in voluntary associations is a key aspect of social capital. Earlier work discussed the potential of participation in local organisations for benefiting health and well being through developing networks, empowering, and fostering values of co-operation, tolerance and solidarity (Cattell 1995). However, in promoting the role of participation, features of local social organisation which are equally important for the viability of the neighbourhood can be neglected. Participation was not the main source of social networks or capital for the majority of participants. There, those elements of a traditional community had many health protecting qualities, mutual aid not least among them (Cattell 1999).

More recently, a concept outlined by the Coalition government concerns the production and fostering of the ‘Big Society’. An early publication of the Coalition Government, *Building the Big Society* (Cabinet Office 2010) sketches out a range of ambitions for the ‘Big Society’:

*We want society – the families, networks, neighbourhoods and communities that form the fabric of so much of our everyday lives – to be bigger and stronger than ever before. Only when people and communities are given more power and take more responsibility can we achieve fairness and opportunity for all. Government on its own cannot fix every problem. We are all in this together. We need to draw on the skills and expertise of people across the country as we respond to the social, political and economic challenges Britain faces. We will support the creation and expansion of mutuals, co-operatives, charities and social enterprises, and support these groups to have much greater involvement in the running of public services. We will take a range of measures to encourage volunteering and involvement in social action, including launching a national ‘Big Society Day’ and making regular community involvement a key element of civil service staff appraisals.*

Runswick-Cole and Goodley (2011: 883) ask: What does ‘Big Society’ mean for disabled people? They argue that a ‘Big Society’ narrative that attributes the underlying causes of poverty to the failings of individuals rather than to socio-economic structural factors (Lister and Bennett 2010) strikes at the heart of social oppression models of disability upon which Disabled People’s Organisations have campaigned for the rights of disabled people over the past 30 years. ‘Big Society’ assumes a ‘competent’, ‘capable’, and ‘independent’ citizen who is able to look after themselves. The subject of ‘Big Society’ who will participate in enabling local communities and, therefore, have things that add to their quality of life is a normative, able citizen. For Runswick-Cole and Goodley (2001: 884) crucially, recipients do not have the right to charity, they must be judged ‘worthy’ of support; charity is based on discretion, not rights (Charlesworth 2011). Such an approach has its roots in the Poor Laws (1601 and 1834) that aimed to identify the ‘deserving’ and ‘undeserving’ poor (Charlesworth 2011). As such, for Runswick-Cole and Goodley (2011) ‘Big Society’

represents an unwelcome regressive move back to models of disability based on charity and pity and away from affirmative and rights-based models. For Morris (2011: 14) the language of social capital is easily subverted to be about the duty of families and communities to 'care for their own', and fits neatly into the Big Society agenda. It also echoes some of the language and assumptions dominant during earlier stages of the development of community care policies, in particular the assertion that '*Care in the community must increasingly mean care by the community*' (Department for Health and Social Security, 1981). There was no mention of the Big Society by anybody in the study; despite this, it was clear that efforts were being made to do voluntary work, whether that was a case of getting shopping for an elderly neighbour or more structured voluntary work in a charity shop, for example.

Interestingly, when asked about their local area, very few participants reflected upon the history or the importance a place can have upon health. Instead, the answer people gave when asked about the area was the same time and time again - '*I keep meself to meself*'. This could be linked to wider feelings of shame and guilt related to receiving IB - as we have seen thus far, often people are reluctant to reveal their claimant identity to friends and family, so perhaps 'keeping meself to meself' is an extension of that when thinking about place and community. For the participants in this study, social networks were perceived and experienced in different ways. In some instances, networks could provide social support, self-esteem, identity and perceptions of control. Yet on the other hand, some participants reported how they have a tendency to shy away from family and friends, in order to avoid revealing the extent of their pain and suffering or even to avoid having to reveal their 'claimant identity', as the previous chapter indicated. Many participants spoke about how they like to 'keep meself to meself' and did not engage with neighbours in their area.

A clear distinction between identifying themselves as 'deserving' benefits recipients and those in the area who they perceived as 'undeserving' was apparent in the narratives. Angie initially told me that there were lots of people on benefits where she lived, yet when she thought about it, she realised that may not be the case:

*Oh gosh yeah, even if they're not supposed to be. The girl who was living next door she's gone now but she was working a couple of jobs and then she was claiming as well and she got caught but I mean...although Amanda next door has jobs, the house at the end Stephanie she goes cleaning, Sally works with handicapped kids, next door they both work, the next door I think they work so...maybes y'know there's not that many. When you sit and think about it, maybe there aren't many on benefits here so it might not be that bad. But like I say I tend to keep meself to meself.*

When asked if there were many people on IB where she lived, Caroline said it was difficult to tell:

*I wouldn't know but then if they're like me they wouldn't tell you anyway would they? I don't know I mean I know there's a lot of people not working but I don't know why they're not working, it could just be that they can't find a job.*

Popay *et al.* (2003) discuss how living in a perceivably 'improper' place can impact upon the ability of an individual to (re) construct a positive identity, and draw attention to the importance of biographical connections with people in particular places. As Williams and Popay note (1999: 169-70):

*New forms of social identity may emerge whilst old ones are resisted, or even become redundant. Furthermore, these new forms of identity may also create the basis for both individual and collective agency.*

The importance of community was alluded to by several participants, such as Linda and Mick, as shown in these extracts below. Linda said:

*I like getting outside, getting out in the back lane when someone's out. We've had some laughs up here it was all community, a hell of a community. Like I say we always have little bonfires, parties...its great up here when it's like that.*

For Mick, it is evident how important it is to him to feel valued and respected within the community:

*I'm well respected in the community...well I hope I am anyway. We had our school summer fair the other day and there was loads of people coming up to us and talking to us and the Head Teacher was praising us for me role and I had a lump in me throat cos you never get to hear stuff like that.*

However, for Shaun, the downside of community could be found in his neighbours' attitudes towards him and his condition:

*The amount of times I've heard the neighbours saying 'He's supposed to be bad but look he's going out for the night' and I felt like turning round and saying 'Hang on a minute' and I hate it, to the point where now that I've moved again to Sunderland I deliberately keep meself to meself.*

Having access to a Motability car was often said to be a 'lifeline' for participants in the study. Often living in rural areas that have infrequent public transport links, for those able

to drive having access to a car was very important. As the quotation from Mick, below, indicates:

*I wasn't able to drive for 4 years but I've recently got me Motability car through the DLA scheme. It's brilliant now I can drive it's unbelievable. I've got more freedom, I can drive meself to school meetings I don't have to rely on Dawn, I always feel awful putting on people. I think a lot of feeling down at times dissipated through that, it was November I got the car and it's really cheered us up.*

Sue echoes the comment by Mick, but also reveals that she does not tell anyone else she has a Motability car as she fears she will be stigmatised:

*I have to say getting the Motability car and that little bit extra has made the world of difference...I mean there's not a lot of people know it's a Motability car or anything, I just don't tell people things cos you think do other people think you're sponging?*

For others who were unable to drive, such as Linda and Sarah, the difficulties of accessing adequate public transport were highlighted. As Linda points out:

*It's a long hike along that road I don't walk along there, I used to work at the garage along there part-time but I don't do it now. They don't even have any buses anymore, but we have a bus stop over the road. They used to have a bus every hour but they've knocked them off, we have one that comes on a morning at 8 o'clock and comes back at half past 3 and that's it.*

For Sarah, making a lengthy daily commute would be impractical not only because of her health, but also because of the cost of public transport:

*I used to have to get a really early bus and just the travelling, that's another thing I don't want to have to commute oh my God that is too stressful for me, I would not be prepared to do that absolutely not. And if they send me for a job in Darlington, how do I afford the bus fare on minimum wage anyway?*

Certainly, Lucas *et al.* (2008: 14) found that transport was a crucial barrier for people seeking a job. They also observe that public transport is vital for maintaining social inclusion of individuals and for maintaining the vitality and vibrancy of low-income neighbourhoods.

### ***Local labour market***

The mid 1980s witnessed deindustrialisation in the UK on a major scale. In County Durham, what is most often reported is the demise of the coal industry and the industrial action associated with this. In March 1985, Britain's coalminers returned to work after the longest and most bitter industrial dispute in modern times in the UK having lost their battle to stop pit closures. The year-long miners' strike was one of the defining events of Margaret Thatcher's reign. Over the months and years that followed, the pit closures that the miners had feared did indeed happen. At the time of the strike the state-owned UK coal industry employed 171,000 miners at 170 collieries, and had a total workforce (including white-collar staff, workshops, opencast mines etc) of 221,000. Nearly 90 per cent of this workforce was shed during the first ten years after the strike, and job losses have continued on a smaller scale ever since. The now privatised coal industry employs fewer than 7,000 in total, of whom only 4,000 work at the eight remaining collieries. One of the most important features of this job loss is that it has been virtually all concentrated in just a

dozen or so areas across Britain, including Easington and its surrounding areas in County Durham. In most of these areas, coalmining had been the dominant source of employment for men, so the consequences for local labour markets were always going to be serious (Beatty *et al.* 2007: 5). In its scale, speed and geographical concentration, the contraction of the UK coal industry is arguably the definitive example of deindustrialisation in Britain or Western Europe. What's more, the decline of this shipbuilding industry in Tyneside represents another shutting down of opportunities in the local North East labour market for many (Tomaney *et al.* 1999). The coal, steel and shipbuilding industries-historically located at the heart of the Northern economy since the nineteenth century-had been both nationalised and then rationalised, leading to considerable reductions in capacity, output and employment (Hudson 1986; 1989). Whilst de-industrialisation via nationalisation pre-dates the politics of Thatcherism, undoubtedly Thatcher accelerated the shutting down of these nationalised industries in the 1980s as part of a politically informed process of industrial decline (Beynon *et al.* 1986; 1990).

Previous research suggests that the strength of local labour markets is crucial in explaining sickness benefits rates. Disabled people are most likely to be economically inactive in areas with weak labour markets and most likely to be employed in areas with strong labour markets (Beatty *et al.* 2000). As the OECD (2008) highlighted, sick and disabled people are particularly exposed to worklessness during periods of economic crisis when the demand for labour is weakened further. In an area such as County Durham, a region replete with a coal mining legacy that relates to wider, long-term processes in the economy and regional labour market, such an imbalance in the local labour market leads to this group of older workers simply being replaced by a younger generation of disadvantaged and marginalised workers with health problems (Fothergill 2010: 5).

In terms of the local labour market and perceived job opportunities, Beatty *et al.* (2007: 50) report that when participants in their study were asked 'Do you think there are appropriate job opportunities for you here in the local labour market?', nearly three quarters of the men who expressed an interest in returning to work, and two thirds of the women, said 'no'. This widespread perspective is of particular importance given the preference for working within Easington district itself. Broader cultural attitudes around gender and work may also persist in areas such as Easington (Smith *et al.* 2010). Mining was from the mid-nineteenth century onwards an exclusively male occupation. Attitudes about what constitutes legitimate 'men's work' and 'women's work' to some extent persist (Nixon 2006), and this potentially explains the reluctance of men to take up employment on a part-time basis or within service based industries such as call centres which have appeared over the past few decades.

On occasions, participants did talk about how the decline of the local labour market in County Durham and the North East had an impact upon their narratives. For example, Linda, below, talks about how she feels her job prospects are restricted and why:

*I couldn't work in a shop, petrol stations aren't the same, I haven't done anything else. All I've ever done is work in a factory since leaving school. There is no factories they're all shut, every one I've worked in has closed down, every single one. Black and Decker they closed down, took it all to Poland.*

Many of the areas I visited whilst carrying out the interview used to be working pit villages. Below, Angie talks about how she was involved in the Horden strike:

*We moved down to Horden because my husband worked at the pit and they were on strike so when they were on strike he didn't get anything. So I ended up working for me friend Margaret down the cricket club down Horden...oh it was horrible, I've*

*never...everything was fine then the strike happened, we couldn't afford to pay the rent in Peterlee and it was only 53 pence for the rent down Horden so we moved down to Horden and stayed there.*

Joan, 52, reflects upon how the area has changed since it ceased to be a working pit village:

*It's not as lively an area as it used to be and there's clubs closing down, there's not a lot of shops open now, the library's gone it's now a car park.*

Indeed, Cattell's work (2001: 1504) highlights how dwindling facilities like social clubs and local shops mean that there are fewer casual meeting places on the estates than there once were, but those remaining continue to have significance for fostering the weak ties necessary for a vibrant community life and which her interviewees suggested contributed to their own sense of well being.

### **Chapter Summary**

In this chapter, the importance of social networks, community and identity in the narratives of the long-term IB recipients in the study has been discussed. The significance of family, friends and key professionals such as GP's or welfare-to-work staff has been debated here, highlighting just how much influence others can have on participants narratives – whether that is in a positive or negative way. Lastly, the chapter discussed the relevance of place and community for long-term IB recipients in areas with higher than average levels of IB take-up. In addition to stigma and the proximity to social networks, the chapter identified how transport and infrastructure also play a role in shaping the narratives presented here.

To summarise, the chapter has highlighted the importance of social networks and community and how they can relate to identity formation for long-term sickness benefits recipients. Clearly, there is a relationship between stigma and social networks for many

participants that is borne out of a reluctance to divulge their claimant identity to friends and family. Negative reactions from friends, family and neighbours can perhaps be fuelled by the ongoing stereotyping of sickness benefits recipients as 'undeserving' and fraudulent by the mass media and government rhetoric. The chapter illustrated how place can impact upon participants; for example, in terms of proximity to social networks, job opportunities, transport, and lastly how stigma can be linked to living in particular areas. Participants rarely reflected upon the history or the importance a place can have upon health. Instead, more often they spoke of how they '*keep meself to meself*'.

## CHAPTER SIX

### 'A WAY OF LIFE': (RE) CONSIDERING PAID WORK

*Kirsty:*

*"The first question people always ask you after your name is 'What do you do?' and it kind of defines you. And people judge you on it, y'know when you meet a GP you automatically assume they're respectable, they're intelligent, and if you meet somebody who is on benefits you generally assume they're not willing to work. People don't assume that you've just fallen on hard times and you're trying, people just assume you're another one of them. I think work is very important, it doesn't matter what the job is, just that you're willing to go out there and earn your own way in life. It's something that I value in other people and I find it very difficult that I'm not doing that. Most people assume when you don't work is that you're on benefits and you don't want to work, and they look at you and think 'There's bugger all wrong with you'. I've had that conversation so many times with people and you're having to justify why you don't have a job. I usually just say to people 'I don't, I retired when I was 30' and they give you a double take and wonder what the heck you're going on about. Mentally my brain works, the majority of me still works but it picks its moments, it isn't reliable and that's another thing I find annoying, mentally I'm fine but physically I'm unreliable...I would willingly have any job, I wouldn't care what it was, it would mean the world. I would rather be able to turn round and say anything really rather than that."*

## **Introduction**

In discussions of long-term sickness benefits recipients, what is rarely heard is any dialogue surrounding what work means to them. This chapter addresses this gap by showing the importance of work motivation and work ethic within these narratives, whilst also illustrating examples of people who have found work again, in some cases after lengthy periods on IB. Alongside this, a reconsideration of the significance of the concept of paid work will be highlighted and related to the narratives.

## **Work motivation**

*It's pride, it's the way you're brought up as well. I've come from a family where on me mam's side they've had their own shops, pubs and clubs and things, me brother's got degrees, another is a professional photographer so it's in there. I think the drive is pride. I don't want to stand in a queue and wait for a handout.*

The above quotation from Jacqui's interview is one of many that could have been selected to show the work motivations of many of the participants I spoke to. Of the 25 interviews carried out, only 6 people reported that they did not intend to return to work. The remaining 19 participants revealed aspirations to return to work – something certainly not reflected in government or mass media rhetoric surrounding sickness benefits recipients. Participants were vocal about the importance of being in work and the benefits it brings – the people who did not want to return to work either found that working made their health deteriorate, or they felt their health was so poor that returning to work was not possible. Indeed, these findings are similar to those of de Wolfe (2012) who remarks that sickness benefits recipients in her study also talked about missing work, wanting to work, or considering an attempt to return to work.

Participants such as Tony spoke of their dogged determination to seek work, including applying for 'hundreds' of jobs and seeking out voluntary work in order to gain new skills and experience. Below, Tony speaks about his efforts to seek work following nine years receiving IB. When asked about how many jobs he's applied for, Tony replied:

*Hundreds, it's got to be hundreds. And in those hundreds I've had maybe about 5 interviews. I went for a job advertised at Redcar and Cleveland for the Council but I didn't have the experience on the construction side which they were looking for and I wasn't up to date with the latest policies really but it was worth a try, I got an interview.*

Kevin told a similar story. He said:

*I was writing on average 50 letters every two days and I was getting maybe one reply from that, there's very few get in touch with you. I mean I went for one job as a parcel delivery driver and I was told they had no jobs but three of me friends got jobs with them that same day.*

Wainwright *et al.* (2011: 146) suggest that an IB recipient 'may present a social identity that emphasise their readiness for work, but if this identity is rejected by a potential employer, that rejection may well have consequences for the person's selfhood'. A similar experience occurred for Mick when he began having job interviews:

*I went for a parent support advisor job and the interview brought us up short cos on the panel the gentlemen asked us 'Could you do 40 hours plus work, study, family life and everything with your disability?' And that was the first time I'd thought about it. I'd put in for lots of jobs but that was the first time they'd asked us and I was just like 'Well I'll be fine, I'll get on with it' but that was the first time I thought*

*could I actually manage. So I think with regards to the future if I get employment then I think it'll be part-time cos I think full time would be too much.*

As the above quotation shows, when questioned on his readiness for work, Mick was forced to re-evaluate his abilities to maintain a full-time job as well as his other responsibilities, convincing him to pursue part-time employment instead.

Yet despite the best efforts of participants, a job was not always found. Kevin felt that his age and disability was directly linked to him not being employed, whilst Mick planned to focus on his studies before seeking work. Kirsty believed that her lack of ability to be flexible was the reason why she was unable to secure voluntary work. Volunteering was a pursuit that five participants were either involved in or had been involved in. Voluntary work was seen as a way of easing oneself back into paid employment, gaining new skills and experience. Kirsty was keen to become involved in voluntary work, but found it difficult as she is unable to commit to set times and days due to the fluctuating nature of her condition:

*I've even been looking at volunteering and that's difficult, there's not much round here to volunteer for and most places want you to commit to set hours or set days. I can understand why cos they've got an organisation to run with set activities but I'm not looking for something where I have to do a Tuesday morning, it's more when I'm up to it and they don't have anything like that. I'd go and answer the phone for a few hours, I don't mind. So when you're offering to work for free even then people don't want to take you on, it's really bizarre. I've been in touch with the local radio station and again they want commitment. I do understand it but it is infuriating and I'm slowly running out of options.*

Voluntary work was also viewed as a way of giving something back for society in order to ease the guilt people felt about claiming benefits. Sarah said:

*I've always done some voluntary work so I actually felt like I was giving back to society. I worked at the charity shop and that's not bad for your Incapacity Benefit is it - 2 full days work for £80. But I haven't done anything these past 2 years so it makes you feel even worse.*

When asked about the possibility of him returning to work, Fred spoke about how the 'physicality' of being able to work jars with his mental ability:

*I would like to. I would love to work in a museum to be honest cos I love history but whether or not I could physically do it. Mentally I could but physically...it's always the physicality – can I do this? I want to feel like I've used me mind, that's why I do the crosswords, that's why I brush up on me history. I'll see something in a film then I'll go and research it.*

A similar occurrence was reported by Kirsty who said '*mentally my brain works, the majority of me still works but it picks its moments, it isn't reliable and that's another thing I find annoying, mentally I'm fine but physically I'm unreliable*'. The dichotomy between physical and mental ability was viewed as a distinct barrier to re-entering the labour market.

The experiences in the narratives presented above highlight the difficulties faced by people who have been receiving IB long-term yet still possess a desire to work. Kirsh *et al.* (2012) remark that in contrast to commonly held beliefs about fraudulence and lack of desire to work, their findings point to employment as a much desired goal for injured workers who have lost their work role. These findings are similar to those of Stone (2003) whose

research revealed that injured workers appreciate their identity as worker and that this identity is central to their sense of self.

Like the findings of this research, Stone's work reports little evidence of a desire to move away from a work ethic. As the start of the chapter iterated, rarely are the work motivations of benefits recipients heard. Instead, and as the previous chapters have illustrated, a discourse surrounding a 'dependency culture' is much more likely to be attached to benefits recipients. Dean and Taylor-Gooby (1992) have attacked the 'myth' of a dependency culture. Their research in 1990 was based on in-depth interviews with 85 social security claimants in London and Kent. They found that; firstly, the vast majority of claimants wanted to work; secondly, problems associated with the benefits system did discourage people from looking for work; and thirdly, such disincentives did not lead to a dependency culture – people wanted to earn their own living and looked on the state only as their last resort. A similar finding was found some 20 years later by Shildrick *et al.* (2010). The study demonstrated the resilience and lasting work commitment shown by their interviewees in a deprived area of Teesside, UK, despite the frustrations and setbacks associated with their repeated periods of unemployment and low-paid jobs. They note that: *'It would not be an overstatement to say that most deplored claiming welfare benefits'* (2010: 5).

However, it should be pointed out that given how participants were recruited, it might be no surprise if they appear motivated to return to work. According to Corden and Nice (2006: 63) those who used JCP 'Choices' services were people who were already focused on working when they went to their first interview with an IBPA, and they were people who saw some possibility of working in the future. Therefore, perhaps the way recruitment was

undertaken means that it was unlikely that I would ever reach totally disengaged long-term IB recipients.

### **People who are active in the labour market**

Employment rates for disabled people are as low as 30 percent according to Berthoud (2006). Berthoud (2003) used a cumulative risk model and found that the higher the number of disabilities experienced and the greater the severity of people's health problems, the higher the risk of non-employment. Previous research on workers with health conditions and/or disabilities has drawn attention to older workers disabled by work in traditional industries and tossed on the scrapheap when those industries disappeared (Fieldhouse and Hollywood 1999). Riach and Loretto (2009) showed the tyranny of the conventional working identity in the way the capacities of workers with disabilities were conceived. Those who saw themselves in 'recovery' were more vocationally oriented, taking up offered opportunities, learning new skills, gaining qualifications or taking on voluntary activities. This enabled them to resume a work identity, although they still retained their experience of illness as a defining, though not all-consuming, feature of who they are, which appeared necessary for them to prevent relapse.

Two of the 25 participants, Tony and Marian, were employed in part-time employment at the time of the fieldwork. However, although not currently employed, Mick was retraining as a social worker and was also active as a school governor. Caroline was doing permitted work, and Sandra had also done permitted work recently. Speaking of doing some permitted work, Sandra said:

*It was hard to start with but I found it...there was more to life than my 4 walls or just popping to the shop. I had an interest, I wasn't just talking about my girls or*

*what was for dinner and things like that, and when I was on the phone you'd get chatting to people about things like the weather.*

Narratives suggest that instead of a 'culture of dependency', in fact IB recipients can have a strong desire to work but are prevented from doing so largely due to chronic health problems and disabilities, alongside perceptions of work. Tony, currently working 20 hours on a placement for the Royal British Light Infantry (RBLI) said when asked about the importance of work:

*I've just always done it, it's my way of life I suppose. It's like someone who's never worked, to me this is all I know. But if I'm doing something I like, I thrive on it. I don't care how much it pays, 15 grand or 50 grand I'm not money orientated, as long as I can pay my rent and have a bit of money to treat my partner, go out for a meal once in a while, that's all I want.*

Marian, 45, returned to a job in cleaning after 11 years receiving IB. She now works two jobs cleaning in an office and a local betting shop:

*I'm working 21 and a quarter hours a week and if my body can cope with that then fine, I know my body couldn't cope with working 40 hours. I mean I know one day I'll wake up and I'll need a wheelchair but my way of thinking is I'll keep on me legs as much as I can, while I can cos I know I could be in a wheelchair in years to come but I mean at the minute I just keep going.*

The process of getting a job was described as much more straightforward for Marian than others such as Kevin and Tony who had applied for many jobs. Instead, Marian was offered the first job she applied for. Describing the interview process, she said:

*Me interview for the Coral shop was about three minutes over the phone that was it, they offered me the job there and then. Then Coral sent me to the office cleaning cos they had the contract and I got that job as well.*

The following exchange in Marian's interview illustrates how important having a job again is to her in financial terms:

MH: *It feels great having some self respect back rather than just living on benefits. Like this week I'm a bit skint cos its pay day tomorrow but when I was on benefits I'd get paid on a Wednesday and come the Sunday I'd be skint, I didn't even have coppers in me purse*

KG: *How did you manage?*

MH: *Well I didn't. Like I used to buy powdered milk in, in case I ran out and didn't have the money to buy it. Now with me working, yesterday I was up the Gala bingo for a few hours or I'll go to Redcar and go on the prize bingo for an hour and I couldn't afford to do that before cos obviously the bus fare and that, where this way I can afford to go out a little bit more. I mean now if I want a new cooker, I can save up.*

Earning money of your own was a key advantage of work or permitted work for participants. For example, the benefits of permitted work were articulated by Sandra:

*I did do a little bit of permitted work it was actually ok. I worked for about 5 months, it was good cos it was 3 hours a week and I could go in when I wanted and all it was doing was just chasing up emails and seeing if they were ok for stock so it wasn't like...cos thats what worries me, what happens if I get a job and I need to go to the toilet? Or if I can't sit any longer, or I need to take a break? Cos that's what worries me, you're there to work. But then they had cutbacks and I had to go, but I*

*was hoping that would turn into something, y'know? Even though I was only earning about £50 odd a month that was mine, I'd earned that and when it went in the bank I said to my husband 'I've earned that', I'd worked for it.*

The importance of earning money for herself, along with the increased flexibility of it being permitted work, was key for Sandra.

## **Employers**

In the UK, the Disability Discrimination Act 1995 (DDA 1995) intended to end discrimination against disabled people. The Act maintained that a person who has '*a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities*' would be protected (DDA 1995 S6(1)). The Act also included an obligation on employers to make reasonable adjustments - changes to circumstances or physical features of the workplace if a disabled person is at a disadvantage. Roberts *et al.* (2004) found many employers are aware of their responsibilities under the legislation, and this knowledge is greater among larger organisations, public and voluntary sector organisations (which may have specialist human resources departments), as well as employers at workplaces where there have been disabled employees. Large employers which have human resources or personnel specialists are more likely to have equal opportunity practices (Goss *et al.* 2000; Hoque and Noon 2004).

Roberts *et al.* (2004) found that the concept of 'reasonable adjustment' was poorly understood, with some employers being unaware of the term and others unsure of its meaning in practice. Kelly *et al.* (2005) noted in their 2004 survey only 12 per cent of small employers reported at least one disabled employee. Stuart (2002) found only 13 per cent of employers reported that they currently employ disabled people. Case study evidence from the same research suggests that this may understate the true position, due to a

narrow interpretation of the term 'disability'. However, as Newton *et al.* (2007: 612) comment, disability campaigners believed the Act was too weak, as demonstrated by several academic writers (Gooding 2000; Goss *et al.* 2000; Lockwood 1999; Meager *et al.* 1999; Woodhams and Corby 2003). The 1995 Act was amended by the Disability Discrimination Act (DDA 2005); including the removal of the concession that failure to provide reasonable adjustments may be justified. The Disability Discrimination Act (1995; 2005) and The Equality Act (2010) were passed into legislation with the specific aim to protect disabled people and prevent disability discrimination. The Equality Act means that employers have to make 'reasonable' adjustments to their premises and/or working practices to assist disabled people in their work. Certainly, for participants in this study, an overriding barrier to employment was cited as employers and their perceptions of employing a long-term IB recipient. Sarah said:

*I just don't know, I don't know who would employ me. I have to sit and drink water all the time, I can't think of a job where they'd say 'Thats alright' you just do 3 hours of work but we'll pay you for 8, it's not going to happen. I just don't know what job I can do and I just don't know who this friendly employer is going to be. I mean you name me one and I'll apply. It's sad really cos it's bleak, very, very bleak.*

Equally, Terry showed concerns over how an employer might react to his bipolar disorder, and said:

*I don't let it annoy me but what employer if I put down on my CV that I had manic depression, what employer would give me a second glance? Not one, you'd have to lie to get a job but to me just keeping a nice status quo is enough for me, let alone having and keeping a job. I don't think work is an option, I'm being realistic - how many employers would employ me for a start, they'd just laugh at me. You get*

*victimised and filtered out as soon as they read that on a CV, I would if I was an employer I'd think they wouldn't be very reliable, too risky.*

Sandra also expressed concerns over her employability; concerns largely centred on her age and abilities:

*It would be great to say I was doing something or earning money but telling a potential employer about my problems, can I do that? It's embarrassing. I mean I can tell you cos you don't know me, but to say that to someone at work I just would want to die of embarrassment. But then...for the future I think is there a future? Is there anything out there? Realistically I worry who will employ me, I'm 52, I can bluff my way into a job but can I do the job? And where are the jobs? When I was younger there were loads of employers, they've all gone now so I think if I applied for a job, how many young people are applying and realistically who will they take? Someone who's been on Incapacity for so long or a young educated person? I mean I'm 52, who wants me? Who wants this broken person?*

In terms of educational background, evidence suggests that people receiving IB tend to be under qualified. Survey evidence from Beatty and Fothergill (2010: 10) indicates that 60 per cent of all IB claimants said they had no formal qualifications at all – not even CSEs or GCSEs. They found this figure varies little by gender or by type of illness or disability. However, whilst the majority of the participants in this study did not possess high levels of formal educational qualifications, others had a high level of education. Below, Sarah, who has an MA in Classics and was studying for a PhD in Arabic Studies when she had to withdraw due to her health problems, highlights the difficulties this can pose when seeking help from welfare-to-work agencies such as Jobcentre Plus:

*They give you all these different little leaflets and they're all a load of rubbish, they're for people who cannot read and write, I just don't fit into any of them. All I can say is 'I've been on the sick' – what employer is going to touch me? They don't have anything for people like me, and I'm not saying this like if it's not academic it's a lower job but I can't find any help for people who are more academic.*

Equally for Laura, who is a qualified teacher complete with a BA degree, told me about her experience of being offered options to go on various courses on the advice of the Jobcentre:

*I mean I couldn't believe this, they suggested I do a flower arranging course, or had I thought about doing literacy and numeracy and I said do you mean teaching it? And they were like 'Oh no'.*

Indeed, as Wainwright *et al.* (2011: 147) comment, it is often difficult for long-term IB recipients to return to their previous career or status. They argue that for many, return to work involves being prepared to accept low-paid, low status jobs or retraining to access careers with more job opportunities. Yet in certain instances, despite having no prior educational qualifications, participants were successfully changing their career. Mick is a prime example of someone with a manual background who was now retraining. Currently, Mick is doing a Masters degree in Social Work despite working in Nissan for over 20 years and possessing no prior qualifications. He describes his previous employer as being incredibly supportive; for instance, Nissan paid for part of his BA Health and Social Care and Mick told of how they did everything they could to support him to remain in employment.

## Reconsidering paid work

When thinking about the narratives presented here, perhaps what is needed is a reconsideration of what work actually is and what it means – does it have to mean paid work, 5 days a week totalling 40 hours? Much previous discussion by disability studies commentators and others has highlighted the need for a radical alternative to traditional conceptions of work (Barnes 2000; Roulstone 2002). Barnes and Roulstone (2005: 315) note how previous literature suggests an alternative approach should include both the reconfiguration of the meaning of work, alongside the de-stigmatisation of welfare provision. They note how in the current context, *'policy developments in the employment field can only have a limited impact on the employment problems of disabled people'* (Barnes and Roulstone 2005: 319). Roulstone (2011) suggests that a new approach would include home-based and remote working; time banking for those whose capacity varies; and widening access to non-typical jobs; all clearly approaches that would benefit the participants in this study.

Such a reconfiguration of work should include everyday tasks that non-disabled people carry out daily without a second thought. Corbin and Strauss (1988) identified three types of 'work' associated with illness management: illness work; everyday work; and biographical work. Moreover, Corbin and Strauss (1988: 228) comment that since everyday life itself is never at a standstill, the work involved in illness management is ever-changing. Even the most routine of everyday tasks can vary in the manner in which, the time at which, and the person by whom they are performed, according to the tasks to be done and contingencies that arise, such as flu or a death in the family. Also, it may be helpful to acknowledge the concept of a meaningful occupation (such as voluntary work or working at an allotment) being a socio-economic contribution which is not necessarily paid work but

does not mean 'idleness'. A reconsideration of paid work would almost certainly be relevant to the narratives of many participants in the study; for example, it has been shown how people such as Kirsty, Sandra and Sarah are keen to work but do not fit in to the typical 9-5, Monday to Friday routine conception of employment. Jacqui, who is trying to set up her own business, said:

*I'm trying to come off Incapacity and I can't, I'm doing one costume every 2, 3 weeks and I should be doing 3 a week but I cannot do it. I should be doing like 9-5 or something like that cos I wanna go online you see so I need quite a few made before I put them online, but that just isn't an option for me.*

Clearly, Jacqui and others are trying to re-enter the world of work, but are finding it difficult to do so because of the rigidity of paid employment.

According to Waddell and Burton (2006), in terms of promoting health and wellbeing, the characteristics that distinguish 'good' jobs and 'good' workplaces might include: safety; fair pay; social gradients in health; job security; personal fulfilment and development; investing in human capital; accommodating, supportive and non-discriminatory; control/autonomy; job satisfaction; good communications. Research shows that poor work - low-quality, insecure employment that fails to provide labour market security or progress - can indeed be bad for health (Butterworth *et al.* 2011; Marmot 2010). Certainly, for Patrick (2012: 13) instead of promoting all paid work, the government should concentrate on how best to improve the quality of work available, alongside reducing the extent of inequalities within the working population:

*Were the reality of human interdependence to be acknowledged, as well as efforts to redefine our understanding of work taken seriously, the dualisms and*

*dichotomies between workers and non-workers - the responsible and irresponsible - would be far less potent and might collapse entirely.*

Indeed, poor work and economic marginality – rather than either regular employment or permanent unemployment – is said to have become more common in recent decades for larger numbers of workers at the bottom of the labour market (Byrne 2005; McKnight 2002). Therefore, not only a reconsideration of what work actually is, but also that work – any work – does not necessarily represent work that is good for you should also be included.

### **Chapter Summary**

This chapter has discussed the importance of work in the lives of the participants in the study. Contrary to populist beliefs surrounding IB recipients, the majority of participants in this study recognised the importance of work as being integral to their identity, even if they were not planning on returning to the labour market. People spoke of work as being highly important to them, ‘a way of life’ – many were desperate to get back into work, yet were prevented from doing so either as a result of their health problems or disability, or due to what they perceived as a lack of jobs and supportive employers. Finally, the chapter discussed the relevance of a reconsideration of paid work and how this could include not only greater flexibility in terms of working hours and days, but also everyday tasks that non-disabled people carry out daily. Such a reconsideration could also foster the new positive identities that could arise from the transition onto sickness benefits, for example becoming a school governor, taking part in voluntary work or participating in a men’s health group.

## CHAPTER SEVEN

### AWAITING THE BROWN ENVELOPE: PERSPECTIVES ON WELFARE REFORM

Sue, 50:

*"I say to my husband when they're on about getting people off Incapacity, yeah there probably is a lot of people they could phase out. But there are a lot of people who genuinely need it and personally if I was to have my car taken off me my life would be 100% worse off. I would lose me independence, I would lose just knowing if I need to go somewhere I've got the money to do that otherwise I'd be stuck in the house all the time. I mean I wouldn't say we go daft by any means, we have our own caravan, we don't go on holidays abroad but I would have to give that up and to me being able to go away is just that little bit more independence instead of just saying 'I'm disabled'. I know it might just be sitting in a caravan somewhere but to me it's the world. I would be devastated if they did take a lot of genuine people off cos it does help them a lot, it gives me a lifeline. I still wish I didn't have to claim it, if me husband was on a big wage I don't think I'd take it...I don't think I would, no. If I didn't need that money to give me that freedom I genuinely, honestly don't think I would accept it. Cos a part of us still thinks that I'm taking money off all these taxpayers, off yourself, everybody is paying for me to sit around and do nothing and have a bit more freedom. But then I suppose I try not to sit and think like that, I try and think it's given me some of my life back."*

## **Introduction**

As previous chapters have illustrated, welfare reform has been firmly on the agenda for IB recipients since October 2008 with the introduction of the Work Capability Assessment (WCA) to determine access to Employment Support Allowance (ESA) or Jobseeker's Allowance (JSA). This chapter uncovers long-term IB recipients' opinions on and experiences of welfare reform, revealing a dichotomy of responses – firstly, a dominant discourse which showed deep seated fear of reform and what it could mean for participants, and secondly, a belief that reform is a positive shift that will not affect them as they are, in fact, genuinely ill. This narrative is situated alongside a wider one that encompasses 'Other' IB recipients as scroungers and adds credence to the distinctions between 'deserving' and 'undeserving' sickness benefits recipients. Again, the language and discourse employed not only by politicians but also by the media when discussing welfare reform will be considered here. Finally, the idea of entitlement will also be discussed in relation to the narratives which will include discussions of under-claiming benefits.

## **Perspectives on welfare reform**

Firstly, this section will begin with the narratives of those who had experienced welfare reform in one way or another, whether that was under the current Atos WCA assessments, or any assessments or medicals they had undergone in the past. Secondly, the perspectives of those who have a fear and suspicion of reform will be explored, highlighting how this fear can impact upon the daily lives of long-term IB recipients. Lastly, the narratives of participants who believe they are 'genuine' so reform will not affect them will be presented.

### ***Experiences of the WCA***

There were only two participants, Kevin and Terry, who had been assessed under the Atos WCA at the time of the research in 2011. Kevin, a former Army recruit and taxi driver, suffers from arthritis and cardiovascular problems. He had been receiving IB since 2006 but was reassessed two years ago and was found fit for work. Kevin and his wife Jennifer described the difficulties they had negotiating the assessment and appeals process:

*KM: I got reassessed two year ago and this nurse assessed me that I was fit enough to work. In that interview she'd seen us hobble to the changing room, try and get on the bed and virtually be lifted on the bed, I was asked to bend down and pick something off the floor which I couldn't do and she said I was able to work.*

*JM: I mean she saw him for what, 15 minutes for this medical? Its nurses, retired doctors looking for extra money that are doing these medicals, they shouldn't be doing them*

*KG: So what happened after they said you were fit for work?*

*KM: They took us off the sick and I had to go for a tribunal and it took three tribunals to win the case in the end...I was still getting normal dole but it's less so I mean really it was a heck of a fight and it put more strain on us health-wise and financially.*

However, Kevin successfully appealed the decision and is now in the Work Related Activity Group (WRAG).

Terry, 53, is diagnosed with bipolar disorder and had recently undergone a WCA with Atos when I interviewed him in August 2011 and was awaiting the outcome of his assessment. Terry spoke of how the assessment had caused him extra stress, stress which he avoids as it

has a detrimental effect on his bipolar. For Terry, the impersonal nature of the assessments fostered feelings of suspicion and fear, as the quotation below indicates:

*I've been on Incapacity for quite a while, for the last 10 years and it's as if they're trying to trick you into admitting that you're well are you with me? They don't...the system doesn't care about you, you're just a number. There's no leeway so I'm waiting for a letter now saying I've been failed, more hassle.*

The latest statistics from DWP indicate the uncertainty IB recipients face when entering the WCA process. In April 2011, the DWP published statistics for all completed WCA assessments (October 2008 to November 2010): 64% of people were deemed 'fit for work', whilst 1 in 4 people (26%) were moved into the work-related activity group and the remaining 10% of people were placed in the support group. The latest statistics from April 2012 show that 46 per cent of claimants were entitled to ESA. Of this 46 per cent, 19 per cent of claimants were placed in the WRAG, and 27 per cent of claimants were placed in the Support Group. 54 per cent of claimants were assessed as Fit for Work (DWP 2012). Most recent figures suggest that in County Durham, nearly half of those tested (45%) were told to look for a job immediately, whilst 26% were placed in the WRAG group and 29% in to the support group. Many people deemed fit for work have appealed the decision; interestingly, of people who made a claim for ESA between October 2008 and February 2010 and who were found Fit for Work at assessment, 37% have had an appeal heard by Tribunals Service to date. The DWP state that in 61% of appeals the original decision was upheld; in other words, 39% of appeals are successful.

### ***Awaiting the 'brown envelope'***

The majority of narratives revealed a huge amount of fear and trepidation over ongoing welfare reform. Participants spoke about worrying about the assessment on a daily basis,

accompanied by a deep mistrust of the entire system. Below, Fred, 53, gives his thoughts on the process:

*I think a lot of people in my situation that are genuinely ill are gonna be pressurised and it's gonna cause breakdowns, possibly even the worst case scenario y'know topping yourself but there again what can you do? If they could cut a penny in half they would. I think if they could bring euthanasia in, they would. If they could find a way of getting round all the moral outrage they'd probably do it. Take all the lame ones out, just like a sick animal.*

This is particularly noteworthy given that statistics suggest sick and disabled people are being driven to suicide as a result of fear over the assessment process. In a survey of over 300 people receiving IB, MIND (2011) found that 51% of people reported the fear of assessment had left them feeling suicidal. Reflecting upon suicide, Terry indicated how important his social networks were throughout the assessment process:

*I mean I've got mechanisms to support me but if I didn't have them I think I'd be beside meself by now, it's no laughing matter when people are playing around with your income. And you don't get a lot, every penny we get we need it's counted for are you with me? For them to mess around with people's income - it's wrong. I don't know what the answer is to catch people who are skiving, I don't know what you could do really but it's terrible, the pressure they put on you it's enough to drive you to feel suicidal and I'm not a person who has a problem with that, but if I was alone and I didn't have support around me you would, you'd go out and top yourself.*

Some participants specifically mentioned their fear over receiving an official-looking brown envelope through their letterbox – a possible indicator of a communication from the DWP.

This was also found in de Wolfe's (2012) study of people living with ME who were receiving IB. Sarah said of her daily fear of being selected for the reassessment:

*When the postman comes with any sort of brown envelope it is really worrying...I try not to read about it cos it's so frightening, it's like oh my God they'll send you to the dole straightaway is what's in your mind. Who will employ you, and what jobs are there? Where are the jobs? If they send me for a job in Darlington, how do I afford the bus fare on minimum wage? I mean who is gonna employ me, I'll be between an hour to two hours in the middle of the day doing my eyes, it's at least 20 minutes between each drop so that's an hour, then I can't guarantee that I can see for an hour. I cannot see who will pay me to do that. My arm – will that ever work properly again? I do not know. I have absolutely no idea.*

This fear of the brown envelope was also present in Shaun's narrative. He says:

*I panic when any of the brown envelopes come through the door cos if you're capable of walking from the door to the chair they say you're capable of work, that's how they look at it. I think even if you had no legs they'd say you're capable of something so it is quite scary but I just cross each bridge. I try not to worry about things anymore cos it just does your head in.*

An idea that their fate was in someone else's hands was a sentiment found in many of the narratives. This is also important when we think about the welfare state for sick and disabled people being framed in a more 'active' way than before. For example, people can shift from being a long-term sickness benefit recipient to being found fit for work in a WCA, despite their circumstances not changing. This categorisation from unwell to unwilling is a stark contrast for many sick and disabled people, who then must appeal against any wrongful decision which causes further stress and could worsen existing health problems

and disabilities, let alone exacerbate financial strain and hardship. For instance, for Terry who was undergoing the WCA process at the time of our interview, he felt that he would 'pass' the medical as he had the backing of his consultant. Building on the notion set forward in Chapter Five of the importance of health professionals in determining the narratives of people in the study, the following extract from Terry indicates a reliance on others:

*They send a letter to say I've passed or I haven't passed, if it's passed then all well and good but if its failed...I've got a worker, a something officer I have to see at the psychiatric hospital and she does appeals and claims against decisions and she will handle my case. She's assured me that I'll be ok because my consultant will write a letter to them saying I'm unable to work but all this rigmarole you have to go through...they don't realise how stressful it is, just waiting and waiting for a sword of Damocles hanging over you.*

Regrettably, I got back in touch with Terry following the outcome of his assessment and he had been found fit for work and placed in the WRAG group. As a result, Terry was appealing this decision.

Language referring to 'passing' or 'failing' the WCA was often found in the narratives in the study, which can be problematic as people feel they are under intense scrutiny, resulting in stress and perhaps further health complications. Indeed, as the Work and Pensions Select Committee report (July 2011) stresses:

*Care should be taken in the language used in all Government communications, and in the contacts Jobcentre Plus and Atos Healthcare have with claimants, to stress that being found fit for work is a positive outcome and should not be interpreted as "failing the test".*

Again, this further highlights the importance of language when talking about sickness benefits receipt and welfare reform

***No fear of reform: 'it'll separate the wheat from the chaff'***

Whilst the dominant narrative portrayed distinct fear and suspicion of welfare reform, others said they had no fear at all as they were 'genuine'. When asked if she was concerned about the reforms, semi-retired teacher Laura, 57, said:

*No not at all. I mean last year when they were talking about reassessing people at first I was thinking 'What will I do?' but then I thought if I come off it, I come off it that's fine. I have thought about accessing my teacher's pension so I'm trying to hang on until I'm 60 to draw that so it won't be reduced.*

Similarly, for others such as Angie, imminent reform was not something to worry about:

*The way it's changing it does get people cos they think 'What am I going to do?' I must admit it doesn't get me, if it comes to it where I'm chucked off I'll just have to find something else, I'd have to sell me house and go into a council house. I've done it before so I'd get by, but a lot of people I mean if I was the way I was before, it pushes people over the edge. I don't think they realise that it can really make you think 'I can't live like this anymore'.*

Jacqui believed welfare reform was positive as it could help to alleviate the stigma she feels of being associated with other 'scroungers':

*I think it's a good thing. People like me who's genuine are getting stigmatised for the people who are just layabouts, you see them digging gardens or changing wheels on their car and it's not fair...it'll separate the wheat from the chaff, definitely. You can tell when somebody's not genuine, it's not fair for the genuine*

*people. I'm wanting to do something with me life, not just sit about pretending I'm bad y'know?*

So why do people with similar health problems fear reform whilst others do not? Hardship could be relieved somewhat where participants had other sources of income. For Laura, losing her IB would not be a worry to her as she described herself as not needing IB financially as both her and her husband had teacher's pensions. Angie also said her decision to claim IB was not motivated by financial reasons as she had received compensation following her car accident. Equally, Jacqui spoke of her husband's well paid job and she was also in the midst of setting up her own business, which she believed was going to be successful. Interestingly, Laura, Angie nor Jacqui described IB as being part of their identity, which may also help to explain why they did not experience fear, shame or stigma as a result of welfare reform. These perceptions can also be linked to the dichotomy between 'undeserving' and 'deserving' sickness benefits recipients, as those undaunted by reform view themselves as 'genuine'.

### ***Language and stigma***

An increasingly unavoidable occurrence in the media and within government rhetoric is the negative labelling of sick and disabled people who are receiving welfare benefits. Ministerial talk of a 'sick-note Britain' has led to an abundance of articles excoriating benefit 'scroungers' (Disability Now 2011). There is no mention of the causes, symptoms, lack of diagnosis and treatment or support. Such a language of scroungers and benefit cheats is not conducive to encouraging potential employers to employ someone who has a history of IB receipt. This following section illustrates how language and stigma feature in the narratives of long-term IB recipients. Aside from the palpable fear presented in the

narratives, a feeling of stigma and shame was described as being created by political representations of the reform process. As Mick shows below:

*I haven't had that assessment yet and that worries us, definitely. When David Cameron said all that saying there's a lot of scroungers I mean I do recognise there's a lot of people who shouldn't be on it but its generalisation and it's just upsetting. But yeah it is stigmatisation when you're on benefits it does upset us it's not fair but I just get on with it basically. I feel under the Labour government they were more sort of friendly towards people with social problems and disabilities etc but I think the Tories have come in at a difficult time and it's an easy group of people to target.*

Research from MIND (2011) suggests that 87% of people told the charity that the prospect of reassessment had made them feel anxious, and over a third said that this has led to them increasing their medication. Interestingly, the most common source of information was the mass media, which is littered with scaremongering stories of 'lazy', 'work-shy' benefit cheats, as has been clearly shown throughout this thesis.

Another example of the importance of media portrayals of benefit recipients can be found in Alice's story. Alice, 54, suffers from arthritis and various physical health problems such as diabetes and heart problems. She spoke about her annoyance at the link between those who receive benefits and the London riots of summer 2011. When asked about media representations of IB recipients, Alice said:

*It worries us and it's annoying like these riots they're trying to blame people on benefits like me. David Cameron is an arsehole - I can hardly walk to the doctors but he doesn't know that, I cannot stand for 8 hours a day, and then he has the gall to say things like that. He really has no idea whatsoever what it's like to be me.*

Terry also highlighted the impact of how out of touch politicians and the media are when it comes to talking about people receiving sickness benefits:

*I'd say when you look at it in the press there's always that scrounger element, the government, the media, they always use the word scrounger and people on Incapacity Benefit are tarred with that brush, all of them. A lot of people are genuinely ill y'know and they don't realise, they can't empathise. They've never travelled a mile in my shoes and they make no effort to, so until they change their basic premise by which they go about these things, that'll never change.*

Significantly, the narratives presented here identify a clear link between media and government representations of people receiving IB and a distinct fear, shame and stigma for sick and disabled people who receive the benefit. As a result, sick and disabled people are characterised as the 'Other'. Yet such portrayals embedded within the media and in government rhetoric also serve to create divisions between sick and disabled people themselves, fostering resentment and developing increased shame and stigma for those identified as 'undeserving' by IB recipients themselves. The following section looks into this practice in more detail.

### ***'Othering'***

Interestingly, whilst IB recipients spoke of how they felt stigma about receiving IB, they also identified other IB recipients as 'scroungers', 'fake', and 'lazy'. Interviews were scattered with anecdotes of people they knew who were on Incapacity who had a motorbike, enjoyed holidays, mowed the lawn or did repairs to their car. As a result, definite 'us' and 'them' dichotomy was created by the vast majority of participants, including those who

spoke in detail about experiencing stigma themselves. For example, Jacqui, 50, explained it like this:

*I'm not stuck up but I hate being associated with them no hoppers. They don't even want a job and it's like 'God, this is not me' and you're stigmatised, claiming benefit cos you've got a bad back. I'd love to go to work but I can't. You can't tar everybody with the same brush but you're always going to get that, always. If anybody wants to skive, they blame their back and half the time you can't prove that it's not.*

This image of the undeserving unemployed was on a par with Kingfisher's (1996) notion of 'bad-people-exist-but-I'm-not-one-of-them', which was a discursive tool employed by US women welfare recipients to define themselves as deserving. Kingfisher (1996: 58) describes this in the following way:

*The strategy entailed acknowledging the existence of 'bad' individuals – individuals who were lazy, who lied and cheated – while simultaneously claiming that they themselves did not belong to this undeserving category.*

Although Jacqui herself has a bad back, she believes that others who have a bad back are often faking it. For Jacqui, these benefit recipients who fake it are 'no hoppers' who she hates to be identified with. Below, when asked what makes her different from others, Jacqui replied:

*I don't like it, I don't like the stigma, I don't like being on it. The money I get I'd rather have worked for it. There's not many people like me left on the planet. Other people wanna get by, some of them on benefits they have cars, holidays, all sorts and I wouldn't dare say I've got that through nothing, that I've got it through other people going out and grafting. I don't believe in it. Genuine people fair enough*

*there are people like me who've worked all their life so they've paid in to the kitty already, but I still don't like it.*

The distinction between others who are 'no hoppers' and Jacqui herself is defined by a long history of working and how that intertwines with entitlement. For Jacqui, being on benefits and having a car or holiday is seen as a step too far – she believes that as a sickness benefits recipient, she and others like her are not entitled to enjoy those things. The same sentiment was found in Linda's interview:

*Well there is a lot of people milk it. There's a bloke down the street does it, says he has a broken back then he goes out on his motorbike three times a week, mows his garden. I mean I've tried to get the Motability for the car but apparently I'm not sick enough for that. I can't walk along that road without extreme pain but I'm not sick enough for a car apparently.*

In her research with female welfare workers and welfare recipients, Kingfisher (1996: 8) concludes that women welfare recipients in her study:

*Do not simply internalise the views of the welfare system or society at large concerning their self-worth or place in society; rather they interpret these views. In so doing they create and impose their own meanings, of which some may in certain ways accommodate those external images and others resist them.*

Nearly 50 years ago, Briar (1966) suggested that welfare recipients often referred to other recipients as 'they' not 'we', often dissociating from their own position within the welfare system. Perhaps such behaviour can be linked to the negative government and media representations of people receiving sickness benefits currently being witnessed today. Shildrick and MacDonald (forthcoming 2013) show a strong discourse of 'Othering' was

apparent in their study. Even when people were in receipt of welfare, participants were keen to portray themselves as different from those people who they believed to be 'welfare dependent' and uninterested in employment. This ideology of the undeserving poor is shared and enacted by those at the bottom, directed horizontally towards others, objectively, like them. 'The poor' themselves are bound up in this process of labelling and castigating 'the poor'. Another study which reports something similar is by Seccombe *et al.* (1998: 862). 'Us' as the traditional working class has been replaced by 'us' as the decent, respectable, 'deserving' element of the working class set against 'them', the unrespectable and 'undeserving'. Wide solidarity was in short supply; a sense of insecurity, mistrust and hostility was more pervasive.

What is becoming increasingly worrying is how negative representations of sick and disabled people in the media have been linked to disability hate crime. Disabled activists have linked the conviction of a South Tyneside man who called his disabled neighbour a 'benefit scrounger' to hostile stories and comments that have come from the media and the government. Magistrates used disability hate crime law to increase the sentence imposed on David McGregor, who had waged a three-month hate campaign against Peter Greener, accusing him of being a 'benefit scrounger'. The campaign included encouraging his own and other local children to hurl abuse at him, sprayed graffiti on Greener's fence, and threw rocks at his window, much of it caught on CCTV that had been installed by the Greener family. Greener has a fluctuating condition, which means sometimes he can walk and sometimes he uses a wheelchair, but McGregor claimed he was exaggerating his impairment. McGregor was handed a 10-week prison sentence, suspended for 12 months, and must carry out 80 hours of unpaid work (Disability Information Scotland 2012). According to recent figures, there has been a 40 per cent increase in disabled attacks in the

past year alone - hardly surprising when the general public is constantly being fed images of unworthy benefit scroungers using up all of their hard earned taxes.

Soldatic and Pini (2009: 78) highlight the role of 'disgust' in reframing public conceptions of 'deservingness' and citizenship rights for sick and disabled people. They note that in an Australian context, distinguishing between the 'deserving' and the 'undeserving' poor has been central to the moral framework of distributive justice and social welfare within the modern liberal state – as has been the case here in the UK. This point leads us again to the notion of entitlement – are people who are sick and disabled entitled to receive sickness benefits? Do they feel entitled? The following section explores these ideas in greater detail.

### ***Entitlement***

Entitlement was linked to ideas surrounding morals and the language used to describe sickness benefits. Interestingly, people spoke of under-claiming benefits. Instances of under-claiming such as those described here would never make it into government or media discourse about people receiving sickness benefits, yet it does occur. In Kirsty's case, she refused to claim IB because she hated how receiving it made her feel. Kirsty deliberately chose not to claim IB because she did not feel comfortable with receiving IB alongside her Industrial Injuries Pension. When asked what was behind her decision to cease claiming IB, she said:

*Lots of little reasons really, one was the fact that I still felt uncomfortable claiming. If I'd been going onto Jobseeker's it wouldn't have been as bad, again it was admitting there was something wrong with me and thats what really rankled. And I dunno it just doesn't seem right that I can claim from the system but I'm not paying into it, it's probably crazy and people say it's something I'm entitled to and I should be claiming it. Even though I'm entitled, I don't think I should be entitled.*

As this extract shows, Kirsty does not believe she should be one of the 'deserving' ones who should receive IB, one of the reasons she decided to stop claiming it. Tied into this was the fact that Kirsty was reluctant to admit that she was suffering from health problems. Laura explained how she only felt entitled once someone else had convinced her that this was the case, further highlighting the importance of medical professionals in the direction of the narratives:

*I did go through phases of feeling very guilty about it, thinking 'I shouldn't really be having this' but then it was pointed out to me by my GP that I've paid in and I'm entitled for it.*

Kirsty also described another instance of under-claiming. She would not apply for DLA as she did not want to identify herself as disabled:

*Disability Living Allowance I've never applied for it cos I don't want to put my hand up and say 'I'm disabled'. If they called it by a different name, if it didn't have 'disability' in it then I would have applied. The only reason I applied for the Industrial Injuries is I can drop the 'disabled' bit out of it.*

Salway *et al.* (2007) also report a reluctance of people with long term health conditions to apply for DLA and thus accept a 'disabled identity'. Yet Kirsty was not alone in her rejection of claiming further benefits. Angie also spoke of how she refused to claim for a blue disability badge:

*You find that people who are poorly have a tendency not to want to scrounge, they just get what they have to. I mean I could have a blue badge for me car but I won't. I have to take something cos I have to live, but things that I don't really need I'm not going to take, no. A woman I worked with at the charity honestly she was poorly but she was a scrounger as well. When I had to fill one of me forms in she*

*said 'Bring it to me and I'll get you top rate disability and a blue badge', y'know like everything and I said no I couldn't, I couldn't live like that so I said no.*

Similar reactions could be found to applying for DLA. Deborah revealed how she did not claim DLA until a nurse at her local day centre encouraged her to fill in a form and posted it for her:

*People said to me 'Have you not got DLA?' I was like 'What's that?' I'd never heard of it...I've got it now but when I first got the form I read it and thought 'I'm not sending that in'... it felt like I was lying cos I can still walk about and things but the nurse said I had to think about my worst days. I said I'd got a form and she asked what I'd done with it and I said I'd put it in the bin. So she got another form and came out and helped me fill it in and she posted it.*

Again, these extracts show how others are classified as scroungers simply because they choose to take all of the help available to them. For people like Kirsty and Angie, in not doing so they believe they are separating themselves from the 'undeserving', the 'Others' who take anything they can get.

The above extract from Deborah's interview describes how she was told to imagine her 'worst days' when applying for DLA. However, for Lisa, 45, a single parent who suffers with severe back pain, this backfired and she ended up in court for over-claiming DLA. Lisa said:

*They took us to court then dropped the case on the second visit even though they had photos of me doing the washing and stuff...they had a private investigator outside the house for three month but I took it to a tribunal cos I didn't want to be classed as someone who had defrauded. We ended up agreeing that we both had a part to play, they had got the dates wrong but maybe I shouldn't have left it another year because I had slowly started to get better but the way they see it it's*

*not what's wrong with you, it's how you cope with it so I had some good times and they didn't agree with that. When I filled the forms in I said I couldn't hang the washing out, because when you fill the forms in they always tell you to think of your worst days, which is what everybody does but you're not supposed to. I'll pay back £3,000 all in all but they admitted I had major surgery so I was entitled to it at the time but now I cope better cos I'm here in the bungalow so I'm not entitled to it now...until 2020 I'll pay £10 a week off. The doctors say apply for disability (DLA) again but I won't go through that again, I'd rather just live on what I get which is less than me mam gets for herself and she's on her own. When I went for me Incapacity I said I do get good days, when I go into town and do some shopping, I'll be in agony afterwards but I do it cos I'm a single parent and who else is gonna do it?*

As a result of this, now Lisa will not reapply for DLA, despite her GP encouraging her to do so. Lisa's case highlights how entitlement is a fluid concept, one that can change over time and result in negative consequences. Indeed, as was the case for Lisa when she was hanging her washing out, de Wolfe (2012: 8) comments how participants possess a fear of being observed in small acts of normality that might indicate to an observer that they are indeed fit for work. Examples such as those cited here lend further credence to the point made by Patrick (2011b: 289) who states that:

*Conditionality and disabled people are indeed ill-suited companions, and the reforms are unlikely to increase the work rate of disabled people. Reforms would be better focused on taking more determined steps to demolish the disabling barriers which continue to prevent disabled people from participating as equals in the workplace.*

The concept of entitlement will be explored further in the following chapter which explores stakeholders' perspectives of working with long-term sickness benefits recipients.

### **Chapter Summary**

Perspectives on and experiences of welfare reform are central to making sense of the narratives of long-term sickness benefits recipients. For participants in this study, some had already experienced the uncertainty of reform, whilst others awaited it with fear and trepidation. Yet this was not always the case; some people believed as they were 'genuine' they had nothing to worry about. What can be found throughout the majority of narratives, however, is a view that classified other IB recipients as the 'Other'. Descriptions of people who were lazy, work-shy scroungers, feigning their illness was often heard, a sentiment perhaps fuelled by wider media and societal accounts of people receiving sickness benefits. Alongside this, the notion of language and reform was discussed, leading to a final section that unpacked the idea of entitlement and IB. This has been impacted upon by the move from a 'passive' to a more 'active' framing of welfare for sick and disabled people, characterised by increased personalisation and blame being placed at the door of the individual.

Ultimately, the chapter highlighted how government rhetoric and media portrayal of IB recipients as happily living a cosy, comfortable lifestyle is a myth for IB recipients in this study. Fears over welfare reform can evoke consternation and apprehension, but above all, this fear, coupled with government, media and public perceptions, appears to be creating a worrying undercurrent amongst IB recipients themselves that perceives others who receive the benefit are 'undeserving'.

## CHAPTER EIGHT

### 'THE UNWILLING AND THE UNWELL'? STAKEHOLDERS' PERSEPECTIVES

Alan, case manager, NHS:

*"Y'know we'd get up on a morning they get up on an afternoon, they throw their tracksuit on, throw a bit of water on their face and then go to Greggs for a sausage roll or whatever y'know (laughs) So you're breaking that unstructured life up into some structure for them, small steps in a way so they can begin to take bigger steps as the confidence builds. And in terms of what I've been saying you can identify a lot of barriers in that cos there's a lot of fear in people, people are afraid they're not gonna cope they get afraid that it won't work for them, they get anxious it won't last - will they have enough money, will I lose my benefits? They're in the rut and their lifestyle they've constructed becomes deeply entrenched, the mindset they've developed is deeply entrenched and I think it becomes part of who they are in a way and you're looking at a huge psychological shift. And this is maybe not PC but you hear people saying it's their entitlement - I get clients who've been on IB that long they talk about their wages in the bank and no that's your state benefit for people who are unwell, sick and need support it's not a wage and you're getting that because you're unwell or you're supposed to be unwell."*

## **Introduction**

Discussions of Incapacity Benefit largely tend to focus upon those who receive the benefit, rather than those who work alongside IB recipients. However, to fully understand the experiences of IB recipients, it is necessary to consider the experiences and perspectives of the key welfare-to-work providers, clinicians and advisors who work alongside IB recipients on a daily basis. There are relatively few studies that focus upon the experience of stakeholders. Discussions of the barriers stakeholders themselves face, alongside the significance of language and discourse surrounding sickness benefits recipients, are largely missing from such analyses. Firstly, the chapter will examine available literature on the topic of the role of stakeholders within a welfare-to-work framework, reflecting upon barriers, professional identity, and language discourse used. Secondly, this chapter will present empirical findings from the 18 interviews with key stakeholders. Discussions will focus upon the barriers for both IB recipients and stakeholders themselves, language used when talking about IB and those who receive it, before finally considering the impact of ongoing welfare reform for both stakeholders and recipients. The concept of identity will weave throughout all discussions. Finally, concluding comments will situate the findings within the context of the thesis and also within wider social policy concerns.

## **Role of stakeholders**

Both Lipsky (1980) and Wirth (1991) argue that it is not policy makers but the providers of services or 'street level bureaucrats' (SLBs) who are the most important actors in the policy field. SLBs have the power to determine access to services and benefits sought mostly by mandated clients, often providing immediate, face-to-face decisions. Faced with high workloads, limited resources and organisational targets, discretion and quick decisions must be utilised by stakeholders. Therefore, Lipsky (1980:13) argues that SLBs are in fact

'policy makers' because of these high levels of discretion and low levels of supervision, from both superiors and clients. To cope with the demands of their workload, SLBs must develop a strategy to cope with this, and will also attempt to retain discretion wherever possible in order to maximise control over their challenging work role. Indeed, Wright's (2003) observational study found that the introduction of Job Seeker's Allowance relied upon staff on the ground being willing to implement it. Accordingly, much staff behaviour was dictated by a need to fulfil targets.

Moral judgements are also considered important. For example, some clients may be afforded more time and resources, with ideas surrounding clients who are more deserving than others coming to the fore. Lipsky (1980:69) highlights how SLBs construct clients from the beginning of the bureaucratic process:

*The social construction of the client, involving the client, others relevant to the client, and the public employees with whom they must deal is a significant process of social definition often unrelated to objective factors and therefore open to the influences of prejudice, stereotype, and ignorance as a base for determinations.*

However, it is important to view Lipsky's work within the context that it was written three decades ago. In recent years, increased reliance upon technology has occurred, reducing opportunities for discretion (Grant 2011: 41). Overall, it is the nature of street-level bureaucrat work itself which empowers SLBs with policymaking ability (Lipsky 1980). Employment conditions result in both the discretion and the ability to interpret policies to meet specific demands of work.

In response to managing often intense workloads and addressing the needs of clients, street-level bureaucrats possess urgency in making judgments and executing decisions.

Key stakeholders such as welfare-to-work providers ultimately decide on whether a claimant is seriously seeking work and consequently have significant, unavoidable discretion. For Grant (2011), Jobcentre Plus Advisors typically enjoyed high levels of discretion to tailor work plans for different groups of claimants and advisors felt competent in delivering such support (Bellis *et al.* 2011). Knight *et al.* (2005: 59) report that the discretion involved in making decisions about waivers and deferrals was perceived as an important aspect of Incapacity Benefit Personal Advisor (IBPA) autonomy. It was also seen as recognition of IBPA expertise in making judgements about individual customers and the best path forwards for them. It was common to hear IBPAs describe how central the exercise of this discretion was in their day to day management of the WFI process. Less frequently, other IBPAs expressed concern about the leeway this could give IBPAs who could use them 'wrongly' to either manage their workloads (by deferring customers when their caseloads were high) or to avoid dealing with difficult or complex cases (by waiving customers who had made little or no progress or who presented with complex or multiple barriers to work). As Grant (2011: 19) explains, such an approach can either work in favour of claimants by making harsh policies more lenient, or against them, by placing bureaucratic obstacles in the way of policies intending to support the vulnerable.

More recently, Leibetseder (2011: 5) suggests that JCP still establishes an old form of traditional bureaucracy based on rules and regulations towards the clients. The interaction between the client and the public administration can be perceived as coercive and restrictive of individual agency, resulting in clients being seen as passive and having to fit into predefined, rigid categories. Leibetseder (2011: 5) asks whether services are targeted towards individual clients and whether such services are based on administration that involves the public, marketised service providers and the clients. She argues that individualisation, in this sense, simply targets the individual's employability and

competitiveness in the labour market. Certainly, the implementation of the Coalition's Work Programme in June 2011, which replaced a multitude of existing welfare-to-work programmes, enhances the significance of the role of the stakeholder. The Work Programme aims to modernise the way JCP delivers its services, giving more responsibility to advisors to assess claimants' individual needs and to offer the support they think most appropriate. Yet for the first time ever in UK welfare-to-work commissioning, providers will be paid primarily for the results they achieve in an attempt to encourage service providers to help participants into sustained work (DWP 2010c). Thus, the role of the stakeholder becomes increasingly important.

### **Barriers for stakeholders**

Advisors at JCP have to deal with a multitude of problems occurring in recipients' lives – not simply the fact that they are not in employment (Watkins-Hayes 2009). Therefore, a central concern for stakeholders when discussing working with sickness benefits recipients is barriers that prevent people from moving on to the next step of training, education, employment, or health improvement. Previous research has discussed the barriers perceived by stakeholders in terms of low labour market engagement and a lack of motivation and confidence (Beatty *et al.* 2009). Indeed, Bellis *et al.* (2011) found that when interviewed, advisors often referred to claimants' lack of self-confidence as a potential barrier to work. For example, some claimants had poor body language, were unable to hold eye contact with advisors and spoke very negatively about their abilities and skills.

On a more personal level, the relationship between recipients and advisors can also act as a barrier. For example, Dickens *et al.* (2004) comment that IB advisors spoke of a potential conflict between the need to build a good relationship with recipients and their authority

to impose a benefit sanction if claimants failed to attend the interviews. For Drew *et al.* (2010), IBPAs attempts to focus on claimants' plans or intentions to return to work were often deflected by claimants, who instead wanted to emphasise their medical conditions or other complaints as barriers to work. As a result, current strategies for enquiring about return to work – designed, in part, to unearth claimants' barriers to work – seem instead to confirm claimants' own beliefs that they are, indeed, unfit to work.

What's more, the stakeholder - recipient relationship is a power relationship (Lukes 1974). Stakeholders can depend on users to a certain extent. For example, compliance is a necessary part of the welfare-to-work process. If claimants fail to attend appointments, then those agencies would not survive and the people who are employed in them would have to look for work elsewhere (Wright 2003). For Prottas (1979: 10) *'the relationship between the street-level bureaucrat and the user is one of mutual dependency, but the client's dependency is more obvious and perhaps more painful'*. In relation to IB customers specifically, earlier research (Lissenburgh and Marsh 2003) has persistently shown the difficulty that personal advisors within Jobcentre Plus had experienced in engaging with and supporting this customer group. Key concerns were identified as: worries about the scope the advisor had to intervene positively when the individual had a certificate from their GP showing they were unfit for work; fears that raising work issues would be insensitive to the individual concerned; and the absence of suitable provision to refer people on to (Lissenburgh and Marsh 2003: 11). Indeed, all of these concerns arise within the perspectives of the stakeholders in this study.

Employers can also act as a barrier to sick and disabled people re-entering the labour market. Although the Disability Discrimination Act 1995 in the UK (DDA 1995) intended to end discrimination against disabled people, potential barriers can still remain. Research

indicates that that frequent and extensive contact between advisers and employers was rare (Knight *et al.* 2005). Where there was contact, this was infrequent and was not an organisation-wide, systematic approach for engaging with employers. Overall, advisers felt that they had no cause to be in contact and that others in JCP had responsibility for liaison with employers. Exceptions were advisers who said they might contact employers about clients involved in work preparation or job interviews, or who had hopes to build up knowledge of employers willing to employ sick and disabled people (Dickens *et al.* 2004).

What's more, barriers faced by stakeholders themselves should also be considered. For example, Knight *et al.* (2005: 25) found that advisors talked about their role with customers being more involved than they had anticipated, and could be emotionally draining when working with customers who had entrenched or severe problems. Some IBPAs felt that there was not enough support in place for them in coping with the impact of seeing these types of customers. Others described a sense of personal responsibility if dealing with, for example, a suicidal customer. Such barriers can undoubtedly have an influence upon the professional identity of stakeholders; this will be discussed in the following section.

## **Identity**

As previously suggested, the relationship between work, or the absence of it, and identity is a central theme of the thesis. Therefore, it is also of key importance to consider the importance of work and identity for professional stakeholders. Work is often considered to be a crucial factor in identity formation (Riach and Loretto 2009). Within the context of work, it can be seen that three types of factors combine to create an individual's identity - the official organisational identity; the identity of the group of workers as a whole; the individual's experiences (Marks and Thompson 2010). Multiple factors combine to create a professional identity, and the same factors may result in a differing identity between

workers in the same organisation and professional group. Indeed, the type of environment in which an individual works can have a significant effect upon their identity, and this has been related to the discretion an individual has and the individual's success or failure in the all important context of work (Gabriel *et al.* 2010).

When considering identity formation, working with benefits recipients can result in distinct categories of 'us' and 'them' for stakeholders. Foster and Hoggett (1999) found that Benefits Agency front-line staff felt that many of their clientele were undeserving, and also identified themselves strongly as dissimilar to the claimants. Howe (1990) found that workers contrasted their own role as a 'deserving' worker with the negative stereotype of the 'undeserving' unemployed person. Research on benefit administrators in the USA found similar negative views of welfare recipients, including their being labelled as dishonest (Kingfisher 1996; 1998). This suggests an implicit moral hierarchy in which advisors can be seen as viewing themselves as more worthy or deserving than claimants. The danger here is of such attitudes creeping into stakeholders' behaviour towards benefits recipients; Lipsky (1980) and Prottas (1979) both point to the ways in SLBs could bias treatment and act according to stereotypes. Consequently, the following section discusses the importance of language for stakeholders when working with benefits recipients.

### **Language**

Research has documented the wide-spread rejection of government initiatives, for example rejecting the changed language introduced in 1998 where claimants should be referred to as 'customers' (Foster and Hoggett 1999; Rosenthal and Peccei 2006). Currently, within the majority of policy documents and DWP research reports, IB claimants are referred to as 'customers'. Rosenthal and Peccei (2006: 72) note that advisors in their study believed the

term 'customer' could be less derogatory than the term claimant, as the quotation from one advisor indicates:

*Claimant sounds like a habitual benefit seeker. It sounds derogatory, like pigeonholing them. It's like a shop where you are looking for a service. They are looking for a service from us.*

The concept of the 'customer' within Social Security, however, is disputed, as benefit claimants do not have many of the rights associated with being a customer (Rosenthal and Peccei 2006; Rosenthal and Peccei 2007). Moreover, moral hierarchies appeared in the views of advisors in Rosenthal and Peccei's (2006) study. The term 'customer' was viewed as respectable by staff, and respectability was garnered through conforming to the work-focused objectives of the agency. People who were seen genuinely seeking work were labelled customers; however, the term was rejected for those who were seen to be 'working the system'. Again, this draws on distinctions between 'deserving' and 'undeserving'. As one advisor in their study stated:

*I view customers as the ones you can help, not the ones who take you for a ride. You can't see them as customers. They have no intention of getting a job. They are just working the system.*

(Rosenthal and Peccei 2006: 72).

Wright's (2003) thesis goes further and identifies the pejorative terms used by advisors when discussing claimants who challenged the workings of the Jobcentre bureaucracy. Terms such as 'nutters' and 'numpties' were used to describe claimants who were long-term unemployed. Behind the scenes, they were referred to derogatorily by staff using such terms as 'wee bastard', 'pain in the arse', or 'arsehole' (Wright 2003: 238).

Language used by advisors can also display hierarchical tendencies. In research that observed IBPAs interviewing recipients in WFIs, Drew *et al.* (2010: 82) witnessed a 'language of imposition' being employed. For example, IBPAs would often use the terms 'have to' or 'need to' in explaining claimants' attendance at further WFIs. What's more, discussions about returning to work were largely framed by a presumption that claimants would indeed be returning to work (Drew *et al.* 2010: 85).

### **Barriers for IB recipients**

The following section outlines the key themes that occurred following thematic analysis of the data: barriers for sickness benefits recipients and stakeholders; perceptions of recipients; and finally, ongoing welfare reform and implications for future practice. The discussion will largely focus on stakeholders' experiences with IB recipients as current ongoing welfare reform meant that the majority of stakeholders were mainly working solely with IB recipients whilst the transition to ESA was ongoing.

Stakeholders frequently spoke of the multitude of barriers long-term IB recipients face in taking the next step towards employment, retraining or improving their health. These ranged from supply side barriers that were seen as being part of the individual – for example, oft cited barriers such as motivation, confidence, culture and a lack of routine (Gardiner 1997), to more structural, demand side barriers including place, discrimination and a lack of jobs. Some stakeholders such as Alan, a case manager for an NHS based organisation, suggested that living on benefits had become 'too cosy and comfortable' for some people:

*In some cases it can be just their mindset. A lot of these guys are healthy, a lot of them are out with their dogs, they have hobbies, some of them play five a side*

*football. So they do have stuff they can do but it's become too cosy and comfortable for them, so it's maybe about making it uncomfortable.*

This suggests IB recipients and IB itself was viewed as a barrier as it makes people feel 'second rate' and isolated from wider society, as Billy, an advisor at a disability training college suggested:

*The thing is what does IB do? It supports you but it says you're only good enough to be given a handout which is really... it's almost like begging and for some people it will make them feel basically second rate and for others they become complacent or they become isolated.*

Wider notions of fear were discussed, largely framed by a consideration of sickness benefits as a safety net. Billy worked with disabled people who were engaged in training courses to help them move further towards employment. Billy asks: '*When push comes to shove, why should they move off the permanence of IB into the impermanence of getting a job and possibly being worse off?*' Notions of fear and confidence were intertwined throughout the interviews, with stakeholders believing that if sick and disabled people were able to believe in themselves more, they may be able to take steps towards improving their health, entering training or employment. Steve, an Incapacity Benefit Personal Advisor (IBPA), Jobcentre Plus, voiced his concerns over the negative effects of being on sickness benefits for individuals:

*I think mentality is the key, and confidence, particularly people on the sick they don't have the confidence to look for a job and they think bad of themselves which they shouldn't, they think they're not worth anything.*

In Beatty *et al.*'s study (2009:6) professional stakeholders also put a strong emphasis on claimants' lack of confidence as an obstacle to moving into employment. Some

stakeholders in this study went even further, suggesting that IB *'doesn't lead anywhere, it's a crutch that becomes like a drug'* (Jim, counsellor, disability training college). This highlights the distinction between individual 'failings' as seen by some stakeholders versus barriers that were viewed as being not the individual's 'fault', such as ill health, place, and employer prejudice.

Although ill health is undoubtedly the key reason why people are receiving sickness benefits, some stakeholders were solely concerned with getting IB recipients into work. Targets and contracts ensure a focus is upon moving people into work, as Rob, a job broker for a local charity, suggests:

*Our only target is to find employment for them, we haven't got anything around training or any soft outcomes or anything like that. It's literally engage with them, work with them and get them into work.*

Drew *et al.* (2010) confirm that it was striking that rarely, if ever, did IBPAs mention the benefits that being in work might bring to claimants' health. Although this is a prominent theme in advisor training, in these initial meetings advisors did not mention health benefits. They referred only generally to the desirability of being in work, without specifically encouraging claimants to consider the health benefits of working. This may also be linked to targets and pressure on advisors to achieve return to work outcomes. Certainly, Dickens *et al.* (2004) report that JCP advisors often regarded targets as a key issue affecting their work. Contractual obligations and targets are likely to increase further with the greater conditionality to be implemented under the Work Programme. Below, Jenny, a personal development advisor who works for a national charity which helps sick and disabled people find employment, clearly outlines the difficulties that can occur when

someone makes the transition from sickness benefits to employment when they are not fully ready:

*The worst part of this job is meeting somebody who's been on Incapacity Benefit who has pushed themselves into a job and they're coming to me to say they need support because they've got a job and you can guarantee they'll come out of work. They're the hardest to help because then all the ground works, all the levels of support you need to put in place have gone and you've got to start at rock bottom to build that person's confidence up.*

However, Knight *et al.* (2005) found that IBPAs did not define success as solely about placing an IB customer into work. They viewed significant reductions in the early barriers facing customers as equally valid as progression into work, and felt that reduction of such barriers might lead to customers accessing work in the future.

Place was also cited as an issue. County Durham is a region replete with a coal mining legacy that relates to wider, long-term processes in the economy and regional labour market. Following the closure of the pits in the 1980s under Thatcher, many miners were placed onto sickness benefits. For those in their late fifties at the time of closure, this was a fairly unproblematic step; few who have worked in the industry for a couple of decades had not picked up injuries that limited their actions in some way (Strangleman 2002). The majority of stakeholders spoke about the aftermath of the collapse of the coal industry for the North East and its impact upon sickness benefit take up. To reiterate, in County Durham, 9.4 percent of the working age population receive sickness benefits, compared to a North East average of 8.4 percent and a national average of 6.5 percent (NOMIS December 2011). Below, Michael, an occupational therapist for CMP, talks about his experiences of Easington, an area of County Durham that often comes a close second to

Merthyr Tydfil in Wales for having the highest percentage of the population receiving IB in the UK:

*It's the culture, the culture and the mindset, how people have been growing up having this industry and the belief that it was always gonna be there and in one fell swoop it was gone. It's interesting cos in some of the outlying districts the smaller pits it hasn't affected them the same as say Easington which solely depended upon those pits. I really don't know the answer cos they've pumped millions into Easington, absolute millions and nothing's changed - in fact it's probably got worse.*

Evidence from Beatty *et al.* (2009: 27) appears to confirm this perception. The stakeholder interviewees in their study seemed to give more credence to the existence of 'dependency cultures' in some districts than others, including Easington in County Durham, part of the research site of this study.

Some commentators have suggested that if an area lacks job opportunities, people should seek work elsewhere. Mead (2011) suggests that for people claiming IB in an area such as the North East, if there are no opportunities then why don't people who are 'fit but jobless' (2011: 281) should move to a more prosperous area, as is the case in America. Agreeing with this perception, Alan (case manager, NHS) suggests that perhaps people do need to look further afield to find work:

*People have lived in those kinda close knit communities there's a whole 'I wouldn't dream of moving to Carlisle, moving to Edinburgh or Leeds cos I've always lived here, this is where I've always been' and that box needs to get bigger'.*

Yet such a stark approach does not take into account the wider barriers outlined by the stakeholders in this study, such as confidence, fear of making the next step and also wider issues such as social networks, including caring responsibilities, housing and transport.

However, this approach has also been favoured by Iain Duncan Smith who suggested that people who are trapped in 'ghettoes of poverty' should be prepared to look further afield for work – reminiscent of Norman Tebbit's famous 'get on your bike' quote in 1981 aimed towards unemployed people. Although Duncan Smith claims he is not insisting everyone moves to the South of England, even travelling 10 or 15 miles can be problematic for someone who has no access to a car, has to use costly and often unreliable public transport, whilst also negotiating caring responsibilities, childcare, and of course, complex health problems or disabilities.

### **Being a stakeholder: difficulties and drawbacks**

The research strongly suggests that within the stakeholders' roles, distinct barriers were evident when working with sick and disabled people and also when working with other agencies. The difficulties faced by stakeholders in engaging with long-term IB recipients were frequently discussed within the research. Working with people who possess complex difficulties was oft cited, as the following quotation from Jim, a counsellor from a local disability training college, shows:

*People on Incapacity Benefit a lot of them don't have the facilities to deal with those issues so it can be quite a complicated role because we're not just dealing with personal issues - we're dealing with housing issues, financial issues and sometimes benefits just get totally mixed up.*

Additionally, time constraints were identified as being a problem in beginning to tackle the multifarious barriers mentioned here. For example, Steve (IBPA, Jobcentre Plus) states:

*If they don't have any questions you might have like two minutes to ask them things and it's just not enough time and its these people who need time. That's why you can book them appointments with an advisor but seeing someone once a week for*

*half an hour is nothing it's...these people need daily contact and we cannot do it. Obviously we don't have the staffing time, but there has to be some sort of help there for them.*

Consequently, the perception that helping people who are closer to the labour market - for example, the short term unemployed or younger workers - was easier and therefore a more attractive prospect than working with someone with a long-term health condition or disability, loomed large. Alan (case manager, NHS) felt that in order to help long-term IB recipients make progress they would need *'at least 2 years to prepare them for that step'* due to *'10,15 years of behaviour, of lifestyle where people have learned to survive and you're looking at unpacking all that'*. This perception could be linked to the target driven nature of welfare-to-work services, as Steve (IBPA, JCP) indicates:

*People who are further away and harder to handle, it's easy to push them away cos you know it's gonna be hard. It is driven by statistics and you have to be looking to get people into work.*

Similarly, deciding how much detail to tell people about services available so that they are best informed to make decisions may require careful assessment of individual circumstances and needs. Other research also shows that it can be particularly hard to enable people to understand, in advance, the processes and approaches involved in some services (Corden and Nice 2006). Additionally, Beatty *et al.* (2009: 65) suggest *'there is a need to carefully target initiatives on those closest to the labour market to maximise policy effectiveness and efficiency'*. Whilst this may be true, in doing so it is essential that people who have long-term health conditions who *do* want to move towards employment are not overlooked because they are not viewed as 'easy to push away' as suggested by Steve, above. This perception was also believed to be situated within employers' attitudes

towards IB recipients, as the following section indicates. Many stakeholders felt that employers do not do enough to give people with health problems or a disability a chance:

*I think there are a lot of good employers but a lot of them don't get it. They see time as money. I think it's that narrow black and white view of the world, it doesn't make a lot of sense cos there will probably be a lot of older workers who will be very good, reliable workers who just need that bit of help and support to get back into work, for those first few months until they get on their feet*

(Johnny, public health, PCT).

Sometimes stakeholders reported how they would refrain from telling an employer every detail about their client's disability or health problem in order to give them a better chance of getting a job. A recent House of Commons Work and Pensions Select Committee report (2011: 37) remarked that the government:

*Will only achieve its objective of getting benefit claimants back into work if employers are willing to employ people who might have been on incapacity benefit and out of work for some time, and who might still have substantial health issues.*

The report went on to suggest the government should play a key role in trying to change employer attitudes to former benefit claimants to ensure people leaving sickness benefits are not just job ready, but have a job to go to. This was a fundamental point echoed by the majority of interviewees, who felt that the system was not 'joined up' enough and could lead to diminished confidence for those trying to find a job. Supporting this viewpoint was the belief of some IBPAs that there was still work to do in terms of persuading employers to employ IB customers and to develop flexible, part-time working for people who employers

perceived to have been 'on the sick', as the following quotation from Jim (counsellor, disability training college) suggests:

*They're capable of work, they can do the job but the employer won't take them on cos their insurance company won't insure them for it and I think the whole system just needs an overhaul. They're not incapable of work, they're able to do work as long as certain things are put in place.*

There was discussion that some employers did not want to employ people with health conditions that affected their work to return to work, a sentiment echoed by Knight *et al.* (2005: 79). Stakeholders made it clear that employers can be wary about employing someone with a disability. Jim (counsellor, disability training college) feels that the word 'Incapacity' can frighten potential employers off:

*I think a lot of people especially when we're trying to get them jobs, incapacity frightens people off. If they're on IB what are they capable off, they can't do this, they can't do that but if you get a decent employer it's not too bad.*

Another key barrier that emerged from the interviews was multi agency working. When dealing with the complex needs of long-term IB recipients, a holistic, multi agency approach is crucial. Largely, JCP advisors have described their engagement with CMP colleagues as '*overwhelmingly positive*' (Dickens *et al.* 2004: 43) and characterised by '*mutually supportive relationships*' (Nice *et al.* 2009: 16). However, the practicalities of engaging with multiple agencies that were often competing against each other to reach their targets meant that tensions could be found. Indeed, Barnes and Hudson (2008) report on the 'rivalry' between job brokers and agencies such as CMP. They found that some CMP practitioners believed that the funding base for job brokers meant that they were a little

too keen to encourage customers back into work, regardless of whether this was appropriate for them, and were inclined to be wary of them for this reason. This point is well articulated by Rob (registered nurse, CMP) who states:

*The first thing I would say is that you can get people who feel they are obliged to come along cos their IBPA told them and that cycle of change, they're just not ready and their motivation to change isn't there. And that's ok cos that's what part of the assessment is about but then if you say you're not going to take it any further, then that impacts on the IBPA who thinks 'Oh God that was an inappropriate referral'. Then they feel bad so then eventually they might not refer, or they're constantly on the phone checking if they'll be a good referral and what we say is just send everybody and we'll decide that.*

This indicates a hierarchy of decision making in relations between Jobcentre Plus and CMP. What's more, some stakeholders felt that mainstream services such as Jobcentre Plus did not do enough to encourage sick and disabled people into work, as GP Diane said:

*Within the mainstream services it's a lot of tea and sympathy, there's a lot of poor me, oh dear you're a victim and therefore they deserve help and the bit that gets me is when people say 'It's my entitlement'. Well no it's not your entitlement, you're not entitled to anything in this life.*

Furthermore, Pittam (2010) comments that the health first approach adopted by CMP can cause tension between CMP and Jobcentre Plus, an issue raised throughout the stakeholder interviews in this study. Drawing on the notion of the respectable customer (Rosenthal and Peccei 2006), Steve (IBPA, Jobcentre Plus) comments:

*People like CMP they're a really good service cos they can do counselling sessions and stuff but at the end of the day they come in for their appointment and then it's gone it's more like case work but it is hard to get the right customers for it.*

Others were critical of the role of GPs in assessing whether an individual was fit to work or not: *'the GPs aren't skilled to say to a person you can do this, you can't do that, have you thought about that transition and that's a big gap in my opinion'* (Jacqui, Customer Engagement Manager, JCP). Indeed, previous studies have pointed to a number of barriers to effective partnership working between NHS organisations and other stakeholders (such as JCP), that are related to a lack of clarity around roles and responsibilities, and problems in information sharing (Hunter *et al.* 2011). Furthermore, some stakeholders felt that it was essential other agencies were fully aware of what they could offer to forge a successful working relationship, as Michael (occupational therapist, CMP) states:

*It does depend on which area you work in and which Jobcentre that you cover. If they feel that CMP is a good idea or if they have a good understanding of how we can help you tend to get better referrals.*

A similar finding is reported by Lindsay and Dutton (2011) who observe that more general day-to-day partnership-working between JCP and NHS staff had initially proved problematic, seemingly due to a lack of communication between senior managers. Having explored barriers for stakeholders, the following section discusses stakeholders' perspectives of long-term IB recipients, including a consideration of the language used not only by stakeholders themselves, but also the wider media, policy and academic discourse surrounding sickness benefit receipt.

## Perceptions of IB recipients – ‘the unwilling and the unwell’

*The unwilling are different from the unwell and I think that what needs to happen is we need to identify the unwell and the unwilling and separate them out and work in two different ways.*

(Alan, case manager NHS).

The following section explores the distinctions of ‘deserving’ and ‘undeserving’ presented by the stakeholders, before thinking critically about the language used when discussing long-term IB recipients. An overarching finding that arose from the research is that many of the stakeholders’ views fell in line with discourse that negatively stereotypes benefit recipients. As Steve (IBPA, JCP) comments:

*It can be that life is too comfortable on benefits. They’ve got their council tax, they’ve got their rent paid, they’re maybe doing a bit of work on the side, they’ve got kids so they’re on that whole Daily Mail thing y’know getting everything provided for them and their family y’know where most of their needs are met, yeah they’re limited needs that are limited in terms of lifestyle but they get used to living in that sort of lifestyle.*

This indicates a clear moral hierarchy by the stakeholders who subscribe to an ‘us’ and ‘them’ dichotomy, with IB recipients being described as the ‘Other’. Research by Shildrick *et al.* (2010: 51) found that stakeholders and employers in their study adopted similar stereotypical attitudes towards unemployed people. A notion of a ‘culture of worklessness’ that was learned in families and passed down through generations was often heard, despite no direct evidence to suggest this. Interestingly, one oft-told story concerned a young man who was forced to give up his job by his parents because they were not happy about him waking others in the household in the morning when he left for work. Even if

this one such case is true, the fact that the exact same story was repeated by other stakeholders and became somewhat of a myth and shows how easily negative stereotypes can be formed and become ingrained.

However, such moral judgements are by no means UK-centric. Research on benefit administrators in the USA found similar negative views, including recipients being labelled as dishonest and lazy, with a clear discourse of 'deserving' and 'undeserving' running throughout the narratives of professionals (Kingfisher 1998). A sympathetic view could suggest that perhaps such stereotypical views could be partially attributed to the large caseload faced by many stakeholders, alongside reduced resources and a difficulty to relate to IB recipients complex needs. Indeed, Webster (2008) suggests that to avoid burnout, advisors de-personalised their customers, acting in a detached way, although this was not a long-term solution and burn out is often a long-term problem. In addition, some advisors felt a tension in their role between attempting to support people and, at the same time, controlling their behaviour (through benefit sanctions, if necessary). This may, in part, explain the feeling that advisors found it easier to progress 'voluntary customers'.

Yet it is important to highlight that not all stakeholders in the study adhered to the 'scrounger' viewpoint. Johnny (public health, PCT) believes only a very small number of IB recipients are actually not genuine, as with any other benefit:

*There's the media perception that's just boozy scroungers, people should be going out to work and I don't subscribe to that, I think you'll always get a percentage of people who try any system on and you'll get that on IB but it's a very small number.*

Albeit less frequently, other stakeholders pointed to the belief of many long-term IB recipients that work would in fact improve their health, as shown by Jenny's (personal development advisor, disability charity) comment: 'We do get an awful lot of people

*through who say 'I'll be alright if I get a job'*. This statement contradicts much rhetoric that assumes people receiving sickness benefits do not want to work. Indeed, this study strongly indicates that many chronically ill and disabled people have a deep seated desire to work, and believe that employment could improve their lives for the better. Patrick (2011b) also reports that disabled people do, in fact, possess aspirations to work; however, such aspirations are undermined by both disabling barriers and the impact of their own impairment – a finding most definitely echoed by the narratives presented in preceding chapters.

Clearly, whilst not all stakeholders viewed sick and disabled benefits recipients in a negative stereotypical way, in certain instances this did occur. This creates obvious tensions for me as a researcher as being presented with views which are derogatory towards long-term IB recipients was difficult for me to negotiate and manage. Throughout the fieldwork with stakeholders, when presented with opinions such as *'life is too comfortable on benefits'* I would ask participants to expand on their answers. I would be met with a response that would list their years of experience and expertise working with sickness benefits recipients, and a confirmation that for them in their role, they truly felt that people either did not want to work, or were happy to live their lives on benefits.

Just as it is not my place to question the 'truth' of the health and illness narratives relayed to me, ultimately I had to accept that for the stakeholders, they were telling me their 'truth' based upon the day-to-day experience of working with long-term IB recipients. I have consistently made every effort to report both the stakeholder narratives and the long-term IB recipients' narratives as they were told to me. Maybe the perceptions held by stakeholders are a result of them not asking, or indeed not having to ask, the right questions. In other words, it is not the role of a staff member at Jobcentre Plus to ask about the daily health and illness narratives of long-term IB recipients, or about how it makes

them feel. Perhaps if that was the case (which clearly is unlikely to occur) then perceptions would alter. However, it would evidently be beneficial to both stakeholders and IB recipients if a consideration of the wider constraints faced by sick and disabled people, including stigma and the impact that a transition onto sickness benefits can have upon someone's daily life, could be taken into account.

### **Professional Identity**

As previously suggested, identity formation is a central interest of the study and therefore the professional identity of the stakeholders was explored throughout the fieldwork. Although stakeholders were vocal about the multiple barriers they faced in working with IB recipients, and despite the stereotypical views they conveyed, high levels of job satisfaction were present. Whilst IB recipients were felt to be a challenging group to work with, advisors talked about the job satisfaction they got from managing to overcome barriers and move people forwards. For example, Jenny (personal development advisor, disability charity) commented:

*I love me job honestly I do I say it every day I love me job (laughs) If you've got the passion and you love the job your enthusiasm spills through. All of the advisors that do this role we have people so motivated by the time they walk out the door it's nice to see a difference in people, they walk out ten foot taller.*

For Alan (case manager, NHS) not having a pure work focus helped him to engage successfully with people:

*You're not imposing things on people and people feel heard, they feel listened to and they feel understood so they're much more willing to engage. And they don't see us as a threat to their benefits we're looking at their health. Ok it's the bigger*

*picture but we're looking at the health and wellbeing and most people see that as non threatening.*

CMP nurse Rob agreed and commented that he was shocked by the way Jobcentre Plus interacted with customers:

*People lecturing the customers was a bit of a shock to me and then they come to us and we don't lecture, we're on their side and I think that is sometimes a revelation to customers. They've been in this Jobcentre culture then they come to us and it's like 'What's he after, he's being nice to me?' So that's helped us I think cos we haven't had to do much to get people to embrace what we do.*

This point is reinforced by the work of Lindsay and Dutton (2011: 11) who describe how CMP practitioners in their study saw their relationship with IB recipients as being characterised by '*values of confidentiality, credibility, clinical expertise and professionalism, and trust*'. Some stakeholders spoke of the power relations between themselves as stakeholders and their clients. For example, Michael (occupational therapist, CMP) stated:

*Well it is a funny job actually that's a good question cos when we started we didn't have enough clients, then we had too many, and now we don't have enough again. The DNA (do not attend) is a problem because if you have a day where only one person turns up it's a bit demoralising not having enough to do, it's quite hard.*

The above quotation from Michael suggests that in the relationship between IB recipients and professional stakeholders, at times power can shift which results in IB recipients possessing the power to make stakeholders feel 'demoralised'. Not attending appointments will not only leave stakeholders questioning their value, but could also negatively affect relations between both parties in future dealings. Having explored

professional identity, the following section examines how language can be of importance when considering long-term IB recipients.

### **Language**

Stakeholders' use of language when discussing long-term IB recipients was laden with moral overtones. Some stakeholders spoke of the creation of a '*diseased personality*', whereby disabled people have '*an investment to staying sick and living out that sickness so it becomes part of who you are*' (Alan, case manager, NHS). For Diane (GP), IB recipients create a '*disabled lifestyle*' that they wished to remain part of. Often, this belief was underlined by the idea that people on long-term sickness benefits had been told they were unfit for work, and had grasped onto that idea and refused to let go, despite possibly being fit for work. Beatty *et al.* (2009) also found stakeholders they interviewed strongly indicated that they believed a culture of dependency does indeed exist. The idea that people on IB fashioned a 'sick' identity or adopted a 'disabled lifestyle' may be implicitly legitimised by the ready-made distinctions created by ESA between the work related activity group and the support group – or, in other words, those who are viewed as sick and others who are simply unemployed with minor health conditions.

In fact, whilst some stakeholders felt that long-term IB recipients created a sick identity or lifestyle, others saw the term 'Incapacity Benefit' itself as placing wider social constraints upon sick and disabled people. As Jim observes (counsellor, disability training college):

*The term Incapacity Benefit conjures up incapable and they're not incapable, they do try and they work really hard but that word 'Incapacity'...a lot of them tell you they're on sick benefit instead cos it sounds better'.*

What's more, the language used to describe IB recipients was highlighted as a barrier in a recent report by the House of Commons Work and Pensions Select Committee (2011). According to the report, *'the language currently used to describe the outcome of the WCA is a barrier to the government's objectives for the reassessment being properly communicated'*. The report points out there are sections of the media that routinely use pejorative language, such as 'work-shy' or 'scrounger', when referring to IB claimants. It continues: *'Portraying the reassessment of incapacity benefit claimants as some sort of scheme to 'weed out benefit cheats' shows a fundamental misunderstanding of the government's objectives'*. Whilst the report, and indeed the government, will have limited power to change the coverage, the situation could be improved if the government were to ensure its own commentary on the statistics and the context that is provided is wholly accurate and does not mislead the general public or create further concerns for sick and disabled people.

### **Perspectives on welfare reform**

The majority of stakeholders agreed that welfare reform was important and it was largely viewed in a positive light. For example, Michael (occupational therapist, CMP) quite simply stated: *'I agree with it cos surely getting people into productive work is the point - I mean sitting on IB for 20 years until you die, what's the point in that?'* However, criticism was aimed at the way in which changes should be implemented, with the belief that *'at the moment they're just kicking everybody off it'* (Jacqui, Customer Engagement Manager, JCP) and instead the changes should be gradually introduced. Indeed, recent reports suggest that the Atos assessments are falling short of what recipients can rightly expect, leading to fear and mistrust surrounding the whole process. This fear was replicated in the stakeholders' own perspectives:

*They're saying they'll make it more simple y'know as in the one size fits all i.e. we don't fit anybody properly at all – it doesn't work because it's oversimplified but I can see where the government is coming from because simplified it would be easier to understand. But at the same time it would inevitably become a problem because some people would lose benefits that they require and it's easier to say it than it is to do it.*

(Billy, advisor, disability training college).

Stakeholders also felt that increased conditionality and sanctions for sick and disabled people will result in widespread fear and anxiety. Amongst others, Cheryl (local partnership manager, JCP) talked about the fear people had about losing benefits, which in turn can have a negative impact on people's mental health. Additionally, questions need to be asked about the type and quality of jobs available to people leaving long-term IB – a point stressed below by Johnny (public health, PCT):

*I wonder if these people do end up in employment what sort of work they'll end up in, will it be a good job, will they be able to sustain that work or will they end up looping back into the system or not and I wonder what will happen to them in the long-term.*

These notions are reinforced by Patrick's (2011b) research which suggests that the government's attempts at raising the employment rate of disabled people are likely to fail. Sanctions and increased conditionality are unlikely to provide a remedy, particularly when the problem is with the disabling structures and practices of society, rather than any individual deficits with sick and disabled people themselves. Some stakeholders expressed concerns over the implementation of the Work Programme and what that will mean for

them as providers. For example, Jeff believed that their approach would have to become ‘a lot more cut throat’:

*I think it'll affect the duty of care. When it gets down to the grass roots I don't think it'll be as much of the care side anymore because obviously now we work with people like drug users, offenders, people with long-term health issues and you've got to put a lot of support in and I think the support'll go when the Work Programme comes in cos it's all targets, target related so we'll end up more...well providers will end up more like recruitment agencies because it'll be more business orientated.*

(Jeff, job broker, local charity).

Indeed, the introduction of the Work Programme could result in the possibilities of creaming and parking (Hudson *et al.* 2010) where contractors might choose to concentrate their time and resources on those most job-ready (creaming) while sidelining those who they view as having little prospect of a working future (parking). Others outlined the potential for error within the new system, with people being classified as fit for work when they genuinely are not:

*I've got one lad who's going blind because he had a bleed on the brain and he's lost his sight and he's in the WRAG (Work Related Activity Group) group when actually his sight is deteriorating so rapidly that he really should be in the support group to deal with the health issues that he's got. So there's a little bit of injustice there as far as the medicals concerned.*

(Jenny, personal development advisor, disability charity).

This point was reinforced by Jacqui (Customer Engagement Manager, JCP), who stated: *'I've got one lady with breast cancer and she's actually still undergoing treatment but she was found fit for work. The medicals are coming back quite harsh cos of the way they are - they're rigid'*. Such examples lend further credence to the idea that welfare reform is contravening the human rights of many sick and disabled people. These narratives echo findings from an independent government review of the Atos process carried out by Professor Malcolm Harrington (2010: 8) that *'the system can be impersonal and mechanistic, that the process lacks transparency and that a lack of communication between the various parties involved contributes to poor decision making and a high rate of appeals'*. Funding cuts and the termination of services was also a topic of concern for stakeholders, who pointed to the fact that *'one minute a service is here and the next minute they're not'* (Helen, occupational therapist, CMP). Such lack of continuity and uncertainty can result in further barriers for IB recipients.

### **Chapter Summary**

This chapter has examined professional stakeholder's perspectives of long-term IB recipients. Whilst all stakeholders recognised the diverse barriers faced not only by long-term IB recipients but also the barriers they themselves contend with, underlying tensions are apparent when discussing stakeholders' opinions. Interestingly, stakeholders often expressed stereotypical views that lend credence to a notion of a 'culture of dependency', with notions of 'deserving' and 'undeserving' recurrently creeping into their accounts. Critical reflections upon the use of language by stakeholders reveals that on the one hand, some stakeholders used language that negatively portrays long-term IB recipients, whilst on the other hand, the word 'incapacity' itself had negative connotations for some stakeholders who felt the term was disabling rather than enabling. Largely, the stakeholders in this study welcome welfare reform but worry about how it might be

implemented, with fears of people being wrongly classified as fit for work under a 'one size fits all' approach.

Whilst such findings may not be wholly surprising, they should not be underestimated or dismissed. As growing negative publicity surrounds sick and disabled people facing welfare reforms, stereotypical views can and do have a real impact upon the lives of sick and disabled people. Government discourse, media portrayals and public opinion of sickness benefits recipients all play a role in shaping the stakeholders' perspectives, further exacerbating notions of deserving and undeserving amongst sick and disabled people. Fundamentally, welfare reform will result in changes not only for recipients themselves, but also for stakeholders who will be required to negotiate an ever-changing welfare landscape. Consequently, it would be beneficial to both stakeholders and IB recipients if a consideration of the wider strains faced by sick and disabled people, including stigma and the impact that a transition onto sickness benefits can have upon someone's daily life, are fully taken into account.

## **CHAPTER NINE**

### **DISCUSSION AND CONCLUSION**

#### **Introduction**

This final chapter begins with a summary of the overarching themes of the thesis. The chapter then reiterates what questions have been answered through the completion of the thesis. Following this, a consideration of how the findings relate to other research in the field will be discussed. Whilst the thesis does not attempt nor claim to generalise to everyone who receives sickness benefits, some of the findings and conclusions are likely to extend to reflect the experiences of others receiving sickness benefits. Consequently, a consideration of future policy implications will be made in light of the findings, together with possible avenues for further research, before finally presenting concluding comments.

This thesis began with the aim of exploring the relationship between long-term IB receipt and stigma in areas of North East England with the highest levels of IB receipt. The research questions asked about the nature of the health and illness narratives of long-term IB recipients, but more specifically how long-term IB recipients respond to stigma in their narratives when faced with political, media and public representations of IB recipients as scroungers. In order to do so, not only were IB recipients included in the study, but 18 key stakeholders who worked with IB recipients were also interviewed. Crucially, all of these narratives need to be interpreted within the current context. Welfare reform has resulted in a shift from a 'passive' to a more 'active' framing of ill health that has placed increased scrutiny and suspicion on the motivations and actions of long-term IB recipients.

Within the Methods chapter, reflections were made upon why people chose to take part in the research, which is especially important when we consider that sometimes people did not share their 'claimant' identity with close friends and family, yet they did so to me for

the purpose of the research. The following five chapters explored the findings from the qualitative interviews carried out with long-term IB recipients and stakeholders, uncovering a wide range of important themes and issues. This chapter seeks to consolidate these themes and issues in an attempt to interpret what the findings could mean for IB recipients themselves in terms of policy and practice, alongside avenues for further research.

### **Main overall themes**

The key findings of this thesis suggest that the reality of living on IB is in stark contrast to the assumed reality so often presented by the government, media and wider public. We are regularly fed images suggesting those on IB are scroungers, fakers, work-shy individuals who are living a financially comfortable and carefree life. However, the findings of this study show that for the IB recipients involved in the research, such assumptions could not be further from the truth. Instead, being on IB brings with it deep seated feelings of stigma and shame, identity disruption and of course for many, daily pain and suffering, both physically and mentally. This is underpinned by financial strain and hardship that is being further exacerbated by welfare reform. This section will take each chapter in turn, outlining the key themes and how they support these arguments.

It is important not to overlook the experience of being involved in research for participants, particularly when engaging with a hard-to-reach group such as long-term IB recipients. Therefore, **Chapter Three** was the first chapter to introduce empirical evidence from the research. Interviews indicated that the interview process made people feel ‘useful’, ‘worth something’, and was often described as ‘therapeutic’. From this chapter, it was evident that identity was going to be a key theme underpinning the narratives. The idea of performance was interlinked with this theme, with IB recipients keen to portray themselves as ‘genuine’ during the interview process, as can be seen in the actions of people who showed me

official letters documenting their benefits, or presented me with bags full of medication. Clearly, how others perceived them was a key concern for the IB recipients in the study, and this process began with the relationship between myself as a researcher and the participants as those being researched. Long-term IB recipients were anxious of others' perceptions of them and were keen to display an identity that did not fit with the scrounger didactics often featured in the public domain.

**Chapter Four** showed that the shift onto IB can be a deeply traumatic and painful process that encompasses not only health, but also family, friends, status, and identity. Living with illness or impairment was described in contrasting ways. Many described a daily routine filled with feeling guilt, boredom, restlessness and frustration at not being able to do the things they used to be able to do. In contrast to much media opinion and indeed the opinion of many within the government, the chapter observed that for the majority of people in this study, being on IB was certainly not a comfortable, agreeable 'lifestyle choice'. Instead, narratives were consumed by a daily struggle of pain, embarrassment, stigma, and financial strain. Identity was an evolving concept that participants negotiated by various means.

Emerging as significant themes, the following resources and strategies were employed to strategically protect and preserve identity. Firstly, participants attempted to construct new dimensions of self following the transition onto IB. For most, this included a rejection of a 'disabled' identity was also accompanied by the dismissal of a 'claimant' identity in most cases. Yet in certain instances, participants created a new, positive identity in their transition, characterised by past achievements and new opportunities. Secondly, the findings show that looking ill and proving authenticity was highly important for long-term IB recipients, perhaps an unsurprising finding given the continued questioning of sick and disabled people from the government, the mass media and the wider public. However, the

chapter showed an ingrained fear and anxiety over others' perceptions of them and their conditions, which particularly for people with mental health problems, can make health a lot worse. Lastly, the chapter showed that the transition onto IB does not necessarily result in a negative identity shift. The term 'incapacity' masks a whole range of realities; for example, pursuing new aspirations and goals allowed some participants to evade the negative connotations attached to being on IB for many participants. Instead, new identities were created that included learning new leisure skills, following different career paths and accepting their new identity.

**Chapter Five** underlined the significance of social networks, including family, friends and key professionals such as GP's or welfare-to-work staff. The chapter showed how friends and family play an important role in the narratives of the long-term IB recipients in this study, whether in a positive or negative way. The findings confirm that the impact others could have on people's narratives cannot be underestimated; being told by a GP that work was not a future option could become a further reason why IB recipients felt they were unable to re-enter the world of work. Yet on the other hand, participants could feel that they had been 'let down' by professionals who had not provided as much support as was expected, leading to feelings of isolation. Linked to this was a retraction from social networks by some participants who reported how they have a tendency to '*keep meself to meself*' and shy away from family and friends, in order to avoid revealing the extent of their pain and suffering or even to avoid having to reveal their 'claimant identity'. Finally, the relevance of place and community for participants was explored. Findings illustrate that for the participants in this study, social networks were perceived and experienced in different ways.

Populist beliefs surrounding long-term IB recipients are full of connotations that suggest people are work-shy and lazy. On the contrary, **Chapter Six** showed that the participants in

this study recognised the importance of work as being integral to their identity, even if they were not planning on returning to the labour market. People spoke of work as being highly important to them, 'a way of life' – many were desperate to get back into work, yet were prevented from doing so either as a result of their health problems or disability, or due to what they perceived as a lack of jobs and supportive employers. Such evidence of work motivation goes against assertions of a 'dependency culture' that is supposedly evident amongst long-term sickness benefits recipients. Additionally, for people with backgrounds of high education qualifications such as degrees, finding the appropriate support to get back to work was seen as problematic as many back to work courses focused on basic skills such as literacy, numeracy and CV writing. Finally, the chapter discussed how a reconsideration of the concept of paid work could be challenged to better fit the needs and complex realities of sick and disabled people. Such a reconsideration could include flexibility in terms of hours, home-based working, and importantly, a recognition that forms of activity such as voluntary work, fostering and participating in community groups can all contribute to society.

**Chapter Seven** delved into participants' views on and experiences of welfare reform. For participants in this study, some had already experienced the uncertainty of reform, whilst others awaited it with fear and trepidation. Yet others in the study believed as they were 'genuine' they had nothing to worry about and held the belief that welfare reform would '*separate the wheat from the chaff*'. What can be found throughout the majority of narratives, however, is a view that classified other IB recipients as the 'Other'. Descriptions of people who were lazy, work-shy scroungers, feigning their illness was often heard, a sentiment perhaps fuelled by wider media and societal accounts of people receiving sickness benefits. Alongside this, the notion of language and reform was discussed, leading to a final section that unpacked the idea of entitlement and IB. Findings suggest that the

ever-increasing talk of IB recipients as scroungers is being internalised and is further enhancing notions of suspicion and mistrust of, and for, sick and disabled people. This has been impacted upon by the move from a 'passive' to a more 'active' framing of welfare for sick and disabled people, characterised by increased personalisation and blame being placed at the door of the individual. Further, an interesting finding that would never make it into government rhetoric or media representations of IB recipients is that of under-claiming benefits. People refused to claim for benefits they were legitimately entitled to because they did not like the connotation attached to being on IB or DLA, or sometimes simply because they were not aware of what they could claim.

Finally, **Chapter Eight**, which presented the perceptions and experiences of key stakeholders who were working with IB recipients, showed that although stakeholders recognised and negotiated the complex barriers faced by IB recipients, stakeholders often expressed stereotypical views that enveloped a 'culture of dependency', with notions of 'deserving' and 'undeserving' recurrently creeping into their accounts. Within this chapter, the importance of language was highlighted - some stakeholders used language that negatively portrayed long-term IB recipients, whilst on the other hand, the word 'incapacity' itself had negative connotations for some stakeholders who felt the term was disabling rather than enabling. Although the majority of stakeholders agreed that welfare reform was important and it was largely viewed in a positive light, concerns remained that increased conditionality and sanctions for sick and disabled people will result in widespread fear and anxiety. Some stakeholders expressed concerns over the implementation of the Work Programme and what that will mean for them as providers, including the possibility of contractors choosing to concentrate their time and resources on those most job-ready while sidelining those who they view as having little prospect of a working future – in other words, long-term sickness benefits recipients.

## **Summary of main overall themes**

Overall, the research suggests a need for a better understanding of the lives of sick and disabled people - not only their attitudes towards working, but also an appreciation of the difficulty of living with impairment. People experienced huge levels of stigma about being on IB, in some cases refusing to reveal their 'claimant' identity to even close friends and family and actively avoiding social events to avoid being asked the dreaded question 'What do you do?' Equally, being faced with the label of 'disabled' was not something that was readily accepted, highlighting the importance of the distinction of the two categories of 'sick' and 'disabled'. The research shows that people on IB are not living a comfortable, luxurious lifestyle. Instead, narratives are awash with stories of daily suffering, frustration and financial hardship. Whilst negative identity formation occurred following the onset of chronic health problems or an exit from the labour market, new positive identities, such as foster carer or voluntary worker, could be created and maintained. Such positive identities can be used to oppose negative characterisations of sick and disabled benefits recipients as non-contributory to society. Underpinning these considerations is the importance of language for long-term IB recipients in terms of identity and stigma, as can be seen in the stakeholder narratives, but also when thinking about the government and media. Finally, welfare reform is creating widespread fear and consternation amongst IB recipients, with language of 'deserving' and 'undeserving' being internalised amongst recipients themselves, thus creating unnecessary categories of other IB recipients as the 'Other'.

## **How do the findings relate to the research questions?**

This section will explicitly link the findings of the study to the research questions that were outlined at the beginning of the thesis. Taking each research question in turn, it will be demonstrated how the findings fully address the questions that were initially asked.

***What are the health and illness narratives of long-term IB recipients?***

It was important to uncover the day-to-day lived reality of being a long-term IB recipient; something that is largely absent from current academic literature. The transition onto IB was made in three ways – people had grown up with health problem; people had become ill gradually, usually whilst working; and finally, people who had experienced a sudden accident or illness, again usually whilst working. For some, leaving the labour market to begin claiming IB was a welcome relief, whilst for others it evoked feelings of shame, guilt and isolation. The findings show that many people described a daily routine filled with feeling guilt, boredom, restlessness and frustration at not being able to do the things they used to be able to do. Yet on the other hand, in some instances becoming ill or more ill and departing from the labour market allowed, or indeed encouraged, people to pursue a different career path or a hobby they had previously not had the chance to take up. An overarching theme that emerged from the narratives was one of a life ‘before illness’ and a life ‘after illness’. A deep sense of longing for the person they once were permeated the narratives. Becoming ill did not just result in losing a job: it could mean losing a wife, home, friends, independence, confidence, identity and a sense of self. Alongside this, health and illness narratives revealed severe hardship, particularly for people who were living alone and only had IB as their sole income. For some people, it was an opportunity to pursue a different career path or achieve aspirations of participating in society through volunteering or sometimes simply taking up a new hobby that previously was not an option.

***What is the relationship between IB receipt and stigma in the narratives of IB recipients?***

Receiving IB was characterised by high levels of stigma and shame for the majority of participants in the study. Government rhetoric and mass media portrayals of long-term IB recipients were closely aligned with participants’ experiences of stigma. Often, this stigma

was so strong that people did not reveal their 'claimant' identity to others, and they would purposely avoid situations where it was possible people would ask 'What do you do?' Stigma was something that IB recipients spoke about largely without any prompting – it was at the forefront of their daily lives, something that was experienced not only as a result of being on sickness benefits, but also due to being ill. People experienced stigma because they could no longer do the things they used to do, ranging from being employed to things like walking the dog or making the tea. What's more, the key stakeholders in the study expressed stereotypical views that enveloped a 'culture of dependency', risking placing further stigma on IB recipients and encouraging the development of distinctions between 'deserving' and 'undeserving' sick and disabled people. If stakeholders who possessed these opinions were able to alter their views towards sickness benefits recipients, perhaps then they could help to challenge the negative stereotyping of sick and disabled people, albeit in a very limited way.

***How do people receiving IB construct their identity amidst political, media and public constructs of welfare 'scroungers'?***

Firstly, participants attempted to construct new dimensions of self following the transition onto IB. For most, this included a rejection of a 'disabled' identity but was also accompanied by the dismissal of a 'claimant' identity in most cases. Yet in certain instances, participants were able to create a new, positive identity as part of their transition, characterised by past achievements and new opportunities. Secondly, the findings show that looking ill and proving authenticity was highly important for long-term IB recipients; perhaps an entirely unsurprising finding given the continued questioning of sick and disabled people from the media, the government and the wider public.

Findings suggest that the transition onto IB does not necessarily result in a negative identity shift. Pursuing new aspirations and goals allowed some participants to evade the negative connotations attached to being on IB for many participants. Instead, new identities were created that included learning new leisure skills, following different career paths and accepting their new identity. A positive identity could also be created through the negative labelling of other IB recipients as 'undeserving'. In distancing themselves away from those who are perceived as feigning illness and who enjoy receiving IB, they could carve out a new identity as a 'deserving' IB recipient who has genuine health concerns which are often accompanied by a lengthy history of employment or a desire to work.

***How do people receiving long-term IB respond to welfare reform and the shift from a 'passive' to a more 'active' framing of ill health?***

Participants were clearly aware of the ongoing welfare reform and although some were more aware of the intricacies of the benefits changes than others, they were all clear on one thing – welfare reform would mean huge changes for long-term IB recipients. The reaction to impending welfare reform was mixed – for some, there were few anxieties over the reform process as they believed their case was genuine so they would not need to worry. Others, although believing themselves to be genuine, had an ingrained apprehension of the reform process. Fears over welfare reform brought with it consternation and apprehension, but above all, this fear, coupled with government, media and public perceptions, appears to be creating a worrying undercurrent amongst IB recipients themselves that perceives others who receive the benefit as 'undeserving'.

Linked to this is an interesting finding that would never make it into government rhetoric or media representations of IB recipients - that of under-claiming benefits. Some people in the study felt such stigma and shame about receiving IB that they decided not to claim it, whilst

others would refuse to apply for benefits such as DLA and additional help such as a blue badge to enable them to access disabled parking. Often, the rejection of these benefits was linked to the language used – for example, it was commented by Kirsty that if DLA did not employ the term ‘Disability’ then she would have applied for it. Of course, DLA is being replaced with Personal Independence Payments (PIP) which in turn brings with it a change of name and perhaps a change in emphasis for sick and disabled people. However, government rhetoric suggests that unfortunately, this may not be the case. Recently, Iain Duncan Smith suggested that the 30% rise for claims for DLA was a result of fraud in the system. This is despite the fact that official DWP figures estimate fraud is a mere 0.5%, nowhere near the staggering 30% suggested by Iain Duncan Smith. Neil Coyle, director of policy and campaigns with Disability Rights UK, says the biggest area of growth is down to the ageing population – people who have been granted DLA earlier in life can continue to claim when they pass pension age. Since this is a relatively new benefit, launched in 1992, the number of older people claiming it has ballooned and there has also been a growth in younger claimants. What’s more, it should not be forgotten that DLA is not an out-of-work sickness benefit; rather, it is intended to help people meet the extra costs of disability-related care and mobility whether in paid employment or not. As part of ongoing welfare reform, in August 2012 the government announced that Atos will be responsible for carrying out the PIP assessment, a contract worth £400m. It will be interesting to see how these assessments by Atos will be received given the reaction to the WCA as essentially not fit for purpose.

### **Interpretation**

The following section will explain how the findings of this study are important and how they relate to wider research in the fields of health, disability studies and social policy. There has been a noticeable scarcity of research exploring the interactions between ill

health and the experience of receiving welfare benefits. Whilst there have been a number of studies of the impact of welfare-to-work interventions on employment rates (Bambra *et al.* 2005), and much is known about the links between unemployment and ill health (Black 2008), far less is known about how welfare reform impacts upon individuals experiencing ill health or disability who are in receipt of sickness benefits. Equally, there is a long history of research that has focused upon illness and identity, yet the experience of illness, identity and welfare receipt is largely missing from such discussions.

Firstly, it is important to point out that studies of people receiving sickness benefits have tended to focus largely upon the labour market, work, employability (Kemp and Davidson 2010) and the changing nature of IB receipt in terms of gender (Beatty *et al.* 2010). With few notable exceptions (Riach and Loretto 2009; Wainwright *et al.* 2011) the issue of self identity and sickness benefits receipt has been somewhat overlooked. Of course, this thesis has discussed a wide range of literature that delves into health and identity formation, but far less is known about the relationship between sickness benefits receipt, identity and stigma. This study has provided a detailed account of life on IB for sick and disabled people – something that is missing from the majority of previous literature. Narratives documenting the daily lives of long-term IB recipients reveal an interweaving of physical and emotional frustration and pain, set amidst a backdrop of distrust, suspicion and ‘scroungerphobia’ – perpetuated by the damning mythology surrounding welfare recipients. The findings presented here provide a detailed insight into this relationship, emphasising that there is a huge stigma felt by the majority of long-term IB recipients, which in turn impacts upon identity and daily activities. Stigma was felt not only as a reaction to government and media portrayals, but also friends, family and other professionals – as confirmed by the findings of the stakeholder interviews in this study. Several stakeholders expressed stereotypical views of IB recipients that directly contrast

with the experiences relayed to me in interviews, representing an uneasy tension between the lived reality of sickness benefit receipt and the perceived reality reported by others. Such an account is essential if the experiences of long-term IB recipients are to be truly understood. Only then can IB recipients be helped towards future goals and aspirations – whether that is related to improving health, returning to work, retraining or voluntary work.

Secondly, the research recognises that people receiving IB do not automatically class themselves as disabled; disability as a category was often rejected by participants, especially if their route onto IB was a result of an accident or injury. Whilst this thesis has not explored this concept, it should also not be assumed that all disabled people regard themselves as sick. This highlights the need to avoid conflating sickness with disability as though they are one category, and vice versa. Having to accept the label of ‘disabled’ was especially difficult for people to face; disability was perceived as being permanent, whereas many people in the study hoped their health would improve and could not accept they were disabled. Yet in certain instances, such as having to attend a WCA or when applying for official assistance such as DLA, people felt they had to present themselves ‘on their worst days’ and portray themselves as being as ill as possible. This is problematic as in doing so, being labelled disabled – for example, people spoke of this in terms of receiving Disability Living Allowance or a blue badge – could inhibit peoples’ likelihood to return to work in the future and could have a negative impact upon their identity, as the findings have shown. On the other hand, people shied away from accepting the label of ‘disabled’ so they are missing out on benefits that they are entitled to, because they do not like the language and terminology surrounding the benefit which is also tied into the wider pejorative discourse churned out by the government and the media. Therefore, the hardship faced by long-term IB recipients could be worsened.

Thirdly, this study has captured the essence of how current welfare reform can affect people on IB at a time of ongoing uncertainty and transformation. Exploring the narratives of long-term IB recipients at a time of tumultuous upheaval has shown that the reform process can cause relentless stress, anxiety and upset that can negatively impact upon peoples' health. As Patrick (2011a) observes, listening to sick and disabled people's views is key in light of ongoing reforms, and as she remarks, sick and disabled people feel they are not being listened to. What's more, the worrying dichotomy between 'deserving' and 'undeserving' sickness benefits recipients created amongst themselves suggests that wider government, media and public discourse is fuelling the mythology surrounding sickness benefits recipients. As a result, this is impacting upon long-term IB recipients perspectives and opinions of other sick and disabled people, creating further distinctions between those perceived as 'genuine' and those who are faking it.

Finally, the idea that welfare payments are nothing more than a drain on the economy and wider society must be challenged. Instead, they should be seen both as '*an indicator of collective social responsibility and social justice*' (Barnes 2003) and as increasing the spending power within the economy. For example, low income households spend most of their money within local economies and disabled people are particularly reliant on labour-intensive services, thereby generating employment. As the findings in this study have shown, sick and disabled people are at risk of missing out on key benefits they are entitled to as a result of stigma, shame and, in some instances, a lack of awareness of help available to them. It is crucial, therefore, for sick and disabled people to be freed from the stigmatisation and social exclusion which is associated with being in receipt of welfare benefits and their contribution to society should be fully recognised.

### **Avenues for future research**

Firstly, in light of the ongoing welfare reforms and stigmatisation of sick and disabled people, it is imperative to continue research into the experience of sickness benefits receipt. Arising from this study, it would be interesting to see how longitudinal investigation could uncover how participants' narratives altered amidst ongoing reform that will see the transition from DLA to PIP, and further towards the Work Programme and Universal Credit. Longitudinal studies are also necessary to map the course of identity development in order to recognise how identity continues to be constructed and reconstructed. This is particularly important in the context of sickness benefits receipt; for example, it would be interesting to see if an unrelenting pejorative discourse attached to sick and disabled people will hinder their work motivations and aspirations. What's more, it would be interesting to see if the ferocity of this negative discourse will ease in coming years.

Secondly, it is important to highlight the positive identities of long-term sickness benefits recipients. An innovative and original way of doing so would be to employ visual methodology to illustrate how sick and disabled people who receive sickness benefits experience life on welfare benefits. This would be important for two key reasons; such a depiction can exaggerate the positive identities that can be formed following the onset or worsening of a chronic health condition or disability, which in turn can challenge negative characterisations of sick and disabled people. Photo methodology would also add a reality to the narratives that will confirm how people receiving sickness benefits are not a separate category in society – they could be any one of us. In addition, by employing visual methodology it is hoped that the research would appeal to a wider audience, thus enhancing the impact of the research. Importantly, working with professional

photographer Keith Pattison, pilot case studies have already been successfully carried out with Mick and Tony in this study.

Thirdly, one of the key perceived barriers to re-entering the labour market was employers. Previous research such as that carried out by Davidson (2011) has studied employers' recruitment behaviour and decisions in employing sick and disabled people in relation to small and medium enterprises (SME). She found that employers looked for various attributes and behaviours in a potential candidate, including flexibility, competence, stability, a good personality, reliability, and attitude to work, amongst others. Given the continued negative portrayal of sick and disabled people, how do employers react to this? There is an obvious danger that they will certainly be less likely to consider employing someone who is characterised as lazy, work-shy and feckless. Taking the participants in this study as an example, Kirsty was certainly competent, had a strong desire to work and portrayed a great personality; however, she felt that her lack of flexibility, stability and possible reliability would hold her back and deter potential employers. Therefore, further research into employers' perspectives on recruiting IB recipients is crucial in order to probe their attitudes towards employing people with a history of sickness, but also a history of long-term benefit receipt.

Fourthly, qualitatively exploring the narratives of people who work but have an illness and/or disability may help to uncover how people in employment manage to sustain their employment despite their health problems. For example, investigating the effects of in-work support services may tell us what is most effective in helping sick and disabled people to sustain employment. One such example is an evaluation of an in-work support intervention in the Tees Valley (Warren *et al.* 2012). The evaluation found that the Tees Valley In Work Support project generally had a positive effect on the service users who accessed it. Analysis suggests that service users reported less health issues after accessing

the service and the validated measures recorded a positive change in general health. Qualitative analysis showed the experience of service users and project workers to have been overwhelmingly positive. However, it seems clear that how any future service could better engage with employers, particularly with SME's will require some serious thought and consideration.

Finally, continued research into ongoing welfare reform for sickness benefits recipients is vital. The next few years will witness the transition from DLA to PIP for *'those who need it most'*, and the introduction of Universal Credit (UC) in 2013, a process which overlaps with the conversion of IB to ESA. UC will bring with it conditionality requirements set according to individual capabilities and circumstances, alongside a set of sanctions if a recipient fails to comply with their work related activity requirements. Importantly, it will also bring a change from fortnightly payments to a single monthly payment which may complicate life for those on very low incomes even further. Also, the existing permitted work system for people who are sick and disabled will be replaced by a system that will not be time limited and which will encourage more disabled people, especially those with fluctuating capacity, to do some work, even if only for a few hours a week.

### **Key Messages for Policy Makers**

The following section discusses key messages for policy makers based upon the conclusions reached in this thesis.

#### ***Recommendation 1: Engage with employers to understand the benefits of employing long-term sick and disabled benefits recipients***

The government should ensure they make concerted efforts to encourage employers to recruit long-term sick and disabled benefits recipients who are able to enter the labour market. Engaging with employers is crucial in order to improve the chances of sickness

benefits recipients in re-entering the labour market. Potential employers' prejudices about the skills and abilities of those on sickness benefits could hinder employment opportunities. Gregg (2011) foresees a crucial role for Work Programme providers in engaging employers if people are to find work. One factor that might help people with health conditions return to work is the willingness of employers to make suitable workplace adjustments. Kemp and Davidson (2011) found that for those in employment at the time of the follow-up interview who were asked whether their employer had made any changes to their job or working conditions to accommodate their health condition or disability, about a quarter reported that some workplace adjustments had been made, but the majority of people said that none were made. However, the most commonly mentioned changes were adjustments to work duties, changes in working hours and more flexible hours of work. Nine out of 10 people who had had changes made to accommodate them at work said that these had helped them to keep doing their job. This finding highlights the important role that employers can potentially play in helping people with health conditions or impairments to do paid work (HM Government 2005, Black 2008). The demand side (e.g. employer attitudes to job applicants with health conditions) also needs to be addressed.

In addition to health problems, other factors which can hinder progress included people's perceptions of their own employability, employer attitudes and job availability, fears about swapping the financial security of benefits for low-paid work, the development of difficult family circumstances or increased caring responsibilities, and resistance to re-training (Corden and Nice, 2006; Tennant *et al.* 2010; Warrener *et al.* 2009;). The availability of suitable job opportunities is also critical, further suggesting a need for interventions that engage employers. All of the above need to be considered in relation to long-term sickness benefits recipients whose primary barrier to re-entering the labour market is their health.

What's more, the role of stakeholders as well as employers will continue to be important in welfare policy. Stakeholders' roles will be changing under the Work Programme and with the introduction of UC, bringing increased challenges and barriers for staff working with long-term sickness benefits recipients. If stakeholders were to confront negative stereotyping of sick and disabled people – including sometimes their own perceptions – then perhaps others, including employers – would follow suit.

***Recommendation 2: The government should avoid stigmatising and dehumanising language***

Stigmatising and dehumanising language directed at people receiving benefit might be good politics but it is bad policy, countering the effect of more practical measures being put in place by government to support people off benefits and into work. As we have seen, it affects people's sense of self and identity, as well as having an impact upon their day-to-day life. Every effort should be made to avoid pejorative language when speaking about sick and disabled people. Perhaps if the government were more careful in their discussions of sickness benefits, the media and the public would be encouraged to do the same.

Following on from the previous recommendation, the stigma associated with claiming benefits can deter people from accessing the support they need leading to under-claiming and the risk of amplified financial strain and hardship. Increased awareness over entitlement to benefits and additional help is required to avoid a blurring of the distinctions between sickness benefits such as ESA and other benefits that are not out-of-work benefits, such as DLA. Alongside this, a principle of reciprocity or entitlement through social contribution must be fostered in order to move away from stigmatising people receiving welfare benefits. A key challenge for government is to consider where it can lead

and shape public opinion. Support appears to be much stronger in relation to some groups than others. The extent of need is relevant and those with children are more likely to be thought deserving. At the same time, groups which are seen to be contributing to society in some way, rather than taking a passive role as a recipient of welfare are also likely to be favoured. Again, this could be tackled through the avoidance of misleading government rhetoric and subsequent media headlines that wrongly report so-called 'evidence' which suggests fraud is rife and that many people are in fact 'undeserving' of their benefits, when in fact they are entitled and in some cases are not accessing the benefits they deserve.

***Recommendation 3: A 'one size fits all' approach needs to be reconsidered***

The research has demonstrated that people receiving long-term IB are not part of a homogenous, one-size-fits-all category. Each narrative brings with it a different reality – a reality that encompasses background, health condition, identity considerations, and place. Therefore, the implementation of the Work Programme and UC is likely to be problematic for people receiving long-term sickness benefits. Instead, what is perhaps needed is a tailored approach that takes into account the varied needs of those receiving sickness benefits.

Evidence from our evaluation of a case management intervention aimed at improving the health of long-term sickness benefits recipients in County Durham suggests that a case management approach can, in fact, have a positive impact upon mental health (Warren *et al.* in press). However, there are limitations in terms of feasibility to such an approach; for example, cost is a major consideration – case management can be extremely expensive, and therefore less attractive in terms of government policy making decisions. The fact remains that sickness benefit receipt is inherently complex and is unlikely to be addressed via an umbrella benefit like UC. Potentially, people who have been receiving long-term

sickness benefits may be pushed to the back of the queue in favour of easier to help customers such as those who have recently exited the labour market, or who are free from health problems. Ultimately, policy makers have little chance of getting sick and disabled people off sickness benefits and into employment unless they arrive at a more holistic range of measures that link intensive support to build individuals' employability with area-based regeneration strategies to promote accessible job opportunities.

***Recommendation 4: Evidence in the framing of disability and welfare policy is crucial***

Although policy makers assert with apparent certainty that conditionality is legitimate, empirical evidence about the need for it in practice, and its effectiveness in encouraging people into work, is less equivocal (Weston 2011). Whilst there are advantages in bringing more people to learn about the availability of support, there are also disadvantages in deterring people from engaging meaningfully in potentially beneficial interventions where offended by the use of compulsion or where motivated solely by the threat to their benefits.

A second point to make is that research with Pathways service users challenges the assumptions that people receiving sickness benefits need to be motivated for work by compulsion and incentives and that these policies are effective in practice (Weston 2011). The only argument in favour of conditionality that was sustainable in the Pathways findings is that some people who would otherwise have chosen not to discuss work at a time of poor health learned about available support, which in turn might have been influential in later returns to work. However, we might suppose that people would willingly seek support at a time when they feel it is appropriate, negating the need for compulsion. This supposition is founded on the finding that, in large part, Pathways participants' desire to work was undiminished, which has been echoed in other research with sick and disabled

people (Kemp and Davidson, 2010) and in research which refuted the existence of a culture of worklessness (Social Exclusion Unit 2004). Whilst these findings support the argument that conditionality is often unnecessary, there is also evidence to suggest that it does not always work. Further evidence that the threat of sanctions does not initiate work-focused behaviour has been found amongst other claimant groups, such as lone parents (Goodwin 2008). Despite this evidence about effective and ineffective measures, the current Government is not only persisting with the belief that '*sanctions are critical to incentivise benefit recipients to meet their responsibilities*' through increasing conditionality, and that 'making work pay' through benefit simplification will motivate people to work (DWP 2010: 28), but is also focusing predominantly on such measures promoting individual responsibility in its presentation of policy (Weston 2011).

A good example of the role of social research and evidence can be found in the work of Shildrick *et al.* (2012) on cultures of worklessness. All too often, the government use the terminology of a 'culture of worklessness', referring to three and sometimes four generations of a family whereby nobody has worked. Shildrick and colleagues set out to find these families in deprived areas of Glasgow and Teesside and found little evidence to support this view. Whether the government will choose to take such research evidence on board is another matter entirely, but research such as this highlights the importance of government rhetoric and how, through mythology, representations are created and redistributed through the media which then merges into public opinion, and as we have seen throughout this thesis, into the thoughts of those receiving welfare benefits. Therefore, the importance of evidence that emerges from research such as this which focuses upon the real lives and experiences of sickness benefits recipients, is crucial.

## **Overall concluding comments**

The narratives presented in this study uncover lives that are fraught with health problems and disability on a daily basis, accompanied by a strong sense of stigma, shame and frustration. Not all long-term IB recipients are resigned to a life on benefits – many possess a deep-seated desire to return to the labour market, including engaging in permitted or voluntary work – a sentiment which strongly refutes any ‘dependency culture’ rhetoric. A recurrent theme that emerged from the interviews was that people are keen to work, but lack the ability, opportunities or support to do so. Tying all of this together is the construction and reconstruction of identity for long-term IB recipients; the rejection of a claimant identity was largely accompanied by the refusal of a disabled identity. Yet long-term IB recipients could foster a positive identity, one that was characterised by new opportunities and aspirations and which can be used to challenge existing negative stereotypes of sick and disabled benefit recipients. Stigma and shame arose as a result of an increasingly popular myth that encourages the widespread suspicion of sick and disabled people, and disturbingly led to a further distinction between ‘deserving’ and ‘undeserving’ amongst sickness benefits recipients themselves. These narratives were relayed against a backdrop of ongoing welfare reform – something which led to feelings of fear and insecurity for many participants who worried that their health would get worse, yet they could still be classified as ‘fit for work’. Further reforms that will impact upon sick and disabled people, such as the transformation of DLA to PIP together with the impending introduction of UC, will not ameliorate the barriers faced by long-term sickness benefits recipients any time in the near future.

Fundamentally, this research calls for the need for a greater understanding of the lives of sick and disabled people, and an acceptance that being on sickness benefits is not the easy way out. After all, absolutely anybody could end up having to leave the labour market due

to health reasons – people who are highly educated, low skilled, young, or old. Poor health does not automatically mean a poor work ethic, and this should be considered carefully when discussing people who receive long-term sickness benefits. By listening to the narratives of people who are labelled in this way, perhaps then the vilifying discourse surrounding them can begin to be erased, or at least be challenged by giving a voice to people who are not the ‘Other’ but who could be any of ‘us’.

## APPENDICES

### Appendix A

#### Peer reviewed publications arising from the thesis:

**Garthwaite, K.** (2011) 'The language of shirkers and scroungers?' Talking about illness, disability and coalition welfare reform. *Disability & Society* 26, no. 3: 369–72.

**Garthwaite, K.** (under review, 2012) Unravelling the Researcher - Researched Relationship: Doing Qualitative Research with Long-Term Health-Related Benefits Recipients. Submitted to: *Qualitative Research Journal*, December 2012.

**Garthwaite, K.** (under review, 2012) Separating the Wheat from the Chaff? Exploring Welfare Reform with Long-Term Sickness Benefits Recipients. Submitted to: *Critical Social Policy*, October 2012.

**Garthwaite, K.** (under review, 2012) Becoming Incapacitated? Exploring Narratives of Identity and Stigma with Long Term Sickness Benefits Recipients. Submitted to: *Sociology of Health and Illness*, October 2012.

**Garthwaite, K.,** Bambra, C., Warren, J. (accepted for publication, 2012) 'The unwilling and the unwell'? Exploring stakeholders' perceptions of working with long term sickness benefits recipients. *Disability & Society*.

## Appendix B

### Conference proceedings and presentations

**Garthwaite, K.** (2011) "I haven't spoken to anyone like this since my psychiatrist": researching long term Incapacity Benefit recipients. Qualitative Health Research Group, Wolfson Research Institute for Health and Wellbeing, Durham University, November 29<sup>th</sup>.

**Garthwaite, K.** (2012) 'Incapacitated? Exploring the health and illness narratives of Incapacity Benefit recipients'. Welfare and Identity in Britain workshop, Oxford University, 10<sup>th</sup> January.

**Garthwaite, K.** (2012) 'Narrating the stories of long-term Incapacity Benefit recipients in the North East'. Researching with disadvantaged communities and other easily ignored groups workshop, Wolfson Research Institute for Health and Wellbeing, Durham University, 3<sup>rd</sup> July.

**Garthwaite, K.** (2012) "I don't want to put my hand up and say I'm disabled": exploring identity and stigma with long term incapacity benefits recipients. Disability Studies conference, Lancaster, 11<sup>th</sup>-13<sup>th</sup> September.

**Garthwaite, K.** (2012) 'Fear of the brown envelope: sickness benefits recipients and welfare reform'. 'Hardest Hit' symposium, Leeds University, 20<sup>th</sup> September.

\*N.B. On 3<sup>rd</sup> October 2012 I will be appearing on BBC Radio 4's 'Thinking Allowed' with Laurie Taylor to discuss welfare reform, sickness and disability.

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