

Portfolio Volume 1: Major Research Project

# **Responses of People with Physical Health Conditions to Changes in Disability Benefits: A Grounded Theory Study**

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*"There may be times when we are powerless to prevent injustice, but there must never be a time when we fail to protest." - Elie Wiesel*

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## Abstract

There is a dearth of literature on the experiences of people with physical health conditions who make disability benefit claims and live as a benefit claimant, particularly since the recent and ongoing changes to the benefits system in the UK. This research aimed to explore the social processes that impact on people with a physical health condition who have experienced a loss of or change in disability benefits, particularly in relation to their identity and their relationships with society. In-depth interviews were conducted with fifteen people with physical health conditions or disabilities. Data was analysed using Grounded Theory methods and a theoretical model was co-constructed. Participants experienced the benefits system as dehumanising, and felt that they lived in a judgemental society, where they were perceived as 'scroungers' and faced discrimination from others. These experiences negatively affected their mental and physical health and wellbeing. Participants often internalised the stigma surrounding disability benefit claimants and they attempted to resist this in order to maintain a preferred sense of self. The findings demonstrate the significant impact of benefit changes on wellbeing and identity. The research highlights important implications for Psychologists, as well as staff in healthcare, the benefits system, and government.

*Keywords: Disability benefit, physical health, welfare reform*

## **Chapter 1 - Introduction**

## **1.0 Introduction**

This research concerns the experiences of benefit changes amongst people with physical health conditions or disabilities in the UK. This section begins with an introduction to the researcher and her relationship to the research. Next, complexities in understanding disability, and its prevalence and cost are discussed. Following this, there is an outline of the recent and ongoing changes in the UK welfare system. A review of the literature regarding the impact of welfare reform on people who claim disability benefits is provided. Lastly, the rationale and aims of the study are defined.

I use the term 'disability' when referring to physical health impairment and chronic illness but I acknowledge that many individuals would not identify with this label. In addition, many people who fall under this category would not be recompensed as such under the current UK government's welfare system.

This thesis will be written in the third person as is typical for formal research reports. However the text will switch to the first person when the researcher wishes to reflect on the processes being discussed and add her personal voice.

### **1.1 Situating the researcher**

The process of undertaking qualitative research demands a self-reflexive approach from the researcher (Watt, 2007). I hope that by considering my position I will be able to reflect on the many (known and unknown) ways that this may influence the

outcome of this research (Elliott, Fischer & Rennie, 1999). In this section, I explain my relationship to the research and describe my epistemological position.

### **1.1.1 Family Life**

For many years I have been keen to work towards a more equal society for people with disabilities, including physical and learning needs. I think that the value I place on the importance of understanding and supporting people with disabilities is rooted in my family of origin.

My maternal grandfather is visually impaired and I grew up with awareness of his additional needs, although he remains actively involved in family life. My maternal grandmother was ill with Parkinson's disease, which affected her balance and mobility, and later she suffered from dementia. I also grew up in a community which supported young people's educational achievements to an appropriate level for each individual. I became conscious of how accessible environments may, or may not, be for people with physical and cognitive needs, and how the level of support a person receives affects their ability to cope. There began my desire to advocate for greater understanding and support for people with additional needs.

My experiences have fostered an ongoing interest in equality of access and in subjective experiences of inclusion. I have no doubt that this influenced my choice of degree and career, as well as much of my voluntary work in facilitating greater accessibility to community services for people with a range of needs. This research

combines my passion to work towards equality for people with varying needs with my skills in Psychology.

### **1.1.2 Reflections on the topic**

Throughout the research, I was aware that this topic was likely to be highly emotional. Many of the articles, particularly media reports with statistics and those describing people's difficult experiences, have been painful to read. At times I have felt great sadness and at other times intense anger about the poverty in which many disabled people live. I have been careful to prioritise self-care, in the form of regular breaks, exercise and socialising in order to manage my feelings. However, these emotions inform me of the value in doing this work. Furthermore, they were likely to have shaped the data analysis, so self-reflexivity was crucial and I discuss this throughout.

There is a debate in the literature about whether it is appropriate for a non-disabled researcher to study disability issues (Barnes & Mercer, 1997). I acknowledge that there are limitations to my being an outsider (Dywer & Buckle, 2009) as someone who has never been disabled. Reynolds (2013) discusses the difficulties in being an imperfect ally. In order to mitigate these limitations, I used service user (SU) consultation to check that my research was useful for this population. My methodology, grounded theory, builds in a protection as it forces researchers to stay close to the data. Additionally I used self-reflection throughout, for example being transparent about my biases. I am aware of the power differential between myself and my participants who might be seen to be in a vulnerable position. However, I felt

that it was important for me to utilise my time for the benefit of others. I hope that my contribution will be valuable.

### **1.1.3 The role of a Psychologist in Politics**

There is a debate in the field of Clinical Psychology about the extent that Psychologists should play a role in politics.

I believe that physical health and mental health are affected by a range of factors, including poverty, isolation, environment, education and housing (Marmot, 2015). I think that if Psychologists ignore the context, systems and surroundings in which clients live, we can actually exacerbate their difficulties, rather than alleviate 'symptoms'. If we were to work only with individuals, we would perpetuate an individualistic understanding of the world. Additionally, if we were to work only within diagnostic structures, such as DSM-V (APA, 2013), we would maintain the prominence of the medical model, which often ignores systemic issues. In that case we might even contribute to forces of oppression (Gergen & Ness, 2016) as particular therapies and diagnostic categories contribute to sexism, individualism, class oppression and other divisive biases. Gergen and Ness (2016, p10) argue that "therapeutic work is necessarily a form of social/political activism". Harper (2016) discusses concerns about Psychologists' over-emphasis on individual therapy; that it will never be available to all who need it, and that therapies do not address the causes of distress. He questions how ethical it is to focus on reactive rather than preventative interventions.

Psychologists are trained to focus on wellbeing within the wider society. Under the guidelines of the British Psychological Society (BPS) Code of Ethics and Conduct (2009), part of the standard for competence for a Psychologist is sensitivity to developments in our social and political context. Psychologists have a role to play in community psychology, working with wider systems to enhance wellbeing and to prevent distress from occurring, rather than simply to 'treat' distress. In the case of widespread problems in our welfare system, I believe that Psychologists, with both knowledge and power, have a responsibility to highlight concerns, for example the impact of the wider system on individuals' health, and in effecting change to the best of their ability. Psychologists also have a duty, in my opinion, to amplify the voices of those who are rarely heard; as Lister (2004, p2) states 'the poor' are "frequently talked and theorised about but are rarely themselves in a position to have their thoughts published".

The BPS views social justice work as core to Psychologists' professional purpose (Rhodes, 2017). It has declared its commitment to promote equality, diversity and inclusion and to challenge prejudice and discrimination (BPS, 2017b). The Division of Clinical Psychology (BPS, 2017c) describes one of its strategic goals as being to improve the wellbeing of the population through working with relevant systems and organisations, such as the NHS, the government and other professional bodies. Psychologists for Social Change (PSC, 2016 - previously Psychologists Against Austerity (PAA)), a group of politically minded Psychologists who oppose austerity measures, argue that we have an ethical responsibility to speak out about the effects of societal and economic conditions on people. Psychologists are becoming increasingly political, for example the BPS call for reform of the Work Capability

Assessment (WCA) (2016) and a letter to the government by a number of psychological organisations detailing the link between sanctions and rising mental health problems (The Independent, 2017). Promoting public health and prevention of ill health is part of the NHS strategic plan (NHS England, 2014), so is the responsibility of all NHS professionals.

#### **1.1.4 Epistemological stance**

It is important to acknowledge my epistemological stance to bring transparency to this research. I believe that truth exists separate from human subjectivity, for example the distress and poverty discussed by my participants exists independently from their accounts or my interpretations of them. However, I believe that the way that people make sense of these truths is socially constructed and can be enacted through discourse (Magill, 1994). I acknowledge that knowledge is generated within networks of social activity (Henwood & Pidgeon, 1995). Charmaz (2006, p14) states, “subjectivity is inseparable from human existence”. As human perception and description are filtered through the lenses of language, meaning-making and context (Oliver, 2011), reality may never be accessed directly. My beliefs are in line with a critical realist position. Critical realism “marries the positivist’s search for evidence of a reality external to human consciousness with the insistence that all meaning to be made of that reality is socially constructed” (Oliver, 2011, p2).

Therefore I do not aim to present an unbiased representation of my participants’ experiences. Instead I aim to explore participants’ constructions of their experiences, influenced by the cultural and discursive resources available to them (Willig, 2008). I

believe that data can tell us something about a shared understanding of reality, even if it may not directly reflect the world in which we live. Although an interviewee may not be aware of all of the factors that influence their experience, they can provide us with some of the picture (Harper, 2011).

Taking a reflexive stance (Charmaz, 2014), I acknowledge my role in shaping the research and the importance of considering my biases in interpreting participants' accounts, such as my western upbringing, knowledge of psychological theory and human rights values. Therefore I see this research as a partial interpretation of the experiences of the changes to benefits for people with physical disabilities, because it is influenced by the contexts of researcher and participants (Madill, Jordan & Shirley, 2000).

## **1.2 Overview of disability**

This section introduces the concept of identity. It then outlines some of the complexities in understanding disability identity and the prevalence and cost of disability.

### **1.2.1 Understanding identity**

Identity, or sense of self, affects how one behaves in the world and how one feels about it. This is a complex concept but I outline some of the key ideas relevant to this research here.

Identity is comprised of the personal traits and characteristics, social relations, roles, and social group memberships that define who one is (Oyserman, Elmore & Smith, 2012). People can consider themselves from both an individualistic sense of self, in how one is separate and different from others, and from a collectivistic perspective, in how they are similar and connected via relationships (Kross, 2009). Social identities (Tajfel, 1981) involve the knowledge that one is a member of a group, one's feelings about this, and awareness of the group's status in comparison to other groups. For example a person may base their identity on being disabled or a benefit claimant, or a member of a particular sociodemographic category such as social class (Frable, 1997). Identities can be focused on the past, the present or in the future, in the person one expects to become, including how someone feels obligated to try to become or how they fear they may become (Oyserman et al., 2012).

Identity was traditionally viewed as a fixed construct, but more recently it has come to be understood as dynamically constructed in the moment (Oyserman et al., 2012). For example, choices or actions that feel identity congruent in one situation do not necessarily feel identity-congruent in another situation, for example speaking confidently at home versus at work. Identity is constructed in response to one's social context. We incorporate how we think others see us into our appraisal of self (Felson, 1993). Identity is a social product in that people are likely to define themselves in terms of what is relevant in their context, and the aspects of someone's identity that matter in the moment are determined by what is relevant at that time. In addition, being a self requires others to reinforce one's sense of self. Therefore, one's current identity is constructed through the discourses available to them, for example discourses about people with disabilities.

Identity is indispensable to understanding how people make choices and how they make meaning of their experiences (McGuire & McGuire, 1988). Identity can explain actions in the sense that one may wish to gain or defend one's dignity or self-respect, and that membership in a social category may lead people to act in a particular way, or follow a social norm (Fearon, 1999). Yet, being a member of a social category does not result in the desire to act in accordance with its norms, and some may wish to separate themselves from this identity. How a person chooses to present their identity may depend on how they think others will perceive them (Fearon, 1999).

In conclusion, the terms 'identity' and 'self' can be used when considering the process of making sense of self and the world or to the consequences of social contexts on one's beliefs and perceptions about the self (Frable, 1997).

### **1.2.2 Understanding disability identity**

Disability is a contested identity, with many different dimensions. It is beyond the scope of this thesis to discuss the broad field of disability literature, so here I provide an overview of some of the key dimensions and complexities of disability.

There is a debate in the field about what constitutes disability. Although physical impairment and wheelchair use may be the archetype symbol of disability (Titchkosky, 2011), disability studies literature shows the growing presence of learning difficulties, mental health issues, sensory impairment and most recently

autism. In legal terms, the development of anti-discrimination law has led to the widening of the disability category in many countries to include illnesses such as HIV and cancer (Lawson & Gooding, 2005).

Historically, disability was understood using a medical model, which explains illness as the result of conditions intrinsic to an individual. Later, the social model of disability distinguished between the ideas of impairment and disability. Barnes (1991, p2) argued “*Impairment* is the functional limitation within the individual caused by physical, mental or sensory impairment. *Disability* is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers”. The social model suggests that disability exists because of cultural representations and social attitudes toward human differences, not because of difference itself (Kauffman and Hallahan, 2009). More recently, theorists have discussed the importance of both biology and social barriers in causing unpleasant experiences for disabled people (Anastasiou & Kauffman, 2013). Political tensions can be found between people with different types of disabilities. For example, some with chronic illness consider that their biological impairment, such as pain or fatigue, prevent them from being active and that this cannot be mediated by society. Consequently they report feeling excluded from the Disability Rights Movement, which focuses on societal oppression (Hale, 2015).

As well as ‘public’ experiences of oppression, such as societal barriers, there are ‘personal’ emotional experiences of oppression (Thomas, 1999). Thomas (1999) discussed the importance of social processes and practices which affect the wellbeing of people with impairments. These psycho-emotional dimensions of

disability (Reeve, 2002) are a result of negative attitudes and prejudices about disabled people within society, and include being hurt by people's reactions and being made to feel worthless or unattractive. For example, disabled people might respond with feelings of anger and frustration to social exclusion and physical barriers (structural disability) such as inaccessible buildings. Another example is internalised oppression, where disabled people internalise prejudices and stereotypes held by a non-disabled majority, such as not having the right to be a sexual being (Morris, 1991).

In order to reduce barriers for people with impairments, people with disabilities are afforded rights to independent living under UK and UN law. Article 19, UN Convention on the Rights of Persons with Disabilities (Hendricks, 2007) describes independent living as:

*"...having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community... it means rights to practical assistance and support to participate in society and live an ordinary life".*

The UK Equality Act 2010 (Government Equalities Office, GEO) decreed it unlawful to discriminate against people in respect of their disabilities in relation to employment, provision of goods and services, education and transport. Therefore services are required to make reasonable adaptations to include disabled people.

However, some people with physical illnesses do not identify as disabled. For example, Watson's (2002) participant Joyce (pseudonym) explains that she does not

see herself as a disabled person but describes her identity as the product of the social roles that she performs within relationships with people. Sometimes self-identity could become a political issue as the presentation of the self involves a rejection of difference (Watson, 2002).

It is clear that “disabled identity can be fluid and diverse” (Reeve, 2002, p494) depending on how people experience their impairments and the impact of society’s responses to them. Multiple factors may affect whether someone *feels* disabled. This includes physical variables such as appearance, how independent someone can be, including self-care, functional mobility and level of sensory impairment. Whether the impairment is congenital or acquired, and progressive or sudden, may affect how someone responds, for example a trauma or illness may result in a changed role or purpose in life. Social factors also affect disability identity, such as support from society, family, friends, whether someone is employed, and whether adjustments are made in the workplace (Behel & Rybarczyk, 2012).

This section has illustrated the complexity in understanding disability identity.

### **1.2.2.1 Defining disability**

Disability can be defined as something which dis-ables someone, or ‘a physical or mental condition that limits a person's movements, senses, or activities’ (Oxford English Dictionary, 2009). Under the Equality Act 2010 (GEO), disability is defined as a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on the ability to do normal daily activities. ‘Substantial’ is defined as more than

minor or trivial, e.g. it takes much longer than usual to complete daily tasks such as getting dressed, and 'long-term' refers to 12 months or more.

### **1.2.3 The prevalence and cost of disability**

#### **1.2.3.1 Prevalence**

According to the Life Opportunities Survey 2009-2012, 1 in 3 people in England have a disability or illness which is likely to be experienced for over 12 months. Almost 1 in 5 people in England are likely to be limited or restricted in different areas of life. This includes visible and invisible disabilities, such as physical and mental health problems, and learning disabilities. Additionally, almost 75% of disabled people have more than one impairment (Sport England, 2016). There is much overlap between mental health and physical health conditions; about 30% of those with a long-term physical health condition also have a mental health problem (King's Health Partners, KHP, 2016), which may be either as a consequence or alongside physical health needs. When mental health and physical health problems combine, people are less able to manage their conditions, and their health outcomes and experiences worsen (KHP, 2016). Prevalence statistics from different sources vary, however it is clear that there are a large number of people in the UK with a disability or impairment that affects their lives. Of these it is estimated that 4.5 million have a significant disability that entitles them to a disability benefit (Duffy, 2014).

### **1.2.3.2 Cost of living**

Living with a disability is associated with higher costs of living. The New Policy Institute (NPI, 2016) described additional costs such as equipment or appliances, as well as potentially higher bills, such as heating, due to immobility. Scope estimated that these amount to £550/month on average (Brawn, 2014). In addition, there is a large disability employment gap, which was 34% in 2015 (Work and Pensions Committee, 2017). Furthermore, there has been a rise in the 'cost of living', i.e. household essentials. Energy bills rose by over 60% between 2008 and 2013, and food, water and transport costs all rose by more than 20% (Adams, Hood & Levell, 2014). In addition, VAT has been increased to 20% in 2011 (HM Treasury, 2010a). These factors mean that disabled people are likely to have less money to support their additional needs.

These additional costs are often not met with income (Brawn, 2014). Those living in a family with a disabled member are more likely to have a low income than non-disabled families (Department for Work and Pensions, DWP, 2016a). Consequently, disabled people are twice as likely to live in poverty as non-disabled people (NPI, 2016).

In summary, there are a large number of people in the UK who have a disability or illness which restricts their lives. Alongside higher costs of living, they are more likely to live in poverty than non-disabled people and less likely to earn an income through employment.

### **1.3 'Welfare reform' in the UK**

'Welfare spending' can be defined as any spending in the provision of the welfare state, including health, long-term care, education and social housing, as well as social security benefits and tax credits, or can be defined more narrowly as the benefits and tax credits systems (Office for Budget Responsibility, OBR, 2016).

#### **1.3.1 Positions on welfare**

The creation of the post-war welfare state had the aims of overcoming the 'five giant evils' of 'want, ignorance, squalor, disease and idleness' (Beveridge, 1942). The subsequent state policies for income maintenance, education, housing, health and employment were based on the principles of 'universalism', providing services free at the point of delivery and lifelong support (Beresford, 2005). However, in practice the UK welfare state did not fulfil all of its aspirations; poverty continued to be a problem and the quality of services was often unsatisfactory.

The political new right which emerged in the 1970s was fundamentally opposed to traditional state welfare intervention (Beresford, 2005). They condemned large-scale state welfare as costly, wasteful, bureaucratic, centralising and inefficient. They did not believe in extending the power of the state at the expense of individual freedom and choice, and felt that welfare provision undermined market principles and competition (Hayek, 1982). They encouraged individual responsibility for welfare and health and limited state intervention and provision of services. This led to a move towards market provision of services, or privatisation. Later political parties, such as

the emergent Social Democratic Party (SDP), created by the fragmenting of the Labour Party, also criticised the welfare state and called instead for 'welfare pluralism' which would give a much larger role to the private, charitable and so called 'informal' sectors (Beresford, 2005). Right-wing libertarians have argued that state welfare is damaging to the people it supports, as it increases dependency on the state. For example, Szasz (2001) described the increasing medicalisation of politics, or "pharmacocracy", whereby issues which had belonged to another field such as education, law and religion have been redefined as medical phenomena. He felt that recovering from illness is related to individual motivation, personal habits, and self-discipline, and that a move towards medical-political responses erodes personal freedom and dignity, as state control and coercion become a public health measure.

There are also a number of left-wing critiques of the welfare state (see Norman, 2010). Left libertarians promote the redistribution of freedom, power and resources more equally and might question powers being centralised by the state. Communitarians (both left- and right-wing) oppose control drawn away from individuals, families, communities and cooperative efforts.

Therefore, there are a number of different factions which might support changes to the welfare system. On this matter, I take the view that the changes that I would like to see in the welfare system would be to improve its quality of service provision and to alleviate poverty, rather than to reduce state support or encourage privatisation.

### **1.3.2 Overview of welfare changes**

Over the past decade there have been many changes to the UK welfare system. This includes a programme of austerity, sustained reductions in public spending, which started in 2010. Changes may have been prompted by the country's economic recession in 2008, with the government's aim of reducing the budget deficit, and also by the aim to improve employment rates (Litchfield, 2013). Reforms were outlined in the 2010 Spending Review (HM Treasury, 2010b) and the Welfare Reform Act (DWP, 2012). Overall spending was forecast to be reduced by 13.5% between 2008 and 2016 (Duffy, 2014). The austerity period was due to end in 2015–16; however, in 2014 this was extended until at least 2018. As a result, any statistics presented in this thesis are likely to be an underestimation of the number of people affected by welfare changes. It is beyond the scope of this research to provide a detailed history of 'welfare reform', however I outline some of the areas where changes have been implemented.

One type of 'welfare reform' has been direct cuts to benefits. For example, the Welfare Reform and Work Act 2016 (DWP, 2016d) mandated a reduction in income for new Employment and Support Allowance (ESA) claimants in the work-related activity group (WRAG) from £103 to £73 per week in early 2017. This applied only to new claimants, who therefore would not experience a reduction in their income, but would be required to live on less money than other claimants.

Since 2010, there have been changes which affect who is classed as eligible for particular benefits. Some cuts have been made by increasing the level of means-

testing. For example, the Welfare Reform Act 2012 introduced a limit of one year for contributory ESA, a non-means-tested benefit. Further changes have reduced eligibility by taking other personal factors into account, such as housing or family situation. An example was the introduction of the 'bedroom tax' which reduces housing benefit for people if they have what is deemed to be a spare bedroom (DWP, 2012). Duffy (2014) claims this change disproportionately affects disabled people with additional care needs, including those who have a care assistant who sleeps at their home and those who need space to store medical equipment.

A further change in eligibility has occurred through changes in types and providers of benefits. For example, the Independent Living Fund (ILF), which supported disabled people with high support needs to live independently, was closed in June 2015. Responsibility for supporting its recipients was transferred to local authorities, but most reported they would not ringfence this money (Disability Rights UK, DR UK, 2014). Additionally, there have been changes to working age disability benefits, including a transfer from Incapacity Benefit (IB) to ESA, and from Disability Living Allowance (DLA) to Personal Independence Payment (PIP). These moves have been closely connected to more stringent assessments, regular re-testing, as well as privatisation of these tests to private agencies such as ATOS and Capita, which adds an additional layer of complexity to the system.

Since 2010, benefit cuts have also been introduced by reducing the rate of growth in benefits, by changing indexation or by freezing any increase for a fixed number of years (HM Treasury, 2009). If benefits do not grow with the economy or average wages, this means that relative poverty increases. Additionally, as basic living costs

have increased above the average rate of inflation (HM Treasury, 2012), then benefit claimants are poorer.

There has been an increase in the control that can be exerted over benefit claimants by the welfare system. For example, the Work Programme (DWP, 2015b), which is designed to help disabled people move into work, demands regular attendance at benefit offices or training centres and there has been increased use of sanctions and conditionality programmes. Despite this, in 2013 only 5% of disabled people on ESA on the Work Programme had found a job (Crowther & Sayce, 2013). Similarly, the system of Universal Credit, introduced by the Welfare Reform Act 2012 (DWP), requires close monitoring of the weekly activities of people on low incomes.

Finally, some academics argue that the negative stigma associated with benefits has been perpetuated by government in order to discourage people from applying for benefits for which they meet the criteria (Duffy, 2017). Increased use of sanctions and conditionality programmes may serve as a deterrent for potential claimants (e.g. Salford City Partnership, 2015).

It has been argued that many of these changes have been implemented with haste, which means that there is little time to oppose them (Duffy, 2017). In addition, new policies have used much technical language, with numerous acronyms, which means that the public, and even academics, may have difficulty understanding changes (Duffy, 2017).

### 1.3.3 'Disability Benefits'

I outline the main benefits for working age disabled people and some of the challenges in claiming these. It is important to note that criteria changes mean that some people have been found to be 'not disabled enough' by DWP measures, although their impairment remains, and therefore have also been affected by changes in non-disability benefits.

ESA is a benefit to support people whose ability to work is limited by ill health or disability. The stated intention of moving from IB to ESA was to shift from a culture of invalidity to employability (Kemp & Davidson, 2010). The new assessment, WCA, divides claimants into three groups, namely fit for work (not eligible for ESA), unfit for work but fit for 'work-related activity' or fit for neither (Support group). The WCA declares a higher proportion of applicants fit for work than the previous system (Grover & Piggott, 2013). Independent reviews of the WCA have raised concerns about its fairness and effectiveness (e.g. Harrington, 2010). They commented that the process can be impersonal, lacks transparency, and there is a lack of communication between the parties involved, which contributes to poor decision-making and a high rate of appeals (Harrington, 2010). They added that the process does not adequately capture the impact of many chronic health conditions. Mortality statistics revealed deaths of 2,380 applicants who had been declared fit for work and 7,200 who had been placed in the WRAG between December 2011 and February 2014 (DWP, 2015a). Inquiries into 49 cases where a claimant died after assessment, including 40 following suicide, highlighted flaws in DWP handling of claims of people with mental health or learning difficulty (DWP, 2016b). A high number of appeals are

successful, e.g. 62% between July-September 2016 (Ministry of Justice, 2016).

These figures also indicate that the assessment is unsuitable, however the government disregarded recommendations (DWP, 2014c) by the Work and Pensions Committee (2014) for a redesign of the ESA process.

PIP is a benefit to help with the costs associated with how a person's condition affects their daily life, and can be paid whether the recipient is employed or not.

Award rates are 47% for new claims and 73% for DLA reassessment claims (April 2013-2016, DWP, 2016c). Motability, a scheme that helps disabled people exchange their mobility allowance for transport, reported that 44% of their customers lost their entitlement through PIP reassessment (Disability News Service, 2016). For those who appeal a PIP decision, in over 80% of mandatory reconsiderations the award remains unchanged (DR UK, 2016); however, 65% of those who appeal independently are successful (Ministry of Justice, 2016). Advice centres have found multiple cases were given a zero score initially and replaced with an enhanced rate of benefit on appeal (e.g. SARC, 2016). These figures suggest that many with disabilities, including those who previously received DLA, are not being awarded the correct level of PIP, which indicates that the assessment process may be unsuitable.

There is some evidence that people have opted out of the benefits system and some people have found work (OBR, 2016). However, it has been shown that major reforms to disability benefits have yielded far smaller savings than originally expected (OBR, 2016).

## **1.4 The impact of ‘welfare reform’ on disabled people**

### **1.4.1 A disproportionate effect**

With the combined impact of cuts in funding for benefits, social care and housing, some are concerned (e.g. Duffy, 2014) that welfare reform has a disproportionately adverse impact on the most marginalised and disadvantaged citizens, including people with disabilities. Duffy (2014) estimated that people in poverty will lose an average of £2689 /year, disabled people in poverty £4605 /year, and people using social care, those with the most severe disabilities, £6354 /year. Therefore, disabled people face cuts four times greater and social care recipients six times greater than most citizens. Others report even higher figures, e.g. that disabled people are affected 20 times more than the average person (McDonnell, 2014). The Disability Benefits Consortium (2015) found, in a survey of over 500 disabled people, that 28% could not afford to eat and 38% were unable to heat their homes. The Equality and Human Rights Commission (2017) reported that disabled people are nearly three times as likely to be in food poverty as non-disabled people.

The UN Committee on Economic, Social and Cultural Rights (2016) expressed serious concern regarding the significant impact of austerity on the most vulnerable and marginalised groups in society, including people with disabilities. Similarly, the UN Committee on the Rights of Persons with Disabilities (2016, p3) described “systematic violations” of the rights of disabled people. They observed financial hardship, resulting in “arrears, debts, evictions and cuts to essentials such as housing and food” (p17). They highlighted the scapegoating of disabled people who

claim benefits, who are regularly portrayed as “lazy”, “committing fraud” and “putting a burden on taxpayers” (p15). They stated that the UK's austerity policies breach international human rights obligations, and called for the benefit cuts that came through the 2012 and 2016 Welfare Reform Acts to be reversed and the use of sanctions to be reviewed. However, the committee has limited powers. Concerns about austerity have also evoked strong criticism from disabled people's organisations. For example, The Black Triangle Campaign (2015), which was established with the aim of stimulating opposition to welfare reforms affecting disabled people, released lists of deaths and suicides of people who had been declared fit for work.

#### **1.4.2 The impact of financial difficulties**

Welfare reform means that many disabled people have become poorer. This section presents research showing that financial difficulties have a pronounced adverse impact on physical and mental health.

People on the lowest incomes are disadvantaged in numerous ways (Office of Fair Trading, 2010). For example, they are less able to buy food in bulk which results in greater costs overall, and they have less access to 'enabling' products, such as the Internet, which improves access to other products. When disabled people lose benefits and live on low incomes, this is likely to adversely affect their physical health. Research shows that low income and financial problems are associated with poor health in mid-life (Arber, Fenn & Meadows, 2014). Since the introduction of austerity, use of foodbanks in the UK has increased (Taylor-Robinson et al., 2013;

Loopstra et al., 2015), which can also be stigmatising (van der Horst, 2014). Researchers have observed widening health inequalities in England (Bambra & Garthwaite, 2015; Gelormino et al., 2011).

There is growing recognition that deprivation and social inequity generate distress and exacerbate the stress of coping with material deprivation (Friedli, 2009). Well-established evidence links financial problems and insecurity to increased stress and mental health problems (e.g. Fitch et al., 2011; Richardson et al., 2013). Loss of income, particularly for people on low incomes, has been connected to mental health problems (Cooper & Stewart, 2015). With a loss of benefits, many disabled people have lost their mobility cars, and therefore their freedom of movement (Power, 2016), which can lead to a decline in wellbeing. There is also evidence of a connection between economic strain and suicide risk (Stack & Wasserman, 2007). Austerity in other countries has been linked to self-harm and suicide (Branas et al., 2015; Corcoran et al., 2015). In the UK, economic hardship resulting from benefit changes, sanctions and debt has been shown to act as a 'final straw' to trigger self-harm amongst patients in A&E (Barnes et al., 2016).

### **1.4.3 Stress surrounding claiming benefits**

This section introduces the stress surrounding applying for benefits and the literature on the stigma associated with being a benefit claimant.

The process of applying and being assessed for benefits has been linked to stress. Previously, DLA application forms were seen as difficult to complete (Banks &

Lawrence, 2005), so it is likely that people would also struggle with PIP and ESA forms. GPs reported an increasing workload (Iacobucci, 2014; Blane & Watt, 2012) and have raised concerns that reassessment has a negative effect on their patients' mental health (McCartney, 2012, 2015; Orr et al., 2013). Fears about benefit changes have been noted to be at least as anxiety-provoking as actual changes, if not more (Barnes et al. 2016). Many in WRAG have mental health conditions so are particularly vulnerable to the adverse mental health consequences of WCA (Davies, 2014). The WCA has been linked to significant increases in suicides, self-reported mental health problems and antidepressant prescribing (Barr et al., 2015). As a result, academics have questioned the future of this assessment (Warren, Garthwaite & Bambra, 2014). In addition, welfare conditionality, where sanctions are given if claimants do not meet conditions such as attending meetings, may disproportionately affect vulnerable groups (Patrick, 2011; Reeves & Loopstra, 2016).

Benefit receipt is known to involve stigma and shame (Lister, 2004; Weatherhead, 2014), and there is also stigma associated with disability (Scambler, 2004, 2009). Many claimants feel that others hold low opinions of them (Underlid, 2005); Baumberg (2016) calls this 'stigmatisation'. Grover and Piggott (2010) view ESA as a means of sorting disabled people into subgroups. Those involved with administration of benefits make a distinction between "the unwilling and the unwell", or the "deserving" and "undeserving" (Garthwaite, Bambra & Warren, 2013, p1105) due to negative stereotyping of sickness benefits recipients (Romano, 2015). Claimants receive much negative media attention with the rhetoric of 'shirkers', 'scroungers' or 'cheats' (Briant, Watson & Philo, 2013; McEnhill & Byrne, 2014). It has been argued

that the many television programmes about people on benefits (MacDonald, Shildrick & Furlong, 2014) cement the binary of 'good' and 'bad', or 'legitimate' and 'non-legitimate' disabled people (Roulstone, 2015). Other offensive terms such as 'scum', 'feckless' and 'work-shy' are also used (Garthwaite, 2011). The National Centre for Social Research found that the discourse about benefits as a lifestyle choice is increasingly accepted by the wider public (Park et al., 2012). Many believe that claimants are 'lazy' and don't deserve help (Baumburg, Bell & Gaffney, 2011). Quarmby (2012) comments how coverage of welfare reform categorises disabled people as either dependent victims or as villains who are falsely claiming benefits, and that this feeds into the fear that claimants face. Being a benefit claimant has become widely regarded as a drain on societal resources (Garthwaite et al., 2014).

This stigmatised view of claimants can be seen to have an impact on their day-to-day lives. It can affect neighbourhood civilities (Airey, 2003; Bailey et al., 2013) and how comfortable claimants feel when talking to others (Garthwaite, 2015b). Another potential product is hate crime (Roulstone, Thomas & Balderston, 2011). The number of recorded hate crime incidents against disabled people grew by almost 50% between 2009 and 2011 (CPS, 2012, in Thomas, 2011). This can be understood in that the political rhetoric is creating an environment of intolerance, misunderstanding and hostility (Shildrick & MacDonald, 2013).

#### **1.4.4 Non- peer reviewed literature**

Since financial difficulties and claiming benefits seem to have a harmful impact on disabled people, I was interested in the experience of claiming disability benefits since the recent and ongoing changes to welfare reform in the UK. As much of the research described above was from broad datasets or professionals' viewpoints, I was particularly interested in first-hand accounts.

A search was conducted on the experiences of working-age people with disabilities or mental health difficulties who had experienced changes to their benefits, or had claimed benefits during a period of welfare reform. It found that much work in this area remains unpublished, for example doctoral theses and reports commissioned by local services or charities. This may be partly due to the difficulty in getting published and the speed of change in this political field, and also because the researchers in local organisations did not intend to publish for an academic audience. These accounts will not be reviewed in full as they are not peer reviewed, however, I think it is important to highlight their findings. I apply Lister's (2004) conclusion on the importance of listening to the perspectives of those living in poverty to those claiming disability benefits and experiencing welfare reforms: "our understanding of poverty is enhanced, if we listen to what people experiencing it have to say" (p. 180).

Two reports on their local areas, London Borough of Newham and Northern Ireland (Roberts, Price & Crosby, 2014; Hickman et al., 2015), emphasised the insecurity of people in disadvantaged areas during a period of welfare reform. Roberts et al.

(2014) discussed insecurity in finances, housing, work and state support. They mentioned how reforms have made people vulnerable to even small changes in income or circumstance, leaving people in 'survival mode' and unable to focus on the longer-term, which was seen as both stressful and unsustainable. Hickman et al. (2015) found that participants struggled to 'get by' and routinely ran out of money, leading them to fall behind on bills and to 'go without', including food and heating.

Four charity or university research reports and one unpublished thesis explored the experience of applying for benefits for people with mental health and physical health problems. Regarding mental health, Earl (2015) found that mental health service users constructed the WCA process as 'something you either pass or fail' (p105) and a 'threat' (p114). Participants felt they were constructed as 'fraudulent versus genuine' (p79), 'workshy' (p87), 'an economic drain' (p94), and 'just a number' (p98). These phrases speak to the stress and the stigma associated with the benefit application process. Furthermore, many people with mental health difficulties described that the WCA caused a deterioration in their mental health which they did not recover from, and in the worst cases generated thoughts of suicide (Marks, Cowan & MacClean, 2017). They noticed an inconsistency between GP and WCA recommendations, and were not confident in the WCA's ability to assess mental health. In addition, many of these participants reported being subject to further distress due to DWP communication being lost in the post. Another study found that respondents with mental health issues thought that their impairments were not taken seriously (Dwyer et al., 2016). These participants were overwhelmingly critical of the WCA, with common concerns related to the appropriateness of the questions asked, lack of empathy, and rigid interpretation of requirements that failed to take into

account the episodic nature of some conditions. They reported inaccuracies in assessment reports and described the WCA as distressing. Many had also experienced sanctions which they felt were inappropriate, for example when they had been unable to attend appointments due to ill health.

People with physical disabilities faced similar challenges. People with arthritis reported that assessors lacked understanding about their condition, and found that the negative focus on their difficulties led them to question their capabilities (Akers, 2016). People with M.E./CFS (Allen, Hale, Seton & Newton, 2016) found their PIP claim process deeply dehumanising, and reported that the assessment criteria were inadequate in capturing fluctuating conditions such as M.E., and were not being fairly and consistently applied. They reported finding themselves increasingly isolated and in some cases the distress caused by the assessment exacerbated their existing health problems.

The unpublished findings indicate insecurity in finances leading to difficulty managing day-to-day, challenges faced in the benefits application process, and negative consequences to mental health. They also refer to the stigma surrounding benefit claimants.

## **1.5 Systematic literature review**

### **1.5.1 Aim**

The focus of this systematic review of peer-reviewed empirical literature was on the experiences of working-age people with disabilities or mental health difficulties who had experienced changes to their benefits or had experienced claiming benefits during a period of welfare reform.

### **1.5.2 Search strategy**

Multiple library searches were conducted for the terms shown in Table 1, using Scopus, PsycINFO and Google Scholar databases. Initially the search was limited to people with physical health conditions who claim disability benefits, but was extended to include those with mental health problems due to a low numbers of relevant papers. The reference lists of the papers found were examined to see if any relevant studies had been missed. Experts in the field were consulted for recommendations of further authors or papers. In addition, the main journals where papers had been published were searched by hand from 2010 onwards, including *Disability & Society*, *Social Policy and Society*, and *Psychotherapy and Politics International*.

**Table 1: Key search terms**

AND	NOT
austerity OR cut* OR "welfare policy" OR "welfare reform" OR "social security" OR neoliberal* OR "Welfare Service*" OR "welfare state"  "disab* benefit*" OR benefit* OR allowance OR "Disability Living Allowance" OR "Employment Support Allowance" OR "Personal Independence Payment" OR "sickness benefit*" OR "Incapacity Benefit*" OR "welfare claim*" OR "Independent Living Fund"  UK OR England OR Scotland OR Wales	Learning disability

Since austerity began in 2010, results were limited to papers published since 2010. Only papers that related to working-age claimants, not young or older people's benefits, were included. Those that referred to taxes that may affect some disabled people were not included (e.g. 'bedroom tax', Moffatt et al. 2015). Papers were excluded if they did not discuss the individual claimant's experiences, including those that analysed trends in newspaper articles (Briant et al., 2013) or interviewed stakeholders who work with disabled people (Garthwaite et al., 2013). Papers were also excluded if they focused on welfare conditionality related to employment programmes (Weston, 2012). Due to the uniqueness of the British welfare system, papers talking about the impact of changes to the welfare system in other countries were excluded. For a diagrammatic representation of how papers were chosen for the literature review, refer to Appendix A.

### **1.5.3 Systematic review findings**

In total 16 papers were included in the systematic review (Table 2). They were written by researchers in the fields of law, geography, mental health nursing, medicine and health, sociology and social policy, and disability. Thirteen used qualitative methods, two used mixed methods and one used quantitative methods, with researchers utilising a variety of survey data, questionnaires, focus groups and interviews.

From this literature review, it seems that researchers have studied the experience of austerity from three different perspectives, namely poverty, health and welfare reform, with a subsection of the latter on the experiences of claiming disability benefits. The findings have been structured according to these areas of interest.

**Table 2: Summary of articles included in literature review**

<b>Authors</b>	<b>Methodology</b>	<b>Participants</b>	<b>Key findings</b>
Clifton et al. 2013	Mixed methods - questionnaire and focus group. Descriptive statistics, thematic analysis.	15 MH service users.	Themes of welfare system being inaccessible, having negative impact on health, wellbeing and financial resources.
Curl & Kearns 2015	Repeat cross-sectional design with nested longitudinal cohort. Analysed measures of financial difficulty and mental health.	Household survey of 15 communities in deprived areas. 2006: n = 5,082; 2008: n = 3,922 2011: n = 3,340.	Increasing rates of affordability difficulty found in costs of food, fuel and clothes among households with disabled adults. Affordability difficulties associated with decline in MH.
de Wolfe 2012	Thematic analysis.	23 people with ME, including 5 interviews and 18 email comments.	Being a claimant can involve effort, anxiety, insecurity, felt stigma, and loss of self-esteem, affecting welfare recipients profoundly and negatively in ways that are largely absent from public discourse. Many reported strong desire to return to paid employment.
Garthwaite 2014	Thematic analysis of interviews.	25 IB recipients.	Themes of fear and suspicion of reform, feelings of stigma and shame related to media portrayal, and poverty and insecurity in contrast to media perceptions.
Garthwaite et al. 2014	Mixed methods - longitudinal health survey data over 18 months. Descriptive statistics, thematic analysis of interviews.	Data from 229 long-term IB recipients. 25 interviews.	IB recipients experience significantly worse, and constant, ill health relative to general population. Their lives are limited by both illness and stigmatisation of benefit receipt.
Garthwaite 2015a	Grounded theory using interviews.	25 long-term sickness benefits recipients.	Participants negotiated changes to their identity in moving onto disability benefits by accepting or rejecting a stigmatised disabled identity, including hiding their identity, by validating their illness, and for some, pursuing aspirations.
Moffatt & Noble 2015	Longitudinal interview data over 16 months, narrative analysis.	23 people with cancer, follow-up with 12.	Data shows financial strain of not being able to work, difficulties negotiating the welfare system, and stigmatised identity when relying on welfare benefits, which compounded the disruption of having cancer.
Morris 2013	Focus groups and online questionnaire.	95 disabled people.	Themes of increasing poverty and precarious nature of household finances when dependent on benefits, and anger at losing financial independence. Those who had experienced WCA found it humiliating, degrading and inaccurate, with negative impact on physical and mental health. Many wished for better access to advice.

<b>Authors</b>	<b>Methodology</b>	<b>Participants</b>	<b>Key findings</b>
Patrick 2014	Interviews 3 times between 2011 and 2013, thematic analysis.	15 out-of-work benefits claimants, including disabled people likely to be affected by migration IB onto ESA	Efforts involved in 'getting by' on benefits were often time intensive, emotionally draining and associated with feelings of shame and anxiety. Findings suggest mismatch between government rhetoric of benefits as 'lifestyle choice' and individual lived experiences.
Patrick 2016	As above	As above	Most recounted experiences of stigma and found the claims process dehumanising, leading to shame. Participants responded to stigmatised narrative by sometimes challenging, and sometimes accepting and internalising. Main strategy to manage stigma involved 'othering' those deemed less deserving.
Patrick 2017	As above	As above	Welfare reform leads to pervasive financial insecurity. Welfare conditionality leads to 'conditioning', where people seek to manage their behaviour to meet the demands of contemporary citizenship.
Pemberton et al. 2016a	Video and audio testimonies	62 participants from low income households	Participants were 'existing, rather than living' due to meagre budgets. The precarious nature of work and social security contributed to a sense of insecurity. They felt their lives were placed under increased scrutiny due to political rhetoric and media coverage of poverty.
Pemberton et al. 2016b	As above	As above	Most participants framed their 'pathway into poverty' in terms of life events beyond their control. They perceived intensified stigma due to media discourses. They felt angry at these perceptions and attempted to distance themselves but also internalised self-loathing.
Porter & Shakespeare 2016	Thematic analysis of interviews.	12 former ILF users	Participants were positive about ILF and worried about local authority (LA) provision. Most received insufficient information and poor communication about transfer to LA care.
Shefer et al. 2016	Thematic analysis of interviews.	17 disability benefits recipients, received for MH and who won appeal	Beyond the practical reduction of income and the related anxiety, interviewees reported considerable stress when coping with the 'never-ending' cycle of bureaucracy. They expressed anger, frustration and demoralisation at mistrust towards authorities partly due to 'invisibility' of their disability.
Wright 2016	Interviews	16 benefit recipients, including IB and Income Support.	Interviewees felt powerless and struggled to get by due to unpredictability in health and finances. Many accepted personal responsibility and attempted, and failed, to change their life circumstances.

### **1.5.3.1 Poverty**

Three of the papers, Curl & Kearns (2015) and Pemberton et al. (2016a and 2016b), studied poverty, where the experience of being disabled formed a small part of the research. The findings grouped disabled people with others in deprived areas. From this literature we learned that there was a significant increase in the number of households in the sample which contained a disabled person of working age between 2006 and 2011. For these disabled adults, almost two in five reported struggling to pay for fuel and a third reported having difficulty affording clothes in 2011, whilst difficulty affording food increased over time (Curl & Kearns, 2015). As difficulties affording items rose, it was reported that mental health problems (stress, anxiety and depression) increased over time.

Pemberton et al. (2016a) found that people in poverty were under pressure due to worsening conditions, including falling incomes, rising prices and a reduction in support services. Participants described “existing, rather than living” (p11) due to meagre budgets, meaning people existed from day-to-day and some had to make a choice to “heat or eat”. This added to the sense of insecurity from the precarious nature of social security, where the threat of sanctions and reassessment was described as a constant source of anxiety and uncertainty. Some turned to high cost forms of borrowing, which exacerbated their financial strain. Pemberton et al. (2016b) reported that the majority attributed their poverty to life events which were out of their control, such as disability. They felt their lives were placed under increased scrutiny due to the political rhetoric and media coverage of poverty, which appeared to give permission for others to denigrate their ‘lifestyle choices’. This

impacted on their wider relationships and sense of belonging, which they found frustrating. Many internalised a stigmatised identity, whilst others seemed to try to distance themselves from this. Distance could be achieved if their situation was viewed as temporary rather than permanent.

### **1.5.3.2 Health**

Moffatt & Noble (2015) explored identity and stigma in cancer, where part of the data explored the experience of claiming disability benefits. The data is from 2009 so must be read with caution regarding austerity. From this, we learned about the impact of financial difficulties caused by interruption to employment, including an inability to pay bills and housing payments, and the additional stress of worrying about finances when unwell. The study demonstrates the unsuitability of the benefits system, for example requiring paperwork when one is undergoing treatment, and inflexibility for those who require a gradual return to work or might relapse into ill health. It demonstrates the difficulties of welfare conditionality when one cannot return to a previous career due to health concerns. Reliance on benefits carried a stigmatised identity that exacerbated the disruption caused by cancer, and which claimants tried to distance themselves from. The authors concluded that people with cancer, and other chronic health conditions, require more assistance to claim benefits.

### **1.5.3.3 Experiences of welfare reform**

Four papers explored the experience of receiving benefits. An unspecified proportion of the participants were disabled and their experiences were grouped with other claimants such as single parents and jobseekers. Patrick (2014) described how participants were 'existing, not living' (p709), which involved going without food so children could eat, and much effort going to several shops to locate the lowest prices. This challenges the idea of benefits as a lifestyle choice. With a focus on paid employment, participants found the care work, parenting and volunteering they did was not valued by the state, although they aspired to paid work. Patrick (2016) focused on the experiences of stigma, both resentment from others and personal embarrassment. The research reported how this led some to under-claim benefits to which they were entitled. Some concealed their stigma identity, and some highlighted the 'deservingness' of most benefit claimants, challenging the dominant narrative that claimants require encouragement to enter paid employment. 'Othering' (p246) was common, where an 'other' was deemed less deserving whilst validating one's own needs, and Patrick noticed this reduced the scope for alternative narratives.

Patrick (2017) discussed how the social rights, i.e. welfare and security (p293), provided to those in receipt of out-of-work benefits, were curtailed. She found that claimants were forced to manage on very low incomes, particularly when assessed as failing to comply with welfare conditions. This often had a negative effect on participants' mental health and their capacity to cope with a day-to-day life of poverty. She noted a chronic state of insecurity and uncertainty, with an associated

fear about the future of benefit changes, such as waiting for outcomes of reassessments. She argued that growth in use of welfare provision such as foodbanks (Garthwaite, 2016) shows that social rights are failing to provide basic necessities. Conditionality was experienced as dehumanising, and the researcher conceptualised that many participants showed conditioning in seeking to fulfil the requirements of a dutiful citizen by gaining employment. For some this appeared to be driven by a desire to leave reliance on benefits, and the associated stigma, behind.

Wright (2016), who collected data in 2008, compared claimants with the dominant model that they are deficient or self-interested, which currently influences policy. She found that benefit claimants often felt powerless and struggled to get by, living with unpredictability in their health, housing and employment. Many participants accepted personal responsibility in their situation (as advocated by this model) and attempted to bring about change, with no success. She noticed that the policy context had an impact on participants' ability to exercise agency, for example by setting living conditions where people are required to meet basic needs on an insufficient income. She concluded that it is helpful to see claimants as active in their attempts to change their situations.

#### ***1.5.3.4 Experiences in the benefits system***

Two papers explored the impact of the changes in the benefits or social care systems on people with mental health difficulties, and six explored the impact on

people with disabilities. I use 'system' and 'benefits system' interchangeably from here, due to word count.

Mental health service users described the current system as inaccessible and non-inclusive, for example ESA, WCA and tribunals not being joined-up and having their own, and sometimes conflicting, requirements (Clifton et al., 2013). Many said the communication they received was not clear. They described the WCA as un-empathetic and not treating people as individuals with their own needs. They reported feeling 'trapped', and increased anxiety and distress in this repetitive system of assessment, which impacted their health and wellbeing. They mentioned additional costs of calling premium rate telephone numbers and paying for medical reports, which led to significant debt. Shefer et al. (2016) highlighted the practical implications of a reduction of income, including debt, poverty and hunger. They described the stress involved in coping with the "never-ending" (p834) bureaucracy around benefits assessments and appeals, and the intimidating nature of these. They noted a sense of anger, frustration and demoralisation at the implication that some claim benefits which they are not entitled to. The authors considered that denying benefits to people with mental health disability was one of the most severe forms of social exclusion.

Of the studies that focus on benefit cuts to people with physical disabilities, most collected data in 2009-2011, prior to the move from DLA to PIP and IB to ESA, so should be read with care. People with M.E. (deWolfe, 2012) reported that applying for benefits was a considerable task, particularly for those who struggle with basic self-care. They described both a physical and mental strain, and for some this

provoked a major relapse in health. Application forms were criticised as ill-suited to fluctuating and multi-symptomatic illness. Anxiety seemed to be generated by the frequency of initial DLA rejection and the seeming randomness of outcomes. The majority of participants claiming DLA reported that they had appealed the initial decision. It was noted that, contrary to other social situations, claimants had to present a public display of disability for their assessment. This requirement stretched to fears of state surveillance near their homes, which led to participants isolating themselves and concealing their claimant status from neighbours and even family and friends. As M.E. is a contested illness, they felt they were particularly liable to be regarded as malingerers. The majority indicated that they were eager to return to work if health allowed, framed as an issue of dignity, a wish to escape dependency, or to gain a sense of social usefulness.

Morris (2013) talked about increasing poverty and the precarious nature of household finances when dependent on benefits, leading to debt problems and low mood. Her participants found the WCA was humiliating and degrading, with assessors who lacked 'understanding and knowledge' (p725) about impairments. A sense of injustice was common. Social care cuts resulted in additional pressure on carers and family. Social attitudes, felt to be fuelled by the government and media, and abusive experiences from the public caused some to fear leaving their homes. Participants expressed a wish for better access to advice, information and advocacy.

Garthwaite (2014, 2015a) and Garthwaite et al. (2014) explored the experience of receiving IB. They found the majority of participants were fearful about ongoing welfare reform, including worrying about assessments and mistrust of the system.

Those who had undergone WCA reported a sense of depersonalisation and feeling powerless. Some respondents mentioned fear over receiving an official-looking brown envelope through their letterbox, a possible indicator of communication from the DWP. Participants described feelings of stigma and shame created from the political and media representations of the reform process, such as being labelled a 'scrounger'. In some cases, stigma deterred people from accessing the support they needed, leading to under-claiming and the risk of amplified financial strain. This may be related to preserving one's identity as 'not disabled' (Garthwaite, 2014, p791). Again, the financial implications of living on benefits were highlighted. Many described how they were eligible for IB but that others were faking it, creating an 'us' and 'them' dichotomy (p793). Garthwaite concluded that this reflects the divisions between disabled people created by the government rhetoric, fostering resentment for those deemed 'undeserving' (p783). This study found that IB claimants had significantly worse health than the general population, which counteracts the media rhetoric of fraudulent claimants. Many participants 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 (Garthwaite, 2015a). Participants moving onto IB attempted to come to terms with becoming 'incapacitated' in different ways. They accepted or, more commonly, rejected a disabled identity, which was related to the labels being given to them and whether sickness was viewed as permanent. Some reported concealing their claimant identity, which sometimes led to avoiding social situations and becoming isolated. Others made an effort to appear genuinely ill, so they would not be disbelieved, due to the felt stigma of claiming benefits.

Regarding social care cuts, those with severe disabilities have reported concern about the closure of the ILF and funds being moved to local authorities (LA) (Porter & Shakespeare, 2016). Many feared losing their independence and the prospect of institutional care, if their LA did not ringfence this funding. They felt they received inconsistent and insufficient communication about this transition and whether their funding would change. This uncertainty resulted in feelings of anxiety, stress and even suicidal thoughts. These findings mirror the themes seen with disability benefits.

#### **1.5.4 Summary of findings**

The research to date suggests that disabled people on benefits experience significantly worse health than the general population. It is reported that changes in benefits have reduced household finances, which has affected the ability to buy food, fuel and clothes. Efforts involved in 'getting by' (Patrick, 2014, p711) on benefits were often time consuming and emotionally draining. For many, the precarious nature of benefits contributed to a sense of insecurity. Claimants reported that they found the benefits system difficult to navigate, with long forms and lack of transparency and poor communication about processes. This has been found to cause considerable stress, fear and anxiety. In particular, the WCA has been found to be humiliating, degrading and inaccurate. The associated emotional and financial stress has been found to have a negative impact on both physical health and mental health.

Furthermore, disabled people on benefits felt that their lives have been placed under increased scrutiny due to the political rhetoric and media coverage of poverty. They reported feelings of stigma and shame when relying on benefits. Many reported feeling angry about these perceptions and attempted to distance themselves by 'othering' those deemed less deserving, concealing their claimant identity or attempting to validate their illness. However, it was reported that many also internalised self-loathing. The stigma appeared to affect welfare recipients negatively in ways that are largely absent from public discourse, and there seemed to be a mismatch between the government rhetoric of benefits as a 'lifestyle choice' and individual's actual experiences.

The findings from the non-peer reviewed reports corroborate and emphasise these findings, especially the stress of applying for and claiming benefits.

### **1.5.5 Critique of the literature**

The quality of the studies in this review was assessed using a framework outlined by Elliot, Fisher & Rennie (1999) (Appendix B). This framework has seven guidelines for both qualitative and quantitative approaches and seven guidelines pertinent to qualitative research.

Papers were generally well written and presented their findings clearly and coherently. Most were clear about their methodologies and used appropriate methods. Use of quotes from participants grounded the findings in data, bringing

data to life and making them engaging for the reader. As this is an emerging and rapidly changing area with little previous research, the findings contributed to knowledge in the field.

Some authors considered the limitations of their recruitment methods and how this might have affected their results, for example the limitations of selecting a sample from a voluntary work-related event, meaning these participants were likely to be more motivated to return to work than others claiming similar benefits (Garthwaite, 2014). Morris (2013) provides an excellent detailed consideration of the advantages and limitations of recruitment through social media, illuminating the relatively smaller proportion of disabled people with access to the Internet, but also the ability of social media to include those who are severely unwell.

One of the main critiques of the qualitative studies was that in attempting to collect a diverse sample of participants, with a range of narratives, or from households with varying circumstances, it is difficult to draw conclusions about the experiences of disabled people in a time of welfare reform. I acknowledge that for some this was not the focus of their work (Pemberton et al., 2016a and 2016b). However, Patrick (2014) for example, did not discuss the limitations of having a sample of benefit claimants which included lone parents, job seekers and disabled people. It would be difficult to develop a clear understanding of the experiences of any of these sub-groups as findings were not separated out, and if they had been, the groups would have been too small to draw conclusions. She makes the assumption that all claimants have a similar experience. Whilst this may be true to some extent, research regarding the sub-groups would be helpful. One study had only five

interviewees, although this was backed up by written communication and mentioned its limitations (deWolfe, 2012). Another study acknowledged the small scale of their research, but proceeded to draw conclusions, perhaps too strongly, despite this (Moffatt & Noble, 2015). Some studies did not provide (Morris, 2013; Patrick, 2004), or in some cases collect (de Wolfe, 2012), full demographic data about participants so it would be difficult to assess the relevance of the data to particular sub-groups.

Another critique was that few researchers declared their relationship to the topic area, although three authors disclosed this work was part of their masters or doctoral research and disclosed the funders or collaborators (Morris, 2013; Garthwaite, 2014; Patrick, 2014). This means that they did not explore how their values, interests and assumptions may have affected their interpretation of data. Only one researcher did this thoroughly and stated her political position on disability movements and relationship to the studied health condition (de Wolfe, 2012).

A final common critique was that, although themes were often grounded in data, few studies provided credibility checks such as verifying whether the participants agreed with the conclusions or using multiple types of qualitative analysis. Garthwaite et al. (2014) however used both quantitative and qualitative data to triangulate their findings. It could also be argued that Garthwaite's (2014) ideas were developed directly from the data, as she used grounded theory methods.

## 1.6 Research rationale

Although the quality of many of the studies in the systematic review was good, the number of studies was limited. Six of the papers referred to only two datasets, which demonstrates the lack of research in this field. Many looked at this topic from a poverty or disability perspective, where the welfare system formed a small part of the research. Others looked at the experience of benefit claimants but grouped disabled people with other claimants. This left a small number which focused directly on disabled people's experiences of changes to the benefits system, and of these an even smaller number with a focus on physical health, rather than mental health, difficulties.

This is an ever-changing field and very few of the studies collected data after the significant changes to disability benefits and social care since 2010. Therefore, the data presented in this review is not current. Garthwaite (2015a) argues that while it may seem obsolete to be discussing IB when claimants have since been moved onto ESA and JSA, many of the debates informing policy on incapacity, work and welfare remain the same, reflecting concerns over eligibility and worklessness. Despite this counter-argument, there are few previously published individual accounts and it is important to research how the recent changes are affecting people with disabilities. Additionally, many of these studies concluded that it is important to listen more to disabled people's narratives (Garthwaite, 2014).

From the literature review, it can be seen that the experience of being a disability benefit claimant has many complex aspects. Conducting research into the

experience of making claims and living as a benefit claimant is increasingly important given the tightened criteria that are currently generating even greater anxiety and risk of impoverishment (deWolfe, 2012). As we know that context and social discourses influence sense of self, it would be interesting to explore the impact of living in the current political climate on the identity of people with physical health conditions. New research would facilitate better understanding of the implications for individual's health and wellbeing. Findings may assist policy makers to make changes to improve the disability benefits experience for service users. To conclude, there is limited research to date exploring individual's experiences of changes to disability benefits. My research aims to contribute to filling this gap in the literature.

### **1.6.1 Research aims and questions**

This research aimed to explore the experience of people with physical disabilities in making disability benefit claims and living as a benefit claimant. This was achieved through data collection with people who had personal experience of this.

The research question was:

- What is the impact of a loss of or change in disability benefits on the experiences and identity of people with physical disabilities?

The sub-questions were:

- How has a change in disability benefits affected...  
... daily functioning and physical health?

... emotional wellbeing?

... ability to participate or engage with their community?

... how others, including family, friends and members of the public, respond to claimants?

... sense of self?



## **Chapter 2 - Method**

## **2.0 Method**

In this chapter I explain my rationale for undertaking qualitative research and my chosen method of Grounded Theory in line with my epistemological position. I detail the study design, participant inclusion criteria and recruitment, data collection and analysis. I describe my consideration of ethical issues and explain how service user feedback affected the research. Lastly, I evaluate my study against qualitative research criteria. I reflect on my experiences of conducting this research throughout.

### **2.1 Design**

An exploratory, qualitative method was favoured in order to gain a depth of understanding of participants' subjective feelings, thoughts and experiences and the way in which they construct and communicate these (Barker, Pistrang & Elliott, 2002). Qualitative methods are particularly appropriate when undertaking exploratory research in relatively neglected areas (Barker et al., 2002), such as this one. This was achieved using interviews and constructivist grounded theory analysis (Charmaz, 2006).

#### **2.1.1 Epistemological position**

The research method was chosen based on its suitability for answering the research question. However, it was also important to select a method that was consistent with my epistemological beliefs. In line with my critical realist position, a constructivist

approach to grounded theory was taken (Charmaz, 2014), as it allows the researcher to explore and value different coexisting interpretations of a phenomenon.

I acknowledge my role in shaping the research design and the effect of my interpretations on the theory developed (Mruck & Mey, 2007). I accept that my prior perspectives and reading of the literature could have guided the research, in that I may have explored areas which interested me rather than those of the participants (Charmaz, 2014). I held a reflexive position throughout in order to consider my impact on the research.

### **2.1.2 Constructivist Grounded Theory**

Grounded theory was chosen, as opposed to other qualitative methods such as Interpretative Phenomenological Analysis, which explores the meaning making of subjective experiences, and Narrative Analysis, which explores personal accounts of events. It was considered that in order to answer the research question, this study required an approach which enabled the *process* of undergoing benefit changes to be explored, rather than narratives or meaning making. Grounded theory was developed by Glaser and Strauss (1967, p1) who criticised the "overemphasis in current sociology on the verification of theory, and a resultant de-emphasis on the prior step of discovering what concepts and hypotheses are relevant for the area that one wishes to research". Grounded theory analyses social processes, actions and sequences, and searches for relationships between processes in order to develop understanding of an area. Grounded theory is useful for under-researched areas and has been favoured for exploring social relationships where there has been little

exploration of the contextual factors that affect individual's lives (Crooks, 2001). As explored in the introduction, experiencing changes to one's benefits is likely to have complex effects, embedded within multiple layers of context. As such, it was felt that grounded theory would bring a valuable perspective to experiences of these changes. It was hoped that the theory generated would be valuable in progressing this area of research, as well as providing a structure in which to understand the phenomenon to disseminate more widely than amongst academics.

Constructivist grounded theory was chosen because it can capture context and political voices, stresses the importance of social contexts and interactions, and views knowing as embedded in social life. Constructivist grounded theory differs from earlier versions of grounded theory, developed by Glaser and Strauss and Corbin, which held positivist assumptions (Charmaz, 2014). It posits that reality is socially constructed, and acknowledges the role of the researcher's position, perspectives and interactions in the research (Charmaz, 2014). Therefore the research is viewed as co-constructed rather than discovered.

### **2.1.3 Using interviews**

Individual interviews were used as the data collection method. Interviewing lends itself well to interpretive inquiry as it enables in-depth exploration of a topic (Charmaz, 2006), including "experiences, opinions, attitudes, values, and processes" (Rowley, 2012, in Iacono, Symonds & Brown, 2016, p3). It allows the researcher to build rapport with participants, which facilitates access to their interpretations of their experiences (Charmaz, 2014). Hiller and DiLuzio (2004) assert that interviews give a

voice to marginalised groups and unheard voices, which was considered important in this study. Britzman (1989) discusses a multi-conceptual understanding of 'voice', including literal, metaphorical and political. Interviews offer the flexibility and sensitivity that is required for vulnerable participants, including those with disabilities (Aldridge, 2014).

However, interviews have a number of limitations, for example the interviewer is not merely a knowledge collector but also has their own knowledge and views, and an interview is an interaction so participants respond using the language of the questioner (Potter & Hepburn, 2005). Therefore, interviews introduce the researcher's agenda into data collection (Harper, 2013), which may affect what the interviewee reports and means their responses cannot be neutral. Additionally, interview extracts are often presented omitting the researcher's preceding question (Potter & Hepburn, 2005), making the context difficult for readers to assess.

In order to counter these limitations, the researcher took a number of actions. As the interviewer was likely to be influenced by her reading, she read broader than the research topic in order to avoid the analysis being narrow and superficial. She used a number of search engines in her literature search, and also read grey literature. Reading widely around a topic can enable a researcher to identify one's own assumptions (Harper, 2013), as well as stimulate the interviewer's curiosity leading to broader questions. In order to facilitate the reader in understanding the context of the study, the researcher provided a synopsis of the political environment alongside an acknowledgement of her epistemology and views. In her discussion, she made

links to various relevant psychological theories in order to avoid reproducing the currently dominant narratives conceptualising a phenomenon (Harper, 2013).

On balance, interviews were chosen given the inability to study participant's feelings and experiences without asking. Individual interviews were deemed the most appropriate method due to the sensitivity of the topic.

## **2.2 Ethics**

### **2.2.1 Ethical Approval**

Ethical approval was granted by the University of Hertfordshire Health and Human Sciences Ethics Committee with Delegated Authority (Appendix C). The research was conducted in line with the BPS Code of Human Research Ethics (2014).

### **2.2.2 Ethical considerations**

#### ***2.2.2.1 Informed Consent***

Throughout the research, I held in mind the BPS Ethics Guidelines for Internet-mediated Research (2013). For example, following the principle of Social Responsibility, I was transparent about my observer status when recruiting participants from a Facebook group for benefit claimants by disclosing being a researcher, so as not to deceive group members.

Before each interview, participants were given a participant information sheet (Appendix D) detailing the procedure, confidentiality and anonymity, and the right to terminate the interview or withdraw from the study at any time, even after its completion. This was discussed and they were given an opportunity to ask questions before consenting in writing (Appendix E). For interviews conducted through Skype, information sheets and consent forms were emailed in advance so participants had time to read them.

### ***2.2.2.2 Confidentiality and Anonymity***

The interview recordings were downloaded to a password protected laptop. The files were named using a letter, which was given a corresponding pseudonym. During transcription, all identifiable information was removed from the transcripts. Therefore, the sources of any quotes used in this research would not be identifiable. A brief demographic information form (Appendix F) and consent forms were kept in a secure place, either password protected if electronic or in a locked cabinet for paper forms. All paper forms will be securely destroyed on completion of the study.

### ***2.2.2.3 Managing potential distress***

Distress was encountered during recruitment, for example one participant who registered interest in the study disclosed suicidal ideation. His email was unclear whether he was emphasising the impact of welfare reform or whether he had current suicidal intent. I followed BPS guidance which states that researchers have a responsibility to protect participants from mental harm and should inform participants

of actions they can take to minimise risks to themselves (BPS, 2009), so I signposted him to appropriate services, including the Samaritans and A&E. This felt extremely worrying and uncomfortable for me, but demonstrates the extent of distress caused by benefit changes. I used supervision to discuss my feelings and to check I was following appropriate procedures.

Further distress was encountered during the interviews. Some participants were tearful and I offered comfort and support. With two participants, I offered to pause or terminate the interview, although they chose to continue. At the end of each interview, I assessed participant's levels of distress using my clinical judgement and by reflecting together on the process. Participants were given the opportunity to ask questions and give feedback. I planned extra time in my schedule so that I could discuss any issues that arose during the interviews. In a few cases where I was concerned about a participant's risk to themselves, we discussed their informal support and professional mental health networks. One interviewee presented as very low, so I also discussed their plans immediately after our conversation, including who was nearby to comfort them. Afterwards, all participants were given or emailed a debrief sheet (Appendix G).

### **2.3 Service user involvement**

I consulted with service users (SUs) throughout the research. Initially, I spoke to a physically disabled advisor, who works for a disability advocacy charity. Conversing with him shaped my research topic, as he briefed me on some of the difficulties in

claiming benefits and we reflected that researching the experiences of benefit changes would be beneficial to this population. He linked me to some members of the charity who might wish to be involved in the research and facilitated access to the charity's offices for these interviews.

I also met with a consultant who has Asperger's, whose work includes advising clients regarding benefits and assisting them to appeal DWP decisions. He outlined some of the key disability benefits, which helped me to gain a broad overview. I had intended to limit my research to one benefit, such as PIP, but our conversation showed me that there is much overlap between claimants of disability allowance benefits (PIP) and work-related disability benefits (ESA). Consequently I decided to research the impact of the loss or change in any disability-related benefit.

Furthermore, I recruited a SU who had previously claimed ESA for mental health difficulties to pilot my interview. The aim was to check that the wording of my questions was sensitive to people who have claimed benefits, in particular regarding personal finances, and whether my demeanour would enable an interviewee to decline an answer if they felt uncomfortable. She recommended no major changes, but emphasised the importance of letting participants tell their disability story at the start of the interview as well as their benefits experience. She stated that my questions were open and not biased towards my expectations about the consequence of loss of benefits. She was able to verify that my information sheets and consent form were clear and acceptable. She also suggested ideas for recruitment and dissemination to a wide audience, and used her social media accounts to broaden my reach for contacting potential participants.

As grounded theory has inbuilt theoretical sampling, I discussed my findings to date with the final three research participants in order to obtain their opinions and comments on the theoretical model that had been co-constructed from the data. Their comments led to further development and clarification of aspects of the model, particularly regarding identity.

Finally, I made contact with a journalist who is disabled and reports on disability issues. She writes a weekly column in a well-known newspaper and is keen to discuss and disseminate my findings.

SU involvement was critical in making the research relevant, useful and accessible to the population I was studying. It is valuable to listen to people who have direct experience of the research topic as they have a unique insight into how the research and its findings may affect the population being studied. In addition, involvement challenges the stigma that these people are unable to work, and can increase their sense of worth and self-esteem (CPFT, 2015).

## **2.4 Participants**

### **2.4.1 Recruitment**

A stepped sampling approach was adopted. Consistent with grounded theory, I was not aiming to sample a representative distribution of people with physical disabilities

(Charmaz, 2006). Instead, initial sampling was purposive, aiming for diversity of participant experience and data with comparative potential (Barbour, 2013). Initial recruitment (Step 1) was through a disability charity. Due to low uptake from suitable candidates, recruitment was rolled out via snowballing (Step 2), and social media, including Twitter and Facebook (Step 3). Recruitment of vulnerable or hard-to-reach populations often relies on informal word-of-mouth practices, such as snowballing, because of difficulties in identifying and gaining access to them (Aldridge, 2013). Gile and Handcock (2010) argue that these strategies are often more successful because previous participants facilitate the sampling of others. Step 3 involved sharing a link to a webpage with information about the study (Appendix H). Use of social media has both advantages and disadvantages. As 34% of disabled people have never used the Internet, compared to only 10% of non-disabled people (Office for National Statistics, 2012, in Morris, 2013), this limits the population that could be reached. However, the method facilitates access to the opinions of those who could not engage in person due to their disability, such as those unable to travel.

From these steps, there were many interested suitable candidates. Initially, convenience sampling was adopted; people who expressed an interest and met the inclusion criteria were selected on a first-come-first-served basis. Later, interviewees were recruited to fulfil theoretical sampling criteria.

#### **2.4.2 Inclusion criteria**

The inclusion criteria were adults with a minimum of one life-limiting or long-term physical health condition or disability, whether or not they also experienced

comorbidities such as other health conditions or mental health problems. Participants were required to have experienced changes to their disability benefits since 2010, when austerity measures were introduced.

It was considered that those experiencing mental health in an acute stage would be too vulnerable to be interviewed and therefore excluded from the study. This is difficult to judge, however one participant was excluded due to suicidal ideation; this case was discussed in the section on managing potential distress (2.2.2.3). Those solely with mental health difficulties were excluded, as that was not the focus of this study. People with learning disabilities were also excluded, due to their vulnerability and the cognitive demand of the interview. People whose first language was not English were not excluded as an interpreter could be employed; however, this did not occur, possibly due to the recruitment methods.

### **2.4.3 Rationale for sample size**

Traditionally data collection in grounded theory ends when categories become 'saturated', when no new theoretical insights may be found with further data gathering (Charmaz, 2006). However, Dey (2007) maintained that data collection is rarely an exhaustive process. Furthermore, Willig (2008) argued 'saturation' is unobtainable, especially from a constructivist epistemological position, given that revision of categories is always possible. It can be argued that saturation is problematic from a position where one assumes that there are multiple alternative constructions of the data.

Therefore saturation in constructivist grounded theory is more open and occurs when no new information emerges to add to meaning (O'Connor, Netting & Thomas, 2008). Poole (2009) recommended aiming for well-developed categories composed of depth and variability. For the purposes of this study, the aim was to recruit until a coherent co-constructed theory had been achieved which could account for the majority of the data, without adding any new categories. I acknowledge that other co-constructions could have been made, for example if another researcher analysed the data. In total, fifteen participants were interviewed.

#### **2.4.4 Participant demographics**

The sample consisted of four males and eleven females, with an age range of 28 to 68 years (Table 3). Four participants were recruited from two disability charities, one by word of mouth, and ten through social media. The participants were all British, with a range of ethnic and socio-economic backgrounds. They lived in a variety of locations across England and Scotland. Most participants lived in council properties, some in rented properties, and one in a homeless facility. Most participants had lost money from their benefits or initially had not met criteria for benefits; for some these had been partially or wholly reinstated; for some their benefits were under review; and for some they had been totally withdrawn. A few participants had transferred from one benefit to another or were awaiting a change in benefits, but had retained their financial income to date.

**Table 3: Participants' demographic information**

<b>Name*</b>	<b>Gender</b>	<b>Age</b>	<b>Type of disability</b>	<b>Ethnicity</b>	<b>Marital status</b>	<b>(Previous) Career</b>	<b>Benefit issues</b>
Adrienne	Female	55-64	Invisible physical condition with pain, mental health	White /British	Divorced	Prev. Teacher	ESA
Bryony	Female	45-54	Visible physical condition; wheelchair user	White	Single	Performer	ILF, Access to Work
Caroline	Female	45-54	Invisible physical conditions, mental health	White /British	Single	Administrator	ESA
Dean	Male	55-64	Invisible physical condition with pain	White British	Married	Prev. Builder	PIP
Eve	Female	55-64	Invisible physical condition with pain	White /British	Divorced	Prev. Clerical worker	ESA
Frankie	Female	35-44	Invisible physical condition with fatigue	Black Afro-Caribbean	Single	Prev. Solicitor	PIP, ESA
Grace	Female	45-54	Invisible physical conditions with pain	White /British	Single	Law degree	PIP, ESA
Hazel	Female	65+	Invisible physical conditions	White /British	Widowed	Retired social worker	PIP
Irene	Female	55-64	Invisible physical condition	White /British	Single	Prev. Insurance worker	PIP
Jonathan	Male	55-64	Invisible physical conditions with pain	White British	Long-term partner	Prev. Engineer	PIP, ESA
Kelvin	Male	25-34	Invisible physical condition	Arab	Partner	Journalist	PIP

			with cognitive effects				
Louise	Female	35-44	Invisible physical conditions, mental health	White /British	Single	Volunteer & artist	PIP, ESA
Molly	Female	25-34	Visible and invisible physical conditions; wheelchair user	White /British	Partner	Trainee Therapist	PIP
Nicola	Female	25-34	Visible physical condition; wheelchair user	White /British	Single	Postgraduate student	Wait for PIP
Oliver	Male	25-34	Visible physical condition	White /British	Single	Journalist	PIP

\*Pseudonyms are being used to maintain participants' confidentiality

#### 2.4.5 Difficulties in recruitment

There were few difficulties with finding enough interviewees once recruitment began through social media, as many disabled people have been affected by benefit changes. However, once theoretical sampling began, it was more difficult to find participants with visible disabilities, such as wheelchair users. This may be due to a smaller number of disabled people having visible disabilities, some being too unwell, or potentially due to them experiencing fewer difficulties with benefits so being less motivated to be involved.

However, there were a number of issues encountered once participants registered interest. Of those who agreed to be involved in the research, some did not attend at the agreed time, either due to current severity of their illness, forgetfulness due to

their condition or many competing demands on their time when navigating the benefits system. This meant that often interviews had to be rearranged, which delayed recruitment, but demonstrates the demands of illness and the benefits system on these participants.

Initially, several interested participants held concerns about the research. Some feared that I would report on them to the DWP so I clarified my position that I hoped that this research would lead to improvements in benefits system processes. Some were concerned about Internet safety for Skype interviews. I agreed to delete participants from my Skype account after our call and, as with other interviews, to store the data securely and to delete audio files after the study, unless they gave consent for use in future studies. Some worried about how the data would be disseminated. Following BPS guidance (2009), I reassured them by explaining anonymity and confidentiality, for example, I clarified that quotes used in any reports would not be traceable to individuals. I emphasised that participation was optional and they could withdraw at any time, although none chose this option. Afterwards, all participants felt sufficiently reassured to consent to involvement.

## **2.5 Data Collection**

### **2.5.1 Resources**

An interview guide was used, with a digital Dictaphone to record the interviews. When interviewing remotely, Skype was used to make calls, together with the

software Evaer, a Skype Video Recorder. A laptop was used to keep a reflective diary and to transcribe the interviews, using Microsoft Word 2013 and the transcription software *transcribe*. NVivo 11 software was used to analyse the data.

### **2.5.2 Developing an interview guide**

An interview guide was developed (Appendix I), designed in consultation with my supervisors, with the aim of maintaining an open stance regarding people's experiences by using open questions. These allow for flexibility to adapt and follow issues that emerge during the conversations (Charmaz, 2014). The questions related to participants' views, experienced events, feelings and actions (Charmaz, 2006). Knowledge of the literature was incorporated by adding prompts which could be employed to find out how different areas of participants' lives were affected. The questions were piloted to ascertain their appropriateness and suitability, as discussed above.

As grounded theory is an iterative process, the guide was tailored over the course of the study in order to explore new issues brought up by interviewees. This enabled me to explore hypotheses or focus in on interesting leads in order to elaborate and refine categories in an emerging theory. In later interviews, ideas were introduced with the explanation that other participants had spoken about particular issues, and asking participants to reflect whether this had meaning for them too. This occurred once participants had answered in their own way in order to avoid limiting possible responses or leading participants. For example, I asked whether ideas from the

model resonated with people with visible disabilities as much as for people with invisible disabilities. In response, participants had different opinions about the extent ideas applied to them, and added new ideas. The intention was to gain a deeper understanding of concepts from the data, in order to saturate categories (Charmaz, 2014).

### **2.5.3 Interview procedure**

The interviews took place at a location of the participant's choice, either their home, a local disability charity office, or via Skype. Only one participant, known by word of mouth, chose their home. For all face-to-face interviews, the University of Hertfordshire lone worker policy was adhered to, most importantly to inform a colleague of my location and to contact them on my departure. Four interviews were hosted by two different disability charities. The majority of the interviews took place on Skype, or were telephone interviews through Skype. The interviews lasted between 25 and 85 minutes. For procedures regarding consent, see the ethics section.

During the interviews I encouraged participants to elaborate their responses by: employing prompts (e.g. "tell me more about that"); summarising to check my understanding, and by empathising with their perspectives (Charmaz, 2014). I checked with participants that I had not missed any key areas. I attempted to end the interview at a positive point by closing with the key points I can take forward, and consider how they would like the findings to be used. I thanked the participants and provided an opportunity to reflect on the interview.

### **2.5.4 Using Skype**

There are advantages and disadvantages to using video technology for interviewing. I outline my experiences in this research, and direct readers to Iacono et al. (2016) for further reading.

The major benefit of using Skype was that it was accessible for people who may find physical re-location difficult but who might be interested to participate. Deakin and Wakefield posit that Skype provides (2013, p5) “an opportunity to talk to otherwise inaccessible participants”. It is also convenient for both parties in that it is free to use, and prevents logistical issues, such as meeting in unfamiliar locations, where both the travel and venue may be associated with a cost. For this research, it facilitated access to participants from a wider geographical area than would have been possible through only face-to-face interviews, which allowed a more diverse sample and prevented exclusion of participants who registered interest but did not live near the researcher.

In addition, I think that participants may have been more inclined to speak openly because they could stay in their own home, which is a “safe location” (Hanna, 2012, p241). A familiar environment may be “more beneficial to participants who are shy” (Seitz, 2016, p232) or, in this research, fearful of the consequences of expressing their personal opinion or reflections.

There were some disadvantages in using Skype for interviews, as well as access to the Internet as discussed previously. A few participants used Skype for the first time

for this research and there was no technical support available so this was sometimes difficult for them. Kings and Horrocks (2010, in Iacono et al., 2016) advise caution because of technical glitches in sound and video transmission. One participant experienced a poor Internet connection throughout our conversation, which made it more difficult to maintain the flow of the interview and rapport with the interviewee, although humour was used to ease this process. Another difficulty regarding participant's worries about online security was discussed above.

Written consent was slightly more difficult than in person, so I sent electronic versions of information sheets and consent forms to participants in advance and gave time to answer questions before the interview commenced. Some printed and signed the consent form then scanned and attached it to an email. Written consent was also assumed if a participant typed their name and the date into the consent form and returned it by email. This was in addition to verbal consent. Participants were informed when the audio recording had begun or was stopped.

Finally, for most calls, I could only see people's faces, therefore was unable to process non-verbal cues from the rest of the body. Bayles (2012, in Iacono et al., 2016, p7) said that "in a head and shoulders presentation we lose the full range of postural, gestural, and expressive movement that the body conveys, as well as the intentionality that is carried and expressed in that movement". In addition, when people felt self-conscious or did not have the suitable technology, then I had no image of the participant. This made it more difficult for me to recall their story as well as for those people who I met in person or when I had seen their face.

Overall, Skype was invaluable to this study as it enabled access to participants who would not have otherwise been able to be included in this research, for health, logistical or geographical reasons.

## **2.6 Data analysis**

Interviews were transcribed verbatim and data was analysed using NVivo 11 software. Analysis followed the principles and guidelines for constructivist grounded theory outlined by Charmaz (2014).

In grounded theory, data collection and data analysis occur simultaneously. This facilitates the emergence of concepts directly from the data through constant comparative analysis between the data and the developing concepts, and between the concepts with one another. Ideally, each interview is transcribed and coded prior to the next so the information generated can inform the focus for future interviews (Starks & Brown Trinidad, 2007). Due to time limitations, this was not always possible. However, preliminary analysis began following each interview, when, following Corbin and Strauss (2008), I used memoing throughout the research to document ideas about potential relationships between codes, between categories, and between codes and categories. I used a reflective journal to note my initial ideas about the interaction between myself, the participant and the setting and my feelings about the data.

The first stage of analysis was line-by-line coding, focusing on action words and processes. This was done for each of the first six transcripts in order to fully immerse myself in the data. Following this, the initial codes were analysed and grouped into focused codes. I used early theoretical sampling to increase the diversity in the sample, namely a spread of gender and to include some people who had dependents. In order to check I was coding effectively and capturing the essence of the participant's experience, a number of peer researchers and one supervisor independently analysed anonymised sections of the transcripts allowing for a comparison of codes. This achieved a high inter-rater reliability between coders.

The next six interviews were analysed using the focused codes, whilst remaining reflexive and open to noticing new and alternative codes emerging. Previous transcripts were frequently revisited and compared in order to explore the emerging categories in further detail. At this point, I began to group the focused codes into categories and sub-categories, using memoing (Appendix J) to aid the process. Diagramming (Appendix K) was used for the purposes of theoretical integration (Charmaz, 2014), and was helpful as it allowed potential relationships between categories to become clearer. This evolved many times before the categories were chosen for a draft grounded theory model depicting the overarching categories and their relationships.

The data raised hypotheses and questions about the social processes that the participants described, so the interview guide was adapted for the next phase of data collection, with the aim of exploring these (Charmaz, 2014). I used theoretical sampling to find participants to check the relevance of my findings, and to enrich my

understanding and further define the properties of emerging categories (Charmaz, 2014). I searched for people with visible disabilities as I noticed there were few in the sample and wondered what role this played in the experience of the benefits system.

Being new to qualitative research, I found the analysis difficult and time-consuming and I did not feel confident at each stage. Use of supervision, a reflective diary (Appendices L & M) and memoing helped me to maintain reflexivity and to gather my thoughts about the process of the research and the content of the data. I also benefitted from peer grounded theory workshops where I could discuss my data and draft models with a tutor and peers. I enjoyed linking emergent categories together so that the final theory developed relates to the experience of each of the participants. I am pleased that I used a method that enabled me to capture context and political voices, and which emphasises the importance of social contexts and interactions.

I found it helpful to use NVivo software as it enabled me to easily code sections of data, and review, edit and group them as I worked with the data, and to move codes around between focused codes. I noticed which ideas came up regularly and this prompted ideas about how the data might fit together, which I noted in memos attached directly to these codes. The software also allows researchers to easily view all the data under each code, which facilitated others to check that the researcher was coding effectively.

## **2.7 Methodological rigour**

The validity of this research was assessed using the framework outlined by Elliott et al. (1999).

When considering the guidelines relevant to both quantitative and qualitative research, this research is explicit in its scientific purpose, by clearly stating the research aims and questions in its introduction section. The rationale is grounded in an argument for the importance of this research. It uses appropriate methods for exploratory research and outlines the use of these clearly in the methods section. It gives clear consideration and respect for issues that might affect participants, including informed consent and any managing distress. The research is discussed thoroughly, with appropriately tentative discussion of its clinical implications, and includes a discussion of its contribution to the field, including strengths and limitations.

Regarding guidelines pertinent to qualitative research, the researcher owns her perspective, including her epistemology and interests, clearly demonstrating awareness of her own values and stance and the way that these interact so the model developed is co-constructed by the researcher and participants. This allows the findings of the study to be viewed within this context, and possible alternatives to be considered. The sample is clearly situated, with recruitment methods explained and demographic information presented in a table. This aids in judging the range of persons and situations to which the findings might be relevant. The researcher grounds the model developed in examples, using quotes from participants. This

allows readers to conceptualise possible alternative meanings. The author also provides examples of her analysis procedures, with an example of diagramming included in the appendices.

In order to check credibility of her results, the author did not use several methods for checking the categories or check these with the original participants, however she used theoretical sampling to check the findings with further members of the participant cohort. Taking a reflexive position allowed her to acknowledge how she may have shaped the research. In order to do this, she met regularly with research supervisors and jointly reviewed the data, and she kept a reflective journal. Some peers and one supervisor independently analysed sections of the transcripts allowing for a comparison of codes ensuring that the researcher was coding effectively.

The researcher found it difficult to achieve coherence in creating a model as much of the data spilled between categories; however, she managed to demonstrate this with a Venn diagram model, which achieves her aim of showing how the data is interlinked, and preserves the participants' accounts. To bring further transparency to the enquiry, an analysis audit trail is included in Appendix N. The researcher is clear in the applicability of the model to her participant group, and states clearly the limitations for generalising to all disabled benefit claimants, however she provides a sufficient sample to make conclusions about what might be relevant for other similar claimants.

Overall, it is hoped that the topic content stimulates interest, with the material presented in a way that readers consider accurately represents the subject matter

and which clarifies or expands their understanding of it. Interest in the topic was stated by participants, peers and also the SU representatives who guided the choice of research topic.

Therefore, the research can be seen to perform well in relation to Elliott et al. (1999)'s guidelines for qualitative research.

## **Chapter 3 - Results**

## 3.0 Results

A short introduction will be provided regarding the experiences of the participants. Following this, an overview of the grounded theory model will be discussed. Subsequently there will be an explanation of each of the domains, categories and sub-categories in turn, with links between concepts provided throughout.

### 3.1 Context

It is important to read these results within the context of the circumstances of the participants. All participants mentioned needing additional resources and/or support due to their physical health difficulties in order to maintain a good quality of life. This included, for example, support with personal care (Hazel) and *“a house that’s been adapted for my use”* (Grace). They referred to the importance of benefits in fulfilling these additional needs, as Bryony states *“just to have an equal chance that’s the thing; it’s not asking for special treatment or extra money, it’s just about having enough so that we are on an equal playing field.”* She added: *“none of us choose to be disabled do we?”*.

Throughout my research, I held in mind that difficulties with benefits were not the only cause of stress for these participants. I feel that the findings should be considered within the context of the ongoing challenges that many of us face.

*“Then in 2007 I lost my benefits, my father in law died and we had an upheaval in moving house and all these things kind of played on.” (Dean)*

### 3.2 The grounded theory model: an overview

Findings were co-constructed in three domains, namely “Navigating a dehumanising system”, “Living in a judgemental society” and “Clinging onto my sense of self”.

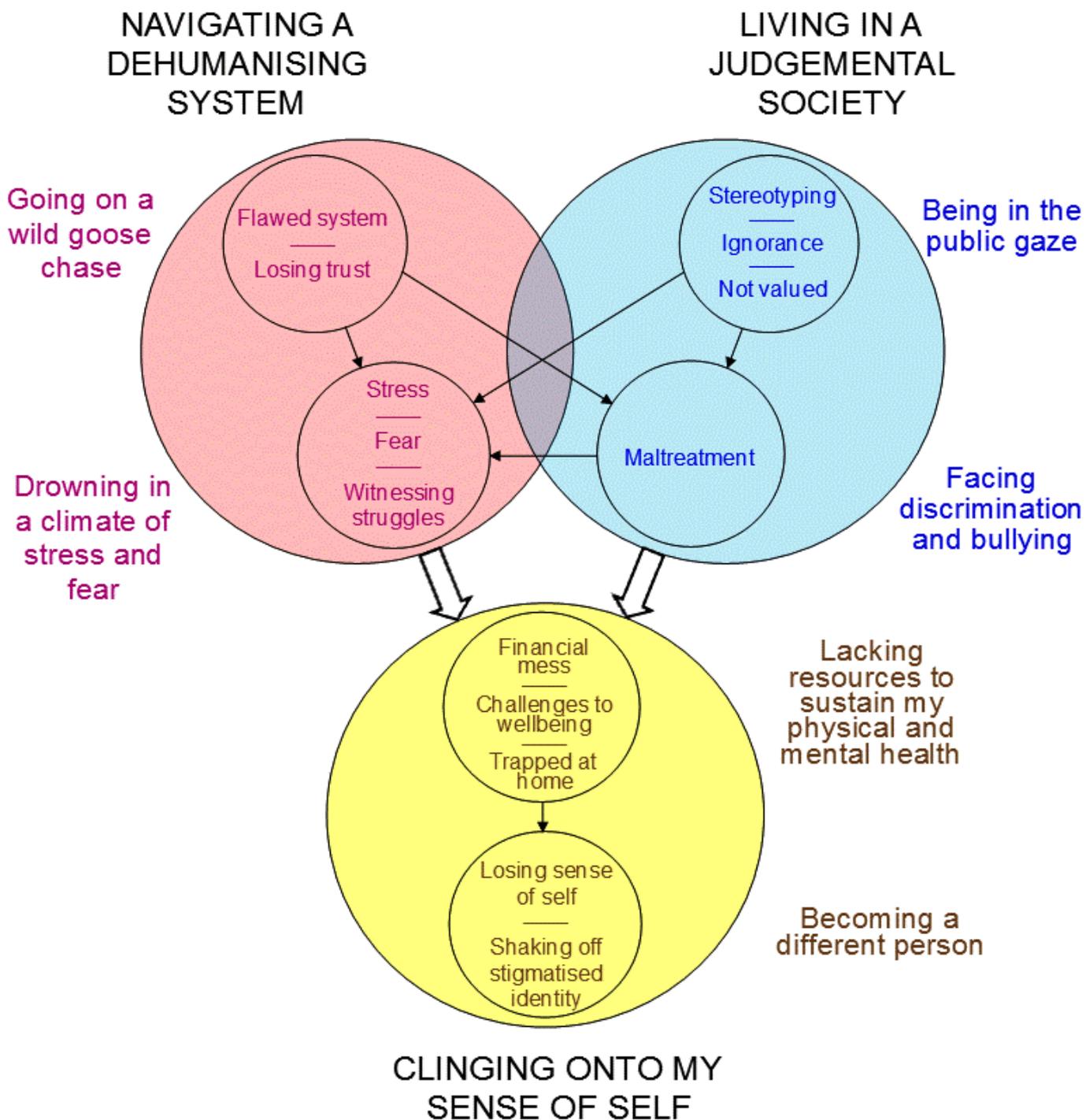
These domains comprise six categories; Table 4 outlines these social processes.

The model (Figure 1) presents each of the categories and shows links between them. As a benefits system exists within wider society, and an individual has experiences relating to both, it follows that each category cannot be truly separated into only one domain, however each is presented under one domain for clarity.

**Table 4: Social processes in the grounded theory model**

Domain	Category	Sub-categories
<b>1 - Navigating a dehumanising system</b>	1A Going on a ‘wild goose chase’	<ul style="list-style-type: none"> <li>• Being assessed by a flawed system</li> <li>• Losing trust in the system</li> </ul>
	1B Drowning in a climate of stress and fear	<ul style="list-style-type: none"> <li>• Being stressed by the system</li> <li>• Being overwhelmed by fear</li> <li>• Witnessing others’ struggles</li> </ul>
<b>2 - Living in a judgemental society</b>	2A Being in the public gaze	<ul style="list-style-type: none"> <li>• Being stereotyped as a scrounger</li> <li>• Encountering ignorance</li> <li>• Being valued as ‘shit under a shoe’</li> </ul>
	2B Facing discrimination and bullying	<ul style="list-style-type: none"> <li>• Suffering from maltreatment</li> </ul>
<b>3 - Clinging onto my sense of self</b>	3A Lacking resources to sustain my physical and mental health	<ul style="list-style-type: none"> <li>• Being thrown into a financial mess</li> <li>• Facing challenges to my wellbeing</li> <li>• Being trapped at home</li> </ul>
	3B Becoming a different person	<ul style="list-style-type: none"> <li>• Losing a sense of myself</li> <li>• Shaking off a stigmatised identity</li> </ul>

Figure 1: Grounded theory model



### **3.3 Domain 1 - Navigating a dehumanising system**

The first domain relates to social processes occurring between benefit applicants and the benefits system, including how they felt they were treated in their contact with the system and the impact of this on their wellbeing. Participants described a system that was dehumanising and unsuitable, as it was riddled with uncertain processes and outcomes, and they reported feeling worried and fearful about how to navigate through them. The following categories were co-constructed within this domain: “Going on a ‘wild goose chase’” and “Drowning in a climate of stress and fear”.

#### **3.3.1 Category 1A - Going on a ‘wild goose chase’**

This category refers to the processes related to interacting with the benefits system. The challenges participants faced are presented under the sub-categories “Being assessed by a flawed system” and “Losing trust in the system”. This section describes how participants found the benefits system complex and confusing to understand, how they felt the system was unsuitable for those who are unwell and how they faced numerous issues. This led to many feeling distrust towards the system.

### **3.3.1.1 Being assessed by a flawed system**

Participants described finding the benefits system complex and confusing to understand. Some found it difficult to understand which benefits they were entitled to and a few even struggled to explain which benefits they were receiving, as they found DWP letters confusing.

*“...when they sent me the letter they didn’t really explain what it was”*

*(Adrienne)*

Some participants had experience supporting others with their claims, and even they found the processes in the system difficult to understand. They found it hard to locate information about which benefits people were eligible for and said that DWP staff gave inconsistent and conflicting advice. The system was so complex that even DWP staff appeared to be *“misinterpreting the guidelines”* (Bryony).

*“I sent it to DWP, maybe, oh it took me ages to get the right people. They don’t give you information you know; it’s all just a wild goose chase.”* (Eve)

The application forms were experienced as lengthy and confusing, *“very, very badly worded”* (Irene) with *“double negatives”* (Grace) and overlapping questions. A few participants highlighted the potential difficulties for those with learning or cognitive difficulties or severe mental health problems. In addition, the length of the form caused difficulties for those with physical difficulties, for example those who found it difficult to hold a pen for long periods of time.

*“You really need a blumming PhD to fill the blumming form in.” (Hazel)*

Participants felt that the system was unsuitable for people who are unwell and for those who have fluctuating or degenerative conditions. They explained that scoring is through use of a points based system, based on yes/no answers, which does not permit people to fully explain their conditions and the impact of these on their lives. This led participants to feeling disregarded.

*“You cannae get a full reading of it, how somebody’s condition is by just asking yes or no.” (Dean)*

They referred to the assessor’s lack of knowledge about particular disabilities.

*“[They] didn’t seem to know what my condition was.” (Dean)*

*“... all it said on the documents was nurse and I did remark to somebody that if she was a nurse, I’m you know, I’m a brain surgeon (laugh).” (Hazel)*

Many emphasised the importance of having assessors and decision makers who are qualified on how particular disabilities affect people.

*“You have assessors that are paramedics...How do they know how to really assess someone’s mental health problems? They don’t! (Irene)*

Participants reported being concerned that the assessments neglected to collect or take into account medical evidence. Many wished for a system where their own medical professionals would assess their suitability for benefit support.

*“They say to you in the form that they contact the health professional. They don’t.” (Irene)*

Many complained of being treated as if their condition was stable, even if they explained that on many days their illness worsens, or that their illness is degenerative.

*“The problem with the benefit system is most people don’t fit boxes. They don’t fit in the tick boxes. Those boxes are either you’re X, Y or Z. You can’t be X on some days and Y on other days and occasionally A, B, C on certain other days. Or not really any of those but kind of something similar but not quite.” (Nicola)*

Those waiting for notification of decisions were forced to make expensive phone calls to follow these up, despite already being in financial difficulty.

*“.. it takes you days to get through to them and get them sorted and get it [benefits] back again.” (Jonathan)*

Furthermore, many participants faced ongoing challenges. They were required to have separate assessments for each benefit they were eligible for, which was felt to be unnecessary. If an application was rejected then participants often submitted a mandatory reconsideration, which in many cases involved writing a long, detailed critique of the assessment report, and if this was rejected then an appeal process was started, which might go to tribunal.

*“...but when this stops, what's next? Another benefit review? It's like an ongoing cycle of stressful assessments.” (Frankie)*

Also, if claimants lost one benefit, this had an impact on the stability of their other benefits, which was described as a “*domino effect*” (Louise).

*“So with that they stopped my Employment and Support Allowance which then caused me a lot of stress because once one benefit is stopped, it stops all your benefits. It like reduces your housing benefit, Council Tax Benefit, Employment and Support Allowance so then I had to keep going to appeal and an appeal and an appeal.” (Louise)*

Another area of concern was about errors in paperwork and assessment scoring. Many had the experience that the assessment report they received did not reflect their own experiences of their current health and ability.

*“The whole of the assessment report was a complete lie...” (Jonathan)*

Sometimes this seemed to be due to the assessor making assumptions and sometimes discrepancies arose through clerical errors. Participants reported that mistakes seemed to be commonplace and decisions did not clearly follow on from the assessment.

*“The descriptor states – needs to be able to reach above your head height to a shelf to pick something up and bring it down. In her own words on the report, it said ‘was unable to lift his hands above shoulder height’ yet I still got zero points on that particular descriptor.” (Jonathan)*

In addition to errors in the paperwork, participants experienced other incidents such as documents being lost and found days later.

*“They’re forever making mistakes, they’re forever suspending your benefit for no reason.” (Jonathan)*

Claimants also commented that even if the assessor was sympathetic, the report was sent to a decision maker, who had never met the claimant, to select the outcome. This was described as *“like Chinese whispers” (Kelvin)*.

As some participants’ health conditions worsened, they notified the DWP as advised, but found that instead of receiving a higher rate of benefits, they lost all their support.

*“I did a change of circumstances in March, um, because, this is when the muscle wastage started really affecting me, and that's when I got zeros across the board.” (Irene)*

### **3.3.1.2 Losing trust in the system**

Due to the issues they experienced, participants reported a significant distrust of the benefits system. There was a sense for many that assessments were politically driven rather than based on their needs and some considered them “a scam” (Dean). They thought that neglecting medical evidence was unethical, and implied that this was intentional. They reported feeling frustrated with the assessment and felt it was intended to “...catch you out...”. (Jonathan).

Many doubted that the errors that they experienced were genuine mistakes.

*“I don't think it was a mistake, I think it was deliberate. I think that everybody that was called in was assumed to be a liar.” (Grace)*

Some felt the whole system was “completely skewed in their [DWP] favour” (Kelvin), as claimants were given less time than assessors to do paperwork.

*“I was given 28 days to fill out a 30-40 page form detailing my illness, and then I sent it off and I went to the assessment and it was rejected and then*

*they get 8 weeks to decide whether the appeal should be upheld or rejected.”*

*(Kelvin)*

Many participants reported that they felt that they were assumed to be lying about their conditions.

*“...this is what the assessment is. Tell us exactly what is wrong with you and then prove to us that you are unable to work and unable to look after yourself.” (Kelvin)*

*“It’s like you’re lying all the time. You’ve got to justify everything.” (Adrienne)*

Many feared that the system was intentionally complex to reduce the number who were receiving benefits. Some commented that assessment companies had targets for numbers in different benefit categories.

*“The system has been deliberately slanted to remove people from social security.” (Grace)*

*“...the whole process is, always seems to be designed to get rid of as many people as possible” (Kelvin)*

Overall most participants felt that the system was inherently unfair, particularly for those who were chronically unwell or disabled. The issues caused many participants to feel “so angry” (Adrienne).

*“...the way that the system treated people was unfair like automatically saying that you're well when you weren't and then overturning it when you appealed”  
(Frankie)*

*“...there is an inbuilt kind of imbalance in that there are people on the boundaries who effectively might fail because they don't know what is the right way to phrase a sentence.” (Oliver)*

In “Going on a ‘wild goose chase”” participants described their experiences of interacting with what was experienced as a deeply flawed benefits system, including perceiving it as complex, misleading and unfair. There appeared to be a deep sense of distrust in the system. The complexity and apparent inconsistencies in the benefits application process, alongside distrust in the fairness of the process left participants with feelings of anger and frustration.

### **3.3.2 Category 1B - Drowning in a climate of stress and fear**

This category outlines some of the feelings that participants described in relation to interacting with the benefits system. These are presented under the sub-categories “Being stressed by the system”, “Being overwhelmed by fear” and “Witnessing others’ struggles”. This section explains how participants reacted to the uncertainty of the system with feelings of discomfort and stress. It highlights the overwhelming levels of fear and worry that participants experienced due to benefit cuts, anticipating

future changes, and fear of not being believed. This fear seemed to be exacerbated by hearing about others' experiences with benefit changes.

### ***3.3.2.1 Being stressed by the system***

Participants described the stress, frustration and uncertainty caused by the process of applying for benefits, with the difficulties described above.

Participants made several comments that related to the personal discomfort and intimidation that they had experienced in the process. For example, having to discuss personal issues with a stranger during the assessment left some feeling *“really uncomfortable” (Louise)*.

Oliver described an informal observation component of the assessment, of which many participants were unaware. He commented that he felt he must be careful about his language and what he said throughout the assessment.

*“It’s like they seem like they are just having a chat with you but they are not.*

*Like everything that you say is assessed against a criteria.” (Oliver)*

Participants were confronted with many changes in the system, such as the move from DLA to PIP, from IB or Income support to ESA, and changes in the Access to Work criteria. They faced an introduction of new types of assessments and of regular re-assessments, including those who were previously on indefinite benefit awards.

The changes were often sudden and unexpected, and participants found this distressing and frustrating.

*“All of a sudden this new ruling came in.” (Bryony)*

When participants found out their benefits were due to change, the resulting impact on finances was sudden and they found this stressful.

*“...they said to me that it hasn't been awarded and that I wasn't going to be paid that week.” (Caroline)*

Further examples of stressful situations include errors and *“stringent time limits”* (Kelvin) for paperwork as discussed above, and participants who were too unwell to travel being asked to attend assessments away from their home or to participate in work-related activities.

*“And then they give unrealistic deadlines to try and get the paperwork in.”*  
(Nicola)

*“It was difficult for me to even get to the assessment... [my mum] was literally holding me up to cross the road...When we got there...I just collapsed in the first chair that I could.” (Frankie)*

### **3.3.2.2 Being overwhelmed by fear**

Some had a more severe reaction and spoke of being overwhelmed by fear. They described being “*absolutely terrified*” (Adrienne) of having their benefits cut and the impact this could have on their lives. They described worrying about the assessment itself and the uncertainties of the system, as well as being frightened about being a burden on their families. They described being “*held in this climate of fear*” (Caroline) and “*living on a knife edge*” (Bryony) because they anticipated changes to their benefits, and knew these changes could be sudden.

*“I’ve been you know excessively worrying and, you know, just been really fearful and anxious about it all.” (Caroline)*

Participants reported worrying during periods of protracted waiting for reviews and benefit decisions, as they were concerned about the potential outcomes.

*“Well because you’re always waiting...it always feels like there’s something hanging over you, like you’re always waiting for the hammer to fall kind of thing cos you don’t know what they’re gonna cut next or how they’re gonna do it...” (Bryony)*

Some participants mentioned fear of receiving or opening official-looking brown envelopes, a possible indicator of communication from the DWP.

*“...anytime a brown envelope comes through my door I'm ‘God no, what is it this time?’” (Nicola)*

This fear prevented some participants from complaining when they felt they had been maltreated, as they feared retribution through further cuts to their benefits.

*“...so you don't complain, cos you just wanna get your benefits back in place.”  
(Caroline)*

Some avoided reporting changes in their conditions or attempting to appeal to receive a higher rate of benefit for fear of losing all of their benefits.

*“I've been told if I really want to get that component I have to go through the tribunal. But then I risk losing everything!” (Louise)*

### **3.3.2.3 Witnessing others' struggles**

Participants described hearing about other peoples' struggles and this playing into fear about their own situation. Many spoke about the cuts that disabled people have been facing and how this has impacted significantly on peoples' lives. They mentioned how cuts had affected friends' lives, such as losing their homes, not having enough money to eat, losing access to carers and deaf people losing their sign language interpreters. Some mentioned others taking their own lives out of fear, and hearing about people who had died after they lost their benefits despite being

declared fit for work. Hearing these “*horror stories*” (Oliver) heightened their worry about what might happen to their own benefits.

*“I had a friend who committed suicide because she was so scared she was going to be cut.” (Bryony)*

*“...so many people have died as a result of losing their benefits. Like surely that's against you know human rights.” (Louise)*

In “Drowning in a climate of stress and fear”, participants described their feelings of stress, discomfort, frustration and uncertainty in the benefits system. Some described feeling terrified, particularly in anticipating future changes to their benefits and the impact it might have on their lives. They described how hearing about other peoples’ experiences exacerbated this fear, which affected participants’ own mental health.

The domain “Navigating a dehumanising system” described the challenges and uncertainties that participants faced in what was experienced as a dehumanising and flawed benefits system, including assessments unsuitable for people with disabilities, complex application forms and multiple changes and errors. This led to extreme distrust in the system, and a climate of overwhelming stress and fear surrounding these processes.

### **3.4 Domain 2 - Living in a judgemental society**

The second domain relates to the social processes occurring between benefit applicants and society. The following categories were co-constructed within this domain: “Being in the public gaze” and “Facing discrimination and bullying”.

Participants found they faced scrutiny, ignorance, judgement and discrimination from people in the benefits system and society. They found themselves being judged and denigrated by the public, and not being understood. Consequently, they described feeling disrespected and being treated unjustly.

#### **3.4.1 Category 2A – Being in the public gaze**

The following sub-categories were co-constructed within this category: “Being stereotyped as a scrounger”, “Encountering ignorance” and “Being valued as ‘shit under a shoe’”. Participants reported being aware of a discourse around claiming benefits and being stereotyped as ‘scroungers’. They reported facing ignorance from others about the impact of disability on their lives and the difficulties they encountered in the benefits system. They described feeling that they were judged as having less value than non-disabled people.

### **3.4.1.1 Being stereotyped as a ‘scrounger’**

Most participants were aware of and felt personally affected by what they experienced as the current social and political discourse surrounding benefit claimants. They felt that this permeates the attitudes of members of the public, leading to scrutiny from others who take on a surveillance and policing role.

Many participants described members of the public using extremely negative language such as “*benefit scum*” (Frankie). They found the stereotype of claiming benefits extremely stigmatising.

*“...society looks down on you when you’re claiming benefits.” (Jonathan)*

Participants described the rhetoric in society that benefit claimants were lying about their illnesses, ‘scrounging’, or lying about their inability to work, ‘shirking’.

*“...[seen] as a scrounger, as a benefit cheat, even though you’re not cheating.” (Adrienne)*

They felt that this perception of claimants had “*become the norm*” (Frankie), and were concerned that they had all been tarred with the same brush.

*“Everybody seems to have accepted the idea that people on benefits are like bad.” (Frankie)*

Participants tended to think that there are some people who are fraudulently claiming on the system, but they differed in the extent that they believed that this was widespread.

*“There are some that do try and fuck the system as such, but on the whole, people are honest.” (Irene)*

Participants commented that members of society had started to take on the role of policing others, and this angered them.

*“I'd park up, put the blue badge out, get out of my car and then somebody comes over to you and starts to give you a lecture because in their mind you don't look sick to them. And I'm thinking who the hell gives you the right to come up to me and say that? Who makes you a doctor? How can you tell if somebody's sick by looking at them? But suddenly now everybody's, everybody's a judge, everybody's a juror, everybody thinks they know.”  
(Frankie)*

Due to worry about not being believed about their condition, some participants feared going out in case their neighbours or officials saw them and thought them to be well and therefore not eligible for benefits.

*“It's the paranoia. That somebody's gonna dob you in, somebody's gonna, that they'll be watching you.” (Grace)*

Participants thought that the media exacerbated and perpetuated the “*scrounger rhetoric*” (Grace), and that the public believe it. Grace talked about “*benefit porn*” on the television, and Caroline described this as “*media brainwashing*”.

*“You look at the press it’s always about the benefits. You know Channel 5 all their programmes: ‘Life on Benefit Street’, ‘Holiday on benefits’ and things like that, I mean they are the worst, Channel 5. That’s the only programming they seem to have..... But people believe it all.” (Adrienne)*

*“...they [the public] presume that everybody on benefits lives this kind of lifestyle.” (Louise)*

Bryony commented that one of the outcomes, and possibly aims, of these TV programmes has been to set people up against each other, for example workers versus non-workers, and disabled people against other disabled people, comparing their worthiness to each other.

*“Is it someone behind that saying well let’s make all these awful programmes about people and then it will set people up against each other and justify all these cuts?” (Bryony)*

Some avoided focusing on the current political climate by avoiding news in the papers or on TV, and avoiding TV programmes on benefits.

*“I never watch it and I don’t often read the newspapers... I don’t read that trash.” (Adrienne)*

Those participants with visible disabilities had a slightly different experience. They reported that the general attitude around benefits was negative, but felt that it may be worse for people with invisible impairments or mental health difficulties.

*“...people can... much more easily understand a wheelchair user can’t get up the 50 steps to cross the footbridge but they are less able to understand somebody with severe anxiety can’t... get on the bus.” (Molly)*

#### **3.4.1.2 Encountering ignorance**

Whilst feeling publicly scrutinised as a benefit claimant, participants found that members of the public did not understand the impact of their disability on their lives, and were often unaware of the extent of the difficulties they faced in the benefits system. Thus, participants described feeling misunderstood.

Participants felt that others, within the benefits system and the public, and sometimes even family, did not understand the full impact of their illness or disability on their day-to-day living. This explains why many emphasised the importance of having a qualified assessor, as discussed in “Going on a ‘wild goose chase’”. Participants explained this ignorance of the impact of disability by saying that people would not understand unless they knew someone with a disability.

*“I can understand why they would think that because they’ve never experienced it.” (Bryony)*

Those with visible disabilities encountered different problems, for example those in a wheelchair reported being infantilised or perceived as stupid.

*“...if I buy something... then the sales assistant is giving my change to the person behind me that I have never met before, which is ridiculous or perhaps asking my partner whether or not I can do something.” (Molly)*

Most participants felt that the wider public were ignorant about the changes to the benefits system and its effects.

*“...they know that the benefits system has changed but I don't think that they realise the suffering.” (Louise)*

They found it difficult that in their experience many people believed the rhetoric about benefit claimants at “*face value*” (Kelvin) and therefore did not understand that the changes meant that many are not having their needs met.

*“...I think people just think that we are ‘looked after’ and all the rest of it, that we are being well cared for and that the money is there...” (Bryony)*

Many also felt that members of the public did not understand that, even if they received the benefits they felt they were eligible for, they would still be living in poverty.

*“...it's not as though we're being given billions and able to live a life of luxury because of the money we're being given.” (Nicola)*

Some thought that even politicians were unaware of the outcomes of benefit changes, as they were not listening to disabled people, and therefore not understanding their needs. As a result, claimants became “*collateral damage*” (Bryony).

*“They are so cut off from those people's experience they can believe that, can't they?” (Bryony)*

Similarly to understanding the impact of disability, proximity to disabled people was perceived to be key in understanding the impact of navigating the benefits system on disabled people. Participants mentioned that family and carers who knew about their experiences often felt shocked and angry.

*“You know unless you know somebody you don't know about these things.” (Adrienne)*

Some commented that members of the public did not know about their difficulties because it is not reported in the media, whilst others stated it is often written about,

but people do not want to believe it. This made some feel like they were “*alone*” (Caroline).

*“...they don't know about it because it's not been really widely reported on the mainstream media.” (Frankie)*

*“Mainly because people don't want to believe that this is happening. People don't want to know that hundreds of thousands of people have been treated this way.” (Kelvin)*

Others argued that the complexity of the system made it difficult for others to understand.

*“People start to glaze over when you try to explain the different benefits and different funding streams cos it is so much to take in....” (Bryony)*

Some participants added that welfare reform has societal costs for people's independence or wellbeing, of which they thought others were ignorant. Many considered that receiving less benefits income means that people are less likely to be well enough to work and therefore more likely to need medical or financial support, so that in taking benefits away there may be a greater cost to the system overall.

*“There's a societal cost to this. So if you reassess someone and take away their mobility car then that has the cost of their independence. It has knock on*

*costs further down the line so that is kind of a social argument about this stuff. But it's not a black and white cost because if you reduce somebody's independence then that costs more in the NHS or the system..." (Oliver)*

### **3.4.1.3 Being valued as 'shit under a shoe'**

Many participants felt that disabled people are not valued as equals in society.

*"...in most people's perceptions we are lesser because we're disabled."  
(Nicola)*

Participants considered that many people *"look down their noses at you..." (Eve).*

*"...it was like I wasn't there and like I was shit under her shoe." (Frankie)*

The language used in society was perceived to reveal the low value placed on disabled people.

*"There are definitely people with attitudes like maybe that perhaps see me as somehow less of a person and even just in the way that language is used in society." (Molly)*

In a few cases, participants implied that they were not being viewed as human.

*“...what about people that can’t? So what does that say to them, that they’re not worth anything?” (Bryony)*

*“I am just a number, I am a case, I am several thousand pounds a year that could be saved.” (Kelvin)*

They mentioned voluntary work or raising children as having low value in society compared to earning money.

*“But I think the most important thing is money, not people.” (Frankie)*

Some discussed how some disabilities seemed to be valued more highly, and more often believed, than others. A distinction was made by many participants between visible disabilities, such as those requiring a person to be in a wheelchair, and invisible disabilities, such as long-term health conditions, particularly rare ones, and mental health conditions. Some participants suggested that there may be a hierarchy of disabilities, with different value assigned to each level.

*“...mental health is always put to the bottom of the pile.” (Louise)*

Many participants with invisible disabilities, such as pain, fatigue, cognitive difficulties and poor mental health found they were often not believed, as these impairments cannot be seen. They felt that they were judged to be undeserving of benefits or adaptations for disabled people, such as sitting on public transport, having a blue badge or having a parking space outside one’s house.

*“They can’t see what physical pain I’m in everyday because you can’t see it.”*

*(Louise)*

*“I feel that they are cynical or sceptical about my disability because I appear to be quite normal.” (Kelvin)*

Interestingly, a few participants reflected that being disabled is sometimes valued when one is able, such as Paralympians, although they added that even these sportspeople have had their benefits removed. They reported that although there is a spectrum of disability, society’s expectations of disabled people are at either extreme.

*“You are either expected to be a Paralympian or benefit scrounging scum.”*

*(Nicola)*

In “Being in the public gaze”, participants described the scrutiny they faced in society, being judged as ‘scroungers’ and ‘scum’, and policed by members of the public. Despite feeling that they were being observed, they felt their experiences of disability and claiming benefits were not understood. They described being judged as having lesser value in society, and even being viewed as less human.

### **3.4.2 Category 2B - Facing discrimination and bullying**

The discrimination that participants described will be presented under the sub-category “Suffering from maltreatment”. Participants described that they were

disrespected, treated unjustly, and even bullied, by both staff in the benefits system and by members of the wider society.

#### **3.4.2.1 Suffering from maltreatment**

Due to the judgement they faced, participants spoke of being treated as *“like you're nothing”* (Frankie) and *“a piece of dirt”* (Caroline). They interpreted systemic problems in the benefits system such as waiting a long time for decisions as being disrespectful. Participants experienced benefits system staff as rude and disrespectful, and applicants being treated unfairly. This behaviour surprised participants, and they often felt upset and frustrated as a consequence.

*“...and when I went to the job centre the person there who I saw was really rude to me and I ended up in absolute tears...”* (Caroline)

Many felt that staff were *“condescending and patronising”* (Caroline), and even threatening or bullying towards them. Some felt that they were being infantilised.

*“I'm treated like I'm a very naughty little teenager.” “Bullying. That's all I can think is bullying. ‘Oh I'm going to get you sorted out little madam, don't pull your little stunts with me.’”* (Eve)

They found assessments humiliating as they felt staff were testing their abilities, and because they were asked personal and sometimes embarrassing questions by strangers. This was described as “*getting kicked around*” (Eve).

*“...you have to take all your tablets in. And I take quite a lot so basically I’ve got a bag full of tablets and she managed to tip them all on the floor and then watched me for five minutes trying to pick them up before she bothered offering any help.” (Grace)*

Participants felt that they weren’t believed by staff about their needs, as if they were fraudulently applying for benefits. Caroline was investigated for fraud when her adult son who was living with her gave her a payment towards his upkeep.

*“He [son] was giving me a little bit of money each week. And she said ‘What’s this?’ and I explained what it was. And she went ‘Oh that’s going to be treated as an income’. And I said ‘but that’s for his food, to put a little bit towards the bills’. I said I can’t as a person on benefits be expected to keep another adult who’s working...” (Caroline)*

Participants experienced not being listened to or cared about, thus they described feeling humiliated.

*“The woman that I spoke to when I first tried to apply, she said I am telling you this because I have to tell you this I am just asking these questions*

*because I have to, I don't care about, I think that she actually said I don't care about your answers I don't care about how you feel about them..." (Kelvin)*

Many participants also experienced themselves facing discrimination from members of society, including hurtful comments suggesting they should be working and not claiming benefits. Some even mentioned upsetting remarks from friends and family.

*".. then she started judging me on my appearance and saying 'oh some of us have jobs to go to, not all of us are on benefits'." (Louise)*

Comments by and confrontations with members of the public caused participants to feel judged, hurt, misunderstood, upset, and in some cases bullied.

*"I've been told off for sitting on the bus. It's for disabled people, why are you sitting there, it's for disabled people or for old people. And I said actually I'm in a lot of pain and I can't stand for very long." (Adrienne)*

Some experienced hate crime, such as verbal harassment by neighbours or local children, violence to their property and threats of physical violence. Many were aware that there had been a rise in hate crime, and some felt that the public have become less compassionate in the way that it views people on benefits.

*"I'd park up, put the blue badge out, get out of my car and then somebody comes over to you and starts to give you a lecture because in their mind you don't look sick to them." (Frankie)*

In “Facing discrimination and bullying”, participants reported that they felt disrespected and were treated unjustly by staff in the benefits system and by wider society. This may have been fuelled by others’ lack of understanding of disability.

The domain “Living in a judgemental society” described how participants faced scrutiny, ignorance, judgement and discrimination from within the benefits system and from society. They felt that whilst they were being stereotyped as a ‘scrounger’, their disability and experiences were not understood. They felt they were not valued which they reported as being unfair. The domain also describes how some participants experienced hurtful comments and bullying from others.

### **3.5 Domain 3 - Clinging onto my sense of self**

The third domain relates to the social processes relating to individuals’ identity. It demonstrates the significant impact of the first and second domains on individuals in the study. It shows how the difficulties with claiming benefits and living within a judgemental society negatively affected participants’ finances and physical and mental health, and had an impact on their sense of self, as well as how participants attempted to distance themselves from the associated stigmatised identity. The following categories were co-constructed within this domain: “Lacking resources to sustain my physical and mental health” and “Becoming a different person”.

### **3.5.1 Category 3A - Lacking resources to sustain my physical and mental health**

The following sub-categories were co-constructed within this category: “Being thrown into a financial mess”, “Facing challenges to my wellbeing” and “Being trapped at home”. Participants described that navigating the benefits system and living in a judgemental society led to them having difficulties with finances, difficulties with health, and as a result, being able to do less.

#### ***3.5.1.1 Being thrown into a ‘financial mess’***

Most participants said that they did not want to rely on benefits and would rather be well and be able to earn their own money. However, due to their circumstances (being disabled and, for some, being unable to work), they spoke of not having enough money when they lost their benefits. As a result, some struggled with debt. Some mentioned not having enough money to live on when receiving benefits.

*“So it kind of threw me into this financial mess.... yeah, it was just all a big mess so I’ve ended up in debt and overdrawn.” (Caroline)*

Many experienced difficulties paying for necessities, and some had to make the difficult choice between eating and heating their homes.

*“I wouldn’t have been able to pay the electricity, the gas, the water bill, the heating bill and eat. It would have to be one or the other.” (Adrienne)*

*“I literally got to a point of heat or eat” (Grace).*

Jonathan reported that he sometimes only had enough to feed his daughter not himself, and described his family’s reliance on a foodbank. He expressed his embarrassment about this.

*“There’s days where I have to make sure my girl, my little girl, eats, and I don’t eat myself. I just haven’t got enough money to buy enough food.” (Jonathan)*

Healthy eating was difficult for many due to the high price of vegetables. Eve explained that she could not afford the minimum cost of online shopping but that the nearest affordable shop was inaccessible due to pain when she walked.

*“There’s just not enough money to buy decent food shall I say. I can’t buy fruit and vegetables.” (Eve)*

Hazel described how she could not afford to pay a carer to help her dress in the mornings, so had stopped wearing socks.

*“If I was to bend down to put my socks on, I would end up in hospital. I put my trousers on with I have got one of those long stick things and I sort of put it through and pull them up and er it’s not very safe.” (Hazel)*

It seems that lacking finances to maintain their health led to further ill health, which in turn reduced the possibility of working and led to increasing financial problems.

Some participants got into trouble with their landlords and even the law for not paying rent or bills on time. A few could not afford the 'bedroom tax' when their children left home. Many spoke of not being able to afford occasional costs, such as new shoes or fixing a broken fridge.

Many participants compared their financial position to others, either having less than friends or peers, or having more or less than other benefit claimants. For example, Jonathan described how he must save for school trips for his daughter, and that they can't afford the same Christmas presents as her peers.

*"We've explained to her that we're on reduced incomes, money is tight some days... She knows when I say no we haven't got the money, we can't get it."*

*(Jonathan)*

A few participants reported feeling lucky that they had experienced fewer difficulties than others in claiming benefits. One who was not totally reliant on benefits for income said his removal from disability benefits caused him to consider the severity of the impact on others who rely on this money for essentials.

*"And then this happened to me I felt well, that I kind of got a glimpse of what it must have felt like for those like me who depend on these benefits for their livelihoods so it put things into perspective." (Kelvin)*

In order to cope, a few participants managed to source temporary financial support. Some requested discretionary housing payments from their housing association and others told of borrowing money from family, although this income was unreliable.

### **3.5.1.2 Facing challenges to my wellbeing**

Most participants felt that benefits cuts, “Navigating a dehumanising system” and “Living in a judgemental society” negatively affected their physical health and mental health. The lack of money caused participants much worry. They were concerned about being able to pay the rent and bills and being able to feed themselves, their children and their pets.

*“...you’ve got all this worry about money all the time and how you’re gonna live.” (Adrienne)*

A few worried about being evicted from their homes. The majority worried about future cuts and changes to their benefits, and some worried what would happen if they became more ill and needed additional support.

*“I think that at the moment I am a bit frightened but if I were to get poorly again you know who would look after me? Because as they cut my benefits so much, or even with it, I don’t know that I could afford the help that I need.”*  
*(Hazel)*

Some described becoming deeply aware of their own vulnerability.

*“And you know you just think you’re really fearful, cause you think oh my gosh the way everything’s going I could lose my home, or, you know. I just got, it just made me realise how fragile I am and you know, how vulnerable in a way.” (Caroline)*

Many participants described feeling low as a result of the stresses and fear in the benefits system.

*“And my condition did deteriorate after the news that I was going to lose [benefit] because I became more err I went into a low mood, I was becoming more depressed... like the sun’s shining but all you see are dark clouds, and you cannae see any way out of it and it’s kinda like being in a pit... you just feel stuck... ..I was, it was hurting... it was as if I couldn’t live another day feeling the way I did.” (Dean)*

Four participants mentioned feeling suicidal, with two describing suicide attempts they had made.

*“...I tried to kill myself, my carer stopped me from hanging myself, he kicked the door in and then, pulled the thing down....I had really just reached the end, the end of my tether. And I thought 'I can't go through another battle'..... I just didn't think it was worth it, I just didn't want to go through any more.”  
(Frankie)*

Pre-existing difficulties with mental health made it more difficult for some to manage the stresses they were facing. For example, a participant who mentioned being prone to anxiety explained that worries about finances exacerbated her mental health concerns.

*“...it's the worst thing for people with mental health problems to get into debt because it plays on your mind all the time. Yeah and with my health conditions I do worry and I analyse things all the time, so having this to deal with...Yeah another stress.” (Louise)*

Stress and feeling low often exacerbated physical health difficulties, such as chronic pain and fatigue, and sometimes led to new physical symptoms such as high blood pressure. In addition, the converse occurred where physical health exacerbated low mood. There seemed to be a cycle of stress and ill health, where one exacerbated the other.

*“So if I'm stressed, if I'm very stressed then I get a flare-up and then sometimes I can't get out of bed for a week.” (Adrienne)*

### **3.5.1.3 Being trapped at home**

As a result of a poorer financial situation and poorer health, most participants reported going out and doing less. Some described feeling trapped in their financial

situation, for example, being unable to socialise or to plan ahead or buy food for more than one meal in advance.

*“I’m living one day at a time and that is not the way I like to live.” (Eve)*

Others described being physically limited, for example being unable to leave the house due to not being able to afford transport. Generally, participants felt like they had few options of how to live their lives.

*“Because I’ve got no car, I’m trapped.” (Grace)*

There were a few participants who found cuts to their benefits less difficult than others, due to having an income from work or using savings. However, even they mentioned budgeting more carefully, therefore not being able to go out as much as previously.

It was noticed that ill health limited opportunities for work and social interaction, which seemed to cause further ill health. Participants commented how their mental health, including low mood and anxiety about the future, prevented them from going out or socialising, and affected the type of work or volunteering they were able to do, if any.

*“I never wanted to go anywhere. It’s only recently I’ve started to try and push myself to go out and mix with people. It does help your mood but I find it very difficult...” (Dean)*

Some told of being too physically unwell to go out or to socialise.

*“I didn’t really want to see people because talking and interacting that’s all like an energy drain and, all I wanted to do was just concentrate on building up my energy so that I could go back to work.” (Frankie)*

Participants noticed that going out less, due to both health and finances, had a further negative impact on their moods. Some participants reported becoming isolated.

*“...it is a two-way thing so I am unable to go out because I feel awful and then because I can't go out I feel doubly awful.” (Kelvin)*

*“...everything sort of, everything became small. Just me and my little estate.” (Grace)*

This happened even though most recognised the importance of going out for improving their mood, gaining support from others, and helping others understand their situation.

*“Cause you’re feeling better if you’re socialising and you’ve got support and other people who understand.” (Caroline)*

In “Lacking resources to sustain my physical and mental health”, participants described how they lacked financial and emotional resources to sustain themselves as a result of changes to their benefits and their experiences in the benefits system and in society, and how this led to them doing less. This seemed to further exacerbate their poor health.

### **3.5.2 Category 3B - Becoming a different person**

The following sub-categories were co-constructed within this category: “Losing a sense of myself” and “Shaking off a stigmatised identity”. Participants described an increased focus on their limitations, feeling embarrassed about being a benefit claimant, and internalising a stigmatised view of themselves, thus losing their previous sense of self. Many described ways in which they attempted to fight against this. This included maintaining hope about the future, distancing themselves from a stigmatised identity, acts of resistance, and seeking support from others.

#### ***3.5.2.1 Losing a sense of myself***

For those with acquired disabilities, becoming disabled often meant that they lost not only their health, but also had to give up their job or volunteering role, which in turn affected their financial independence. Some struggled to feel that they had any worth if they were unable to work, which caused them to feel low in mood. A few mentioned mental health ‘breakdowns’ and feeling like their situation was too much to cope with.

*“And people like me have no worth because I’m not producing right now in terms of making anything.” (Frankie)*

As well as the impact on their mental health, this affected their sense of who they were and their self-confidence.

*“I used to teach and do reports. It’s like I’m a completely different person. It’s like your life’s been taken away.” (Adrienne)*

Claimants felt they were required to present themselves as more disabled for benefits applications than they would in other social situations. This caused them to focus on their limitations, rather than strengths and abilities.

*“The focus has to be on all the things that you can’t do in life... certainly that isn’t the way I tend to live my life and wouldn’t be a way that would be helpful to live my life. So I think that if even if you have a strong sense of identity that filling in that form can be quite a miserable process.” (Molly)*

As a result of experiencing stigma and feeling discriminated against, many participants felt embarrassed and uncomfortable about disclosing their benefit claimant status to strangers and sometimes even friends. Participants explained that they felt torn between wanting to talk and wanting to keep details private, as they feared judgement about claiming benefits.

*“It’s private! I don’t like the fact that I claim benefits for a start.” (Grace)*

Others held this position with the exception of close family, or friends or neighbours who they felt could be trusted. However, some kept details from close family to prevent them from worrying.

*“.. not even our immediate family... We don’t tell them how bad things are some days.” (Jonathan)*

Some felt apprehensive about *“people [feeling] sorry for me” (Hazel)*, or thinking they were asking for support as opposed to sharing their emotional experiences.

*“I want to be able to talk about it without people thinking that you’re hinting for money.” “I didn’t wanna feel as if I was getting a violin out.” (Caroline)*

Some were even private about the details of their illness with friends and colleagues, so explained that naturally they would also be private about claiming benefits.

*“Why would I be talking about my benefits when I am quite reserved or apprehensive to even discuss my illness?” (Kelvin)*

In addition, being confronted with the ways that others constructed them and experiencing maltreatment, as discussed in *“Living in a judgemental society”*, affected participants’ self-confidence.

*“The driver would shout down the bus that the wheelchair needs to get off. It is just a tiny thing that I think undermines, or can undermine, the sense of self and confidence and at times I have almost apologized for my existence.”*

*(Molly)*

Many participants internalised the narrative of being less worthy than others and the stigma of claiming benefits, and spoke about feeling undeserving and judging themselves. As a result, some did not claim benefits until they ran out of savings, or claimed less than they could have done.

*“Judgements come along with that [telling people I claim benefits]... Even my own self judgement.” (Grace)*

They reported noticing themselves, and other disabled people, doubting each other, for example judging neighbours or people in the assessment waiting room.

*“...when you walk into an assessment office you see people on crutches and you think this guy has crutches but does he, is he putting this on when I really have a disability?” (Kelvin)*

Many participants reported that, at times, they felt like giving up. After a series of challenges in the benefits system and in society, some lost hope about their futures, as discussed above, for example by attempting to commit suicide. A few mentioned that they had given up applying for benefits, or would do if their current appeal failed.

Others spoke of giving up hope of recognition of their ordeal, and as a result feeling “hurt” (Frankie).

*“I’ve got nothing to aim for at the moment apart from being a bag lady. If there was something positive to aim for but there isn’t anything, I can’t see anything.” (Eve)*

*“I think at the end I ended up giving up trying to get somebody to acknowledge that the way I’ve been treated was wrong.” (Frankie)*

### **3.5.2.2 Shaking off a stigmatised identity**

However, all participants described attempting to pull back from or distance themselves from the stigmatised identity of benefit claimants, and searching for an alternative identity that seemed acceptable and meaningful for themselves.

For example, some commented how they felt uncomfortable when they noticed their judgements of others, noticing that they had internalised a stigmatised perspective of disabled benefit claimants, and they attempted to draw back from this.

*“This woman’s, her daughter drives around in the mobility car and she can lift half a tonne of gravel in the back yard! Yet walks out on the front road with a walking stick. I’ve even filmed her, this is how bad, this has got me, this is the bit I don’t like, I’ve even filmed this woman doing it and just thought what are you doing, hating myself for it.” (Grace)*

Most participants attempted to maintain a sense of hope about the future. For some, this involved having an identity other than being disabled.

*“I’m a freelance writer and performer.” (Bryony)*

Many told of hoping for a healthier future, both physically and mentally, and described being determined to reach that better place. For many this included a hope for future employment and a move away from reliance on benefits.

*“Me, I’d rather have a job and be able to buy my girl better things and look after her better you know. I don’t want to be taking money like this, just to live and buy food....” (Jonathan)*

Some spoke of having always been a determined person, for example saying *“I think I’ve always had the fighting spirit in me.” (Louise)*

Some reflected on their privileged position, in having supportive family and friends and in being educated and therefore able to do research about what to expect in the benefits system. Many knew others who had similar experiences, which helped them to prepare, including considering how to present oneself in an assessment.

*“I am able maybe to reclaim a lot more power because I am fortunate to be well educated and be well supported by my family and friends.” (Molly)*

Others reflected that they had remained resilient compared to other claimants who might be more vulnerable. This led Eve to not use a foodbank as she considered that others' needs were greater.

*"I would not have gone to a food bank, not because I'm stuck up but because people with families, they're the ones who need it not me." (Eve)*

Some distanced themselves from the stigmatised identity of claimants by acknowledging that there are some claimants who are fraudulent, whilst validating their own disability and needs.

*"I know there are many scroungers but I think it is very unfair to generalise and say that everyone is a scrounger until proven innocent. Erm but it just is a symptom of how toxic this issue is, that people have had to justify their disabilities and prove that they're unwell." (Kelvin)*

Many participants described how their political beliefs enabled them to separate themselves from a stigmatised identity. They considered that this stigma is based in the politics of the day and placed responsibility for their difficulties with the government, suggesting that austerity was a political, rather than financial, strategy. For example, some thought the changes were due to UK Conservative party ideology that people should look after themselves; *"every man for himself" (Frankie)*.

*"..just an excuse to get rid of the welfare state." (Dean)*

Some felt “*disabled people are scapegoated*” (Caroline), because they are vulnerable and therefore an easy target.

*“I expect that the government through the DWP will go for the low hanging fruit first, that is the bad back and CFS malingerers’ brigade which is pretty much me.” (Grace)*

Some felt the ‘scrounger’ narrative assisted the government in justifying their austerity policies. They suggested that politicians have been perpetuating the stigma around claiming benefits because the government intended to degrade the perception of disabled benefit claimants.

*“...is it some sort of political thing that’s fed into the media to give people a perception or to justify all these cuts in a way?” (Caroline)*

*“They [the government] pump TV programs to demonise these benefit claimants.” (Kelvin)*

Many believed that policy changes were designed to remove people from benefits. Furthermore, some had extreme, and powerful, views that the government’s policies were “*measured*” (Caroline) to reduce total numbers of disabled people. Some mentioned or alluded to Hitler, Fascism, and Germany's 'Final Solution' which led to the Holocaust. They linked this to the low value they felt that the government placed on disabled people. To these participants, the system felt designed to cause people to give up hope of living, so that they would no longer claim benefits.

*"Perhaps they'll keep carrying on until they've all sort of killed themselves"*

*(Eve)*

Although some perceived politicians as ignorant of the negative outcomes of cuts, some wondered whether politicians deliberately ignored or *"washed their hands"* (*Frankie*) and attempted to conceal this, for example by avoiding releasing statistics about deaths.

*"I think certainly the government actually are aware, they just don't want it spoken about." "The government have been trying hard, fighting hard, not to release information about the deaths." (Frankie)*

Many felt extremely angry about benefit cuts and wanted politicians to be made accountable for the deaths of benefit claimants.

*"So I believe that the government should be, there is campaigns going on at the moment for, that the government be made accountable for what they've done. Because you're not talking about one or two, you're talking thousands of people across the country who've lost their lives." (Louise)*

These political opinions often encouraged participants to fight against a stigmatised identity through small acts of resistance against the benefits system or against public opinion. This seemed to help in validating themselves as 'truly disabled' and not 'scroungers'. Some of the methods they described were disagreeing with their

benefit decision and appealing the decision, writing a critique of the assessment report and including more medical evidence, or re-applying for disability benefits. A few even reasoned with benefits system staff.

*“...it wasn't until in the assessment I actually said to the doctor 'I'm a trainee solicitor' ...'Why would I leave my career and my job, my training contract, for a little tiny bit of incapacity benefit?’” (Frankie)*

Some went further than this and found purpose in becoming an activist. They thought that speaking up would highlight and address ignorance about difficulties in the benefits system and would stimulate changes, so that the issues they had encountered could be prevented for others.

*“If more people knew in general then quite possibly these cuts wouldn't take place in the first place.” (Bryony)*

*“But the thing is I think that what they're relying on to a large extent, the media and the government, is a lot of people aren't prepared to talk about what's going on. They do withdraw so much into themselves they will not say look this is how hard it is, and that's why they get away with it. I refuse to.”  
(Jonathan)*

These participants wrote complaints to Downing Street, campaigned for disabled people's rights in their local area, contacted their MP about their benefits situation, had interviews with local journalists, spoke on the radio, or wrote opinion pieces

online. Some assisted others with their benefit applications, for example completing forms on behalf of their neighbours and advising them on charities for support.

*“I was just so insulted I think I remember emailing Downing Street just complaining, and saying I just thought it was hate speak and it was disgusting.” (Frankie)*

Some joined up with others who shared their political beliefs, both in person and online. They found support for both individual and political acts through solidarity with peers and collective resistance, using online groups or local charities. Irene became an administrator of an online group in order to use her expertise to help others. Participants appeared to be motivated because they realised they could help others in a similar position.

*“It’s still carrying on. It’s not just for myself, it’s for everybody out there that is in the same position.” (Dean)*

Most people who performed acts of resistance explained that they did this because of what they believed is morally right.

*“I’ve always been brought up to not hold my tongue if something is wrong...”  
(Jonathan)*

Finally, participants reported seeking support from family and friends, charities, and professionals, which appeared to mediate the impact of a negative sense of self.

This came in the form of financial, emotional and practical support. The main source of support described was from family, with many having supportive family or partners. Family provided financial support, including money and food, emotional support, for example when feeling frustrated, and practical support, such as personal care and helping with benefits applications. Some who felt particularly fortunate acknowledged how others may not have this support.

*“That’s the frightening thing. There must be a lot of people out there who don’t live near family or whatever or the means of the family to help them.”*

*(Adrienne)*

However, receiving support from family was not always easy. It was often accompanied by a sense of discomfort or guilt, particularly when borrowing or being given money. Additionally, some described complex relationships with family who were not empathetic with their situation.

*“It’s horrible being a burden on your family.” (Adrienne)*

Most participants referred to emotional support from peers, including friends, neighbours, fellow activists, or professional carers. Neighbours grew more important when participants were housebound or isolated; however, as discussed earlier, they were not always helpful or deemed to be trusted.

*“I’m lucky here because if my neighbours don’t see me for a little while they will come and knock on the door.” (Grace)*

Support from others in a similar position was found to be very important. The participants who used a Facebook group or attended charity activities reported finding these both supportive and informative.

*“Cos so many of us are in this situation we just try and keep each other afloat really.” (Bryony)*

A few participants explained the importance of their pets, who they felt sustained them and kept them alive, due to both their attention and because they felt responsible for their care.

*“...having my dogs they make me, they force me to get up every day. Basically it gives me a reason, a sense of responsibility and it gets me out of the house.” (Louise)*

Some reported seeking support from professionals, including medical evidence from GPs and support from MPs or work unions. Some professionals were supportive whilst others ignored requests or charged money for medical letters. Most participants could name local support services and charities, such as Citizen's Advice Bureau, but many mentioned that these were under-resourced and therefore often unhelpful.

*“Then like everything else they [mental health activity classes] had these cutbacks.” (Dean)*

In “Becoming a different person”, participants described how they lost a sense of themselves, including losing hope. As a result of the benefits application process, claimants were forced to focus on their limitations and some felt unable to free themselves from the stigma of being a benefits claimant. However, most attempted to pull back from this in some way, by maintaining hope about the future, distancing themselves from others who may be fraudulent or from a stigmatised identity through their political beliefs, acts of resistance, and seeking support from others.

The domain “Clinging onto my sense of self” relates to identity. It describes the effects of navigating the benefits system and living in a judgemental society in terms of struggling to have enough financial and emotional resources to maintain their physical and mental health. This led to participants doing less, and in cases becoming isolated. It describes how participants felt they had lost some of what they valued in their lives previously, felt embarrassed about their situation, and internalised a stigmatised narrative. Many noticed this and attempted to fight against it in order to hold onto a sense of themselves.

### **3.6 Relationships between issues**

Participants made many comments that indicated complex relationships between all of the issues discussed under the domains, categories and sub-categories in this theoretical model. It seems that the experiences, perceptions and dominant discourses experienced within a benefit system and those experienced within wider society, including participants’ immediate community, powerfully mirrored and re-

enforced one another, creating a powerful negative feedback loop.. This included a climate of uncertainty, stress and fear; other's lack of understanding about disabilities and benefits; a negative stereotypical discourse in society about benefit claimants; an increased level of scrutiny, prejudice and discrimination from others. This feedback loop not only led to predictable financial hardship, but also had a significant impact on participants' mental and physical health and led to social isolation.

This led to powerful negative identity implications for participants, including an increased focus on their limitations, feeling embarrassed about being a benefit claimant so keeping this private, and internalising a stigmatised view of themselves. In turn, these identity implications had significant implications for participants' wellbeing and quality of life, thus arguably potentially increasing the likelihood of reliance on benefits and prolonging their experiences of living as a benefit claimant within the benefits system and wider society.

Despite this, it was shown that many participants contested these identity conclusions about themselves and on behalf of others through small acts of resistance. For example, some disagreed with their benefits decisions, spoke out about the issues in the system, or helped others with their benefit claims.

The implications of these findings will now be discussed.

## **Chapter 4 - Discussion**

## 4.0 Discussion

The findings of this study will now be discussed in relation to the research question and existing literature. The potential clinical implications, methodological issues and areas for future research are examined and the research experience is considered.

### 4.1 Overview of results

The following section discusses the main findings of this research and relevant literature in relation to the research question which was:

What is the impact of a loss of or change in disability benefits on the experiences and identity of people with physical disabilities and on their relationship with society?

This research found that disabled benefit claimants seem to experience difficulties in navigating a dehumanising benefits system, living in a judgemental society and struggling to cling onto an acceptable sense of self (Denborough, 2005). It shows that a loss or change in disability benefits can have a great impact on the lives of people with disabilities, particularly on their mental health, but also on their physical health and their relationships with others, including family, friends, their communities and wider society. It indicates that many claimants are aware of a negative rhetoric regarding claiming benefits, and many face ignorance and disrespect from others in society. As well as the adverse impact of having less money, the findings demonstrate the impact of the stigma associated with being disabled and with

claiming benefits on claimants' lives, and how many struggle with their identity as a result.

## **4.2 Relevance of the findings to the literature**

Each domain of the grounded theory model will be discussed in relation to theoretical and empirical literature, in particular those papers included in the systematic review. The discussion also draws on PAA's (2015) five 'austerity ailments'; the ways in which austerity policies impact on mental health. These are: humiliation and shame, fear and distrust, instability and insecurity, isolation and loneliness, and being trapped and powerless. This framework is useful as it is constructed from collated research about social inequality from numerous sources.

### **4.2.1 Navigating a dehumanising system**

Participants described a benefits system that was complex and unsuitable, with uncertain processes and outcomes, and they reported feeling worried and fearful, particularly in anticipating future changes. This led to many feeling distrust towards the system.

#### **4.2.1.1 Going on a 'wild goose chase'**

Participants reported feeling confused, as they considered that benefits and changes were poorly communicated. They felt the application forms were too lengthy and complex, as found in research on previous benefits (Banks & Lawrence, 2005). The literature also describes the current system as being inaccessible, for example ESA, WCA and tribunals having their own and sometimes conflicting requirements (Clifton et al., 2013), and claimants receiving inconsistent and insufficient communication (Porter and Shakespeare, 2016).

Participants felt that the system was unsuitable for people with disabilities, which supports research with similar findings, for example with those undergoing treatment or requiring gradual return to work (Moffatt & Noble, 2015), those who struggle with self-care (deWolfe, 2012), or those who have fluctuating illness (Allen et al., 2016). It has been noted that the WCA does not treat people as individuals with their own set of needs (Clifton et al., 2013). Like participants in this study who faced ongoing challenges, the application process has been described as repetitive and entailing “never-ending” bureaucracy’ (Shefer et al., 2016).

Participants described a similar experience to previous research regarding assessors’ lack of understanding about impairments (Akers, 2016; Morris, 2013; Dwyer et al., 2016). Independent reviews have also highlighted difficulties in assessment, particularly when impairment is unseen and variable in presentation (e.g. Litchfield, 2013). Participants noticed numerous errors in assessment reports and decisions made about their benefits, and in paperwork being lost, which were also reported by Dwyer et al. (2016) and Marks et al. (2017) respectively. Academics have highlighted concern about the viability of the assessment (Warren, Garthwaite

& Bamba, 2014) and the urgent need for improvement of the ESA process (Davies, 2014).

Due to the issues they experienced, participants reported a significant distrust of the benefits system. This distrust is well documented, for example a lack of confidence in WCA's ability to assess mental health (Marks et al., 2017). This study found out further details about participants' concerns about the benefits system. Many thought that the process was purposely designed by government to try to reduce the numbers claiming benefits and that this was politically motivated. This belief would clearly undermine claimants' trust in and feelings of agency surrounding these processes.

#### ***4.2.1.2 Drowning in a climate of stress and fear***

Participants reported a climate of fear around future changes to their benefits. The increased anxiety and distress associated with the benefits system is well documented (Patrick, 2017; Clifton et al., 2013; Shefer et al., 2016; deWolfe, 2012; Garthwaite, 2014; Marks et al., 2017). Many researchers have commented that claimants live in a chronic state of insecurity and uncertainty (Patrick, 2017; Wright, 2016), partly due to the "precarious nature of social security" (Pemberton, 2016a, p1). Participants reported the frequency of application rejections and how this generated anxiety; deWolfe (2012, p623) discussed this "seeming randomness of outcomes". Some participants mentioned a fear over official-looking brown envelopes, a possible indicator of communication from the DWP, also documented by Garthwaite (2014). Much stress and frustration was reported, caused by sudden

changes in rules about benefits, or introduction of re-assessments. These participants found that changes seemed to cause most distress when they seemed unfair or were unexpected. Most of the studies on claiming benefits included in the literature review discussed stress caused by the benefits system (e.g. Shefer et al., 2016), so this has been well documented, and the current study points towards this potentially having significant implications for claimants' mental health.

The fear surrounding changes in benefits was exacerbated by hearing about others' struggles, for example avoiding reporting changes in their health due to hearing about others losing all of their benefits when they did this. This social aspect is less well documented in the literature, so this research adds to the field by considering the influence of these social processes on anxieties about benefits.

In summary, the findings presented in this domain support those from previous research which suggest that applying for benefits can be a highly confusing and stressful process, filled with uncertainty and surrounded by fear. This suggests that findings from previous research are still applicable to more recent benefit changes. The findings fit with PAA's austerity ailments of 'instability and insecurity' and 'fear and distrust' (2015). This research extends our understanding of specific aspects of the benefits system and application process, and its impact on the physical, mental and social wellbeing of claimants with physical disabilities. Furthermore, this study illustrates the social processes that occur when claimants hear about others' struggles. This is particularly significant within the current UK context where the lives of people who claim benefits are portrayed daily on television, in print media and on social media. This study raises the question of how the spaces where people

may go for support, such as Facebook groups or charities, where one might regularly encounter stories of others' difficult experiences, might also negatively affect individuals' mental health.

#### **4.2.2 Living in a judgemental society**

Participants described facing scrutiny, ignorance and judgement from people in the benefits system and in wider society, both in person and through portrayals in the media. They felt that they were denigrated by the public. Many of these experiences overlap with those in the previous domain, as does the related literature.

##### ***4.2.2.1 Being in the public gaze***

Most participants felt personally affected by what they experienced as the current social and political discourse surrounding benefit claimants. They thought that the government and the media perpetuated the narratives of being a 'scrounger', implying that they are lazy and deviously stealing from taxpayers. Stigma arises during social interaction, when the social identity of an individual is found to be 'spoiled' by attributes that mark him or her as deviant from the group norm (Goffman, 1963). The findings supports Earl's (2015) findings that claimants felt that they were being constructed as 'an economic drain' (p94) and 'fraudulent versus genuine' (p79). Much research has discussed the increased scrutiny claimants are under due to the political rhetoric and media coverage of poverty and claiming benefits as a 'lifestyle choice' or being labelled as 'scroungers' (Briant et al., 2013; Pemberton et al., 2016b; Patrick, 2014; Garthwaite, 2014). This research adds to the literature in

describing situations where members of the public have taken on the role of policing claimants, and in explaining the fear that claimants have of being judged when they go out. The implications of this stigmatising discourse on participants' identity will be discussed under the third domain.

Despite being in the public gaze, participants found that others did not understand the impact of disability on their lives, as discussed above regarding assessors. They reported that members of the public were mostly unaware of their difficulties with the benefits system, and that only people who knew someone in their position had greater understanding. There is much research regarding stigma surrounding disability benefit claimants (e.g. Baumberg, 2016; Garthwaite et al., 2013), which demonstrates ignorance about the experiences of disabled benefit claimants. For example, Baumberg-Geiger (2016) found that the public overestimate benefit fraud.

Participants felt that disabled people are not valued as equal members in society. Campbell (2009, p19) reported that disability is “cast as a diminished state of being human” due to the disabled body not being perfect. Thus, it can be argued that disabled benefits claimants in our society are ‘othered’ (Wilkinson & Kitzinger, 1996). ‘Othering’ is a system of discrimination whereby the characteristics of a person or group are used to distinguish them as separate, so they are placed outside of the norm. ‘Othering’ has been shown to have significant implications for those who are positioned as ‘non-normative’. This includes that exclusionary ‘othering’ often utilises the power within relationships for domination and subordination (Canales, 2000). Furthermore, ‘othering’ is silencing and delegitimising (Kitzinger & Wilkinson, 1996), leading to the perspectives of those who are ‘othered’, in this case disabled benefit

claimants, not having a voice in society and when they attempt to gain a voice potentially being discredited. Along with being stereotyped as 'scroungers', participants described a two-fold discrimination and marginalisation at the intersection of these identities. Shakespeare (2008) reported widespread and persistent devaluation of disabled people, and added that "discrimination and prejudice almost always play a major part in the lives of disabled people." (p12). Participants reflected on which types of disability are more legitimised, as those with invisible disabilities, such as pain, fatigue and mental health problems found they were often not believed. This supports findings from previous research, e.g. where the difficulties of mental health being invisible were highlighted (Shefer et al., 2016). This caused frustration and participants felt they had to justify their disabilities.

#### ***4.2.2.2 Facing discrimination and bullying***

Participants described experiences where benefits staff were rude, disrespectful, patronising and even threatening. Staff behaviour may be rooted in their negative perceptions of benefit claimants. These experiences have not been described as disrespectful in the academic literature, but have been presented more neutrally, for example assessors not being empathetic (Clifton et al., 2013; Dwyer et al., 2016). However, it is well documented in regional reports (e.g. Roberts et al., 2014; Hickman et al., 2015). Participants thought that issues they encountered, such as errors and not being believed, demonstrated disrespect towards them. Participants found the assessments humiliating, supporting previous research where others found this process and welfare conditionality distressing, dehumanising (Allen et al., 2016; Patrick, 2017; Dwyer et al., 2016) and intimidating (Shefer et al., 2016). Garthwaite (2014) described a sense of depersonalisation and feelings of

powerlessness. Earl (2015, p114) found that mental health service users constructed the WCA process as a 'threat', but this seems to relate to feeling distressed or concerned about not meeting the benefit criteria, rather than disrespectful staff behaviour. I wonder if findings have not been framed from this perspective because this seems to taint the research with moral, emotional and political affiliations, which researchers aspire to avoid (Shakespeare, 2008). However, I feel it is important to present participants' perspectives in their terms as described to the researcher, as required by grounded theory.

These findings should be read in the context of what is known about the difficulties of the organisational context of the DWP, which may also be dehumanising for the staff who work there. Some staff have reported that they have targets for length of phone calls and percentages in different categories of benefits (The Guardian, 2012, 2016), which means they cannot give the time or outcome they would like to each case that they work with. In addition, staff may not have a full understanding of the system themselves and may lack training regarding the complex needs of the people that they speak to. When participants experienced the system as disrespectful, this was due to a combination of factors, such as claimant lack of understanding and a feeling of powerlessness about the processes, not solely interpersonal relations with staff.

Participants described hearing hurtful comments from neighbours, and also described instances of hate crime. Discrimination of benefit claimants by the public is better evidenced in the literature than discrimination from professionals, for example people's fear to leave their homes (Morris, 2013) and neighbourhood incivilities (Airey, 2003; Bailey et al., 2013). Permission to denigrate others' 'lifestyle choices'

may be influenced by the political and media coverage of benefit claimants (Pemberton et al. 2016). One way of understanding this phenomenon could be through the Benjamin Franklin effect (Schopler & Compere, 1971), which describes how humans have a tendency to develop hate for people who they treat badly, in that we resolve the guilt of poor treatment of others by othering those who have been wronged, in order to retain a notion of being a good person. In effect, dehumanising others, as described in “Being in the public gaze”, serves the purpose of justifying continued maltreatment of others. Due to growing media coverage regarding claimants, this may have an increasingly harmful impact on claimants.

The results from this domain are in keeping with existing literature and highlight that disabled benefit claimants experience scrutiny, judgement, ignorance and discrimination both within and outside the benefits system. They seem to fit with the austerity ailment of ‘humiliation and shame’ (PAA, 2015). This research adds to the literature in describing situations where members of the public have taken on the role of policing claimants, and in elaborating participants’ fear of being judged when they go out. Experiences of discrimination within the benefits system have been less well explored in the academic literature, potentially due to the difficulty in criticising the behaviour of professional staff. Whilst recognising the influence of my biases in constructing this grounded theory model, I hope that this research presents participants’ experiences of judgement and discrimination, without presenting shallow or misleading arguments (Shakespeare, 2008).

### **4.2.3 Clinging onto my sense of self**

Participants described struggling with their finances and mental health and this affecting how much they could go out. They felt they lost a sense of themselves, including feeling unable to free themselves from the stigma of being a benefits claimant. However, all attempted to resist this in some way, for example by taking action to distance themselves from a stigmatised identity. When co-constructing this domain, I formulated participants' experiences with regards to identity using Johnstone et al.'s (Unpublished) power-threat-meaning framework. This model frames distress as responses to life circumstances, including how power operates in people's lives and what kinds of threats this poses; for example emotional threat might include feeling overwhelmed or invalidated, and economic threat might include poverty. The model emphasises the importance of what sense people make of their experiences, and how they respond in order to survive. For this study, I considered how participants' lack of power, through a combination of being physically vulnerable, with insecurity in the benefits system and invalidating discourses in society, led them to feel threatened, emotionally, financially and socially. However they attempted to make sense of these experiences, for example feeling humiliated, powerless and trapped, and responded by either giving up, fighting through individual or collective acts of resistance, or seeking support. This framework helped me to consider different aspects of participants' experiences and bring them together into a grounded theory model.

#### ***4.2.3.1 Lacking resources to sustain my physical and mental health***

Participants reported struggling financially if their benefits reduced. This is unsurprising as financial insecurity due to austerity is well documented in the literature (e.g. Curl & Kearns, 2015; Moffatt & Noble, 2015; Patrick, 2017; Roberts et al., 2014; Hickman et al., 2015). A narrative of “going without” has been a central theme in many papers (e.g. Patrick, 2017, p296). People have been described as ‘existing, not living’ due to meagre budgets (Patrick, 2014, p709; Pemberton et al., 2016a, p11), requiring them to make difficult choices such as heating or eating, or not eating so their children can eat. Lister (2004), amongst others, describes this as ‘getting by’, requiring active agency to manage in poverty. The increased use of foodbanks in the UK indicates the difficult financial situation in which many live (Loopstra et al., 2015). Wright (2016) argued that being required to meet basic needs on an insufficient income was one of the biggest challenges for welfare recipients. One participant mentioned how she would not use a foodbank because she viewed herself as less vulnerable than others, or as social comparison theory posits, she made a downward social comparison with others who were less fortunate than herself (Festinger, 1954). This research provides examples of how poverty has a great impact on disabled people, who also have higher costs of living (Duffy, 2014).

Participants described a worsening of mental health in response to their experiences surrounding benefits. The impact of application, assessment and reassessment on mental health were frequently discussed in the literature, including anxiety, low mood and suicidality (e.g. Patrick, 2017; Shefer et al., 2016; Morris, 2013; DeWolfe, 2012;

Marks et al., 2017; McCartney, 2012, 2015; Orr et al., 2013). Participants' difficulties with mental health often exacerbated their physical health difficulties, such as chronic pain and fatigue. This was also mentioned in the literature (e.g. Allen et al., 2016). Moffatt and Noble (2015) emphasised the additional stress of worrying about finances when already unwell. These findings emphasise the potentially severe impact on mental health and suggest that changes in the benefits system have the opposite effect to those intended by the government's policies on wellbeing. For example, the National Wellbeing Programme (Cameron, 2010) aimed to improve wellbeing and health outcomes. It seems that some of the government's initiatives either have opposing priorities or do not produce the desired outcome. Whilst saving money in the short-term, it can be argued that the welfare reforms may have a greater cost, both financially on various public services and societally, due to distress in the short and long-term (PAA, 2015), and this was mentioned by some participants. With people with physical health conditions, an increase in mental health difficulties means that they may be less able to manage their conditions, and their health outcomes and experiences worsen (KHP, 2016).

As mentioned above, participants described being able to go out less due to both financial and mental health reasons, and as a result becoming isolated. Again, this was mentioned in the literature (e.g. Allen et al., 2016). It also fits with the PAA ailment of 'Being trapped and powerless' (2015). Although doing less is an expected consequence of having less money, and a likely consequence of poor mental health, I feel this finding is important because it illustrates the severe potential consequences of changes in benefits for disabled people. Additionally, isolation can lead to mental health difficulties, which may lead to further isolation.

#### **4.2.3.2 *Becoming a different person***

Participants showed that the above difficulties affected their identity. For those whose disability was acquired or degenerative, their life changed when they became disabled and began claiming benefits. 'Loss of self' and social isolation are described in the literature on chronic illness (e.g. Charmaz, 1983). Garthwaite (2015a) described participants' attempts to come to terms with becoming 'incapacitated', and their acceptance, or more commonly rejection, of a disabled identity. For some participants, being unable to work led to them feeling low in worth and in mood. This may be due to the high value that the government and society place on employment (DWP & DOH, 2016), particularly with the stated intention of ESA being a shift from a culture of invalidity to employability (Kemp & Davidson, 2010). In addition, Topor & Ljungqvist (2017) found that having more money increases one's sense of self, therefore being unemployed affects claimants both financially and emotionally. Pemberton et al. (2016a) found that the increased scrutiny participants faced impacted their wider relationships and sense of belonging. Furthermore, claimants felt they were required to present themselves as more disabled for benefits assessments than they would in other social situations. This unusual public display of disability was also observed by deWolfe (2012) and by Garthwaite (2015a) who described this as adopting a 'disabled role'. Akers (2016) found that the negative focus on their difficulties led them to question their capabilities. Garthwaite (2015a) found that people made an effort to appear genuinely ill, so they would be believed, which is regarded as unsurprising given the rhetoric surrounding benefit claimants (Garthwaite, 2011). Newton et al. (2013) report that the experience of being disbelieved is stigmatising in itself. It seems that benefits assessments have a

detrimental impact on both identity and mood as they force claimants to present themselves in the opposite way to how many try to live their lives, i.e. to the best of their abilities.

Due to their experience of maltreatment, along with the 'scrounger rhetoric', participants felt torn between wanting to tell people about their difficult experiences and wanting to keep details private. Many did not disclose their claimant status to others, even to close family. This supports ideas in the literature about how uncomfortable claimants feel when talking to others and concealing claimant identity (Garthwaite, 2015b; Patrick, 2016), which has been found to lead to avoiding social situations and becoming isolated (Garthwaite, 2015a). In turn, this has been seen to affect mood and appraisal of self (Garthwaite, 2015a). The participants in this study mentioned fear of going out due to concerns about their neighbours' judgement of them. When suffering is delegitimised, people are silenced so refrain from telling their story, which means it goes unseen (Ware, 1992, in Bülow, 2008). Those with invisible illnesses, whose credibility is often challenged, have been found to be particularly worried about being regarded as a malingerer (deWolfe, 2012). Not talking to others might exacerbate the pressure of living with a physical health difficulty and the isolation associated with financial difficulties, discussed further below, which may in turn contribute to increasing mental health and physical health difficulties. It could be argued that this might potentially lead claimants to apply for more benefits in the long-term. On the other hand, most participants considered that speaking up might highlight the difficulties in the system and stimulate change. There is evidence that researchers gathering empirical evidence about disabling barriers

and prejudices can stimulate change and publicise oppression (Barnes, 1991). I hope that this research will help to fulfil these objectives in some way.

Due to the stigma in society, participants felt they were seen as 'worthless', which affected their self-confidence. Some participants internalised the narrative of not being deserving which problematises 'welfare' and those who rely on it (Patrick, 2017), and has been reported previously (Patrick, 2016; Pemberton et al., 2016b). Participants reported judging themselves, apparently having internalised an ideal norm, and prejudices and stereotypes held by a non-disabled majority (Morris, 1991). This has been described as the 'normalising gaze' (Foucault, 1977), and has been noted to lead to regulation, or self-policing, of one's own behaviour for fear of deviating from society's ideal. Foucault calls this 'disciplinary power', a form of power that is constant, unnoticeable and internalised, where control is achieved through self-surveillance as the fear of being caught disobeying the rules keeps people in line with society's expectations. He observed this internalised discourse being so powerful that it even moved into the private sphere where surveillance from others is not possible. Stigma seemed to deter some from claiming benefits that they could access until absolutely necessary. Garthwaite (2014, p791) considered under-claiming may be related to preserving one's identity as 'not disabled', and leaves people at greater risk of financial strain. DeWolfe (2012) added that her participants were genuinely fearful of state surveillance near their homes. This internalised ideal also affected participants' behaviour with other disabled people. They noticed themselves judging, and even monitoring, others to see if they were 'genuinely disabled' enough to claim benefits.

At times, some participants felt like giving up, suggesting a loss of a more motivated identity. This may be partly due to the effects of stigma on claimant's lives, as discussed above. It also links to evidence that financial insecurity detrimentally affects mental health (e.g. Fitch et al., 2011; Richardson et al., 2013). Wright (2016) found that financial struggles seemed to devalue claimants' views of their agency to make changes in their lives. At these times, learned helplessness theory (Seligman, 1975), the idea that depression and mental illness result from a real or perceived absence of control over the outcome of a situation, may be relevant. Here, an individual may learn that he or she is helpless or powerless to change their aversive situation, perhaps due to their current financial or mental health status which affects their ability to go out, so they accept that they have lost control and thus give up trying. When people feel that their previously known selves are lost, they can draw negative identity conclusions. Therefore, disability, stigma and financial difficulties contribute to a sense of a 'contaminated' or broken self (White, 1995).

However, all participants described attempting to pull back from or distance themselves from the stigmatised identity of benefit claimants. Wade (1997) observed that whenever people feel badly treated, they resist. He proposed that any mental or behavioural acts may be understood as forms of resistance, including withstanding a situation. Foucault (2000) reported that we attempt to make ourselves in a good image, either reproducing or transforming the image that is held in popular discourses. Participants attempted to maintain hope about the future, including hope for future employment and a move away from reliance on benefits, seen by Patrick (2017) as conditioning to fulfil the requirements of dutiful citizens. Lister (2004) described this as 'getting off', or attempts to leave poverty behind. An eagerness to

return to work has been framed as an issue of dignity, a wish to escape dependency and to gain a sense of social usefulness (deWolfe, 2012). It also counters the stigma of claimants being 'scroungers'.

Participants seemed to search for an acceptable alternative identity. Some claimants engaged in emphasising the non-deservingness of some 'other' while simultaneously defending their own entitlement to benefits, challenging that the dominant narrative on welfare is applicable to them (e.g. Garthwaite, 2015a; Moffatt & Noble, 2015; Shildrick and MacDonald, 2013). Patrick (2016) commented that in highlighting the 'deservingness' of most benefit claimants, claimants challenge the dominant narrative that claimants require encouragement to enter paid employment and behave responsibly. However, she noticed that where an 'other' was deemed less deserving, this employed the stereotype to justify participants' claims. In validating their own needs but not challenging the socially constructed identity and attached stigma, this reduces the scope for alternative narratives around claiming benefits (Patrick, 2016). Garthwaite et al. (2014) described how this creates an 'us' and 'them' dichotomy, reflecting divisions between disabled people created by the government and media rhetoric. It seems to foster resentment for those deemed 'undeserving', and therefore potentially undermines collective action.

Nevertheless, participants were able to challenge the socially constructed identity of benefit claimants in various ways. Many described how their political beliefs enabled them to separate themselves from a stigmatised identity, as they located responsibility for their difficulties with the government. This attempt to make sense of their situation in response to societal discourses was also found by Pemberton et al.

(2016a), but this study adds detail to our understanding of experiences in the current context. This political belief and the feeling of being unjustly treated seemed to enable participants to perform acts of resistance. Lister (2004) described responses to living in poverty, including 'getting [back] at' the system through everyday resistance, and 'getting organised' through collective action to challenge the circumstance of being in poverty. Statistics and research show a high number of people appeal the decision about their benefits (e.g. Shefer et al., 2016), and participants in this study also went further, with some even speaking out publically. It seems that they felt they had some agency over their lives, which PAA (2015) argue is an indicator of a healthy society. This sense of control has been related to better physical health (Lefcourt, 1991) and mental health (Frenkel et al., 1995). These acts seemed to serve to validate participants as 'truly disabled' and to create an identity that was acceptable to them.

Personal relationships are important in promoting wellbeing (Huppert, Baylis, & Keverne, 2005). Participants sought financial, emotional and practical support from family and friends, local charities and professionals, and this appeared to mitigate the impact of a negative sense of self. The importance of pets for emotional support was also highlighted for those with mental health problems, supporting previous research (Brooks et al., 2016). They seemed to instinctively attempt to counter the 'isolation and loneliness' known to be a consequence of austerity measures (PAA, 2015) through connection. This is crucial for building a meaningful identity, as relatedness is a basic human need (Bowlby, 2005), and humans find social exclusion painful (Williams, 2007). However, there was accompanying sense of discomfort when borrowing from or being given money by family and friends, as also

mentioned in Shefer et al. (2016). There was a sense of being a burden on others as a result of their disability (Lawton, 2003). In contrast to personal avenues of support, a shortage of public support services, such as Citizens' Advice Bureau, was mentioned. Given the findings in this study about the impact of cuts and changes, this dearth of professional support seems particularly worrying. Support from others in a similar position was found to be very important, and online peer support groups enabled solidarity with peers, sharing of experiences and knowledge, and as such, collective resistance. Social media seems to have a large role to play in including and enabling people who are unwell or less mobile to socialise with peers (Morris, 2013), and potentially to create contexts for collective action.

The findings from this domain support those from previous research which suggest that experiencing changes in benefits has a detrimental effect on finances, physical health and mental health, and that disabled people take on a stigmatised identity from society, but attempt to distance themselves from this. However, this study collates these findings into a framework regarding identity, rather than exploring each separately. This research furthers our understanding of the meaning-making and political beliefs of claimants who experience difficulties in the benefits system. It broadens our knowledge about collective resistance from online support groups and charities, a relatively new area, and highlights some of the challenges for individual and collective action. It constructs the ways in which people oppose the benefits system from a different perspective to those in the literature review, as acts of resistance in order to hold onto a preferred sense of self.

#### 4.2.4 Reflections on model

Attitudes to and experiences of welfare are inextricably linked, and tend to shape each other (Hudson, Patrick & Wincup, 2016). Therefore, the domains of the grounded theory model may be interpreted as interrelated, but links suggested between them might not be causative. It seems that the experience of being a disabled benefit claimant has many complexities relating to the benefits system, society and individual identity. This is the first study that has created a visual model to help readers to understand the details of these experiences and how they relate to each other. Previous studies have found similar themes, but have not drawn them together in this way. Where this study's findings are similar to previous research, this strengthens our understanding in this area, and shows us that the findings from those studies are still relevant to the current benefits system. For example, there is now a large amount of research describing the difficulties with assessments in the benefits system. These findings help us to empathise with disability benefit claimants.

Although Garthwaite (2014) discussed the relationship between stigma and identity for claimants on an earlier disability benefit, this research is unique in framing responses to difficulties in the benefits system and the narratives in society as issues of identity. In particular, it demonstrates the potentially significant harmful impact of living as a benefit claimant in society and navigating the benefits system on an individual's wellbeing. The research shows us how a change or reduction in benefits may not only detrimentally affect an individual's ability to afford basic life necessities, but also their mental and physical health. For many, this may lead to social isolation.

The research shows how the stigma surrounding benefit claimants and the way that benefit applications and assessments are structured cause individuals to focus on their limitations, rather than their strengths and ability to adapt despite their physical health condition. It also demonstrates the potency of the influence of embarrassment and fear of judgement on how uncomfortable individuals feel about talking about their claimant status, which in turn also affects their level of social isolation. This may further affect their mental health. The research strengthens our understanding of situations where members of the public, including claimants themselves, have taken on the role of policing others and in explaining the significant fear that claimants have of being judged when they go out, as they seem to have internalised the stigmatised narratives surrounding benefit claimants. All of these factors relate to losing a sense of self or identity.

Whilst participants seemed to feel powerless and to have lost their previous motivated sense of self, the research also shows that some were empowered to take action. The research is original in constructing opposition to benefit changes as acts of resistance in order to hold onto a preferred sense of self. It gives us some insight into why participants took action against their benefits decisions, and against the system through various means, for example by helping others or speaking out through media outlets. The research enables us to better understand the meaning-making and political beliefs of claimants who experience difficulties in the benefits system and in society, and the role of this in these acts of resistance. These actions, alongside seeking social support, seemed to enable the participants to hold onto a sense of self that was both meaningful and acceptable to themselves.

The research is novel in considering the social relations between people and how these impact on the process of claiming benefits, for example witnessing others' struggles having an amplifying effect on anxiety and fear about a claimant's own situation. Therefore, whilst social media was viewed by participants as a helpful tool for learning from and supporting others in similar positions, this study raises questions about possible negative consequences. The research broadens our knowledge about collective resistance from online support groups and charities, a relatively new area, and highlights some of the challenges for individual and collective action.

Overall this grounded theory model supports the findings from previous research in this field, whilst also developing our understanding in a number of areas, particularly regarding wellbeing and identity.

### **4.3 Clinical implications**

The findings from this study are useful for Clinical Psychologists, both as a profession and as clinicians who work with individuals with mental health difficulties. They also inform us of changes that could be made to improve the process of accessing benefits for people with physical health conditions.

### **4.3.1 For the profession**

Clinical psychology aims to reduce psychological distress and to enhance the promotion of psychological well-being (BPS, 2017a). Our role involves gathering, implementing and disseminating evidence in a rigorous manner about the causes of psychological distress and how best to address them. Therefore it could be argued that much of what we do as a profession is political.

There have been many changes in the welfare system, under what is described as 'welfare reform', suggesting improvements to policies. However, this research suggests a potentially huge psychological cost of 'reform', for example dehumanising experiences in the benefits system and the effects of developing discourses around benefits in UK society. Mental health is not an individual issue and Psychologists are trained to focus not solely within the clinical room with a client, but also on wellbeing within wider society. Therefore, I feel Psychologists have a responsibility to explore the impact of government policies on individuals and society, and to raise questions about their effectiveness (Knapp, 2012). It is critical that policy makers consider the psychological impact of current and future policies, including changes they make to the benefits system, on those they may affect. Garthwaite (2015a) also stated that drawing attention to the stigma faced by long-term sickness benefit recipients is crucial when thinking about welfare policy. Additionally, as individuals within professional networks, we have a responsibility to challenge the stigmatising discourses that are currently dominant. We have a duty to use our powerful position to amplify the voices of those who are rarely heard (Lister, 2004). The current study aims to fulfil these responsibilities.

However, we must also go further than this. Beresford (2016) argues there is no point highlighting sad narratives to the public under the assumption that change will follow, but we must also be involved in working out the solution. If we feel that people's mental health is at risk then we have a responsibility to work or lobby at a policy level to promote wellbeing within society and to prevent further distress from occurring (BPS, 2009; NHS England, 2014), including opposing policies that threaten the wellbeing of the vulnerable (Kinderman, 2017). In this research, the participants indicate that we should highlight the significant ill-effects of the changes to the benefits system on claimant's wellbeing, both directly by reducing their ability to afford basic necessities for living, and indirectly as a consequence on their mental health, affecting stress levels, mood, and their level of social isolation.

In order to promote wellbeing, we must focus on the economic conditions in which citizens live, bearing in mind that living with disability incurs additional costs. Clearly, when people cannot afford food or a safe environment and live with overwhelming uncertainty, then they cannot achieve their full potential (Maslow, 1943). This research suggests that many disabled people cannot afford a basic standard of living, so this is something that I feel the government should address. We must also remind politicians that we live in complex networks of social relationships (Kinderman, 2017). PAA (2015) highlighted five indicators of a psychologically healthy society: agency, security, connection, meaning and trust. As healthcare professionals we should promote a society where all people have the freedom to live

a valued life (Sen, 2009), including the capacity to be healthy, to think, to feel and act freely, to have control over their environment, and to form communities.

We have a responsibility to promote the discipline of psychology in health and social care (Kinderman, 2017). This extends to disseminating findings beyond Psychology to others who may find this information helpful. Examples may include journalists who can disseminate to the public, research organisations such as the Centre for Welfare Reform and the Joseph Rowntree Foundation, and support groups for benefit claimants. Psychologists might hope to align themselves with user groups differently from when working with colleagues, and ask how we can assist in collective action, acknowledging our outsider position (Dywer & Buckle, 2009).

#### **4.3.2 For clinicians**

On the other hand, it would be unwise to commit all our skills and resources to working at a research or political level. This study points towards the impact of benefit changes on individuals' mental health, so they might be referred onto psychological services, such as IAPT or community mental health teams. We should maintain our commitment to clients who present with psychological distress. There is a role for professionals in interventions to mitigate the effects of austerity, including psychosocial support for vulnerable individuals (Barnes et al., 2016).

This research suggests that disabled benefit claimants experience others not understanding them, being judged and stereotyped as a 'scrounger', and suffering

from maltreatment. In considering what would make therapy meaningful, a therapist might attempt to give claimants a different experience. This might include listening and trying to understand the claimants' experiences, being warm, non-judgemental, and polite and respectful. All of these are key in developing therapeutic alliance (Gilbert & Leahy, 2007). Clients tend to feel powerless to change their situation resulting from 'welfare reform' (PAA, 2015). Having a different relational experience might foster hope, and may be experienced as empowering.

As therapists, we hear the distressing stories clients tell us, but often then locate the causes of the distress as well as potential solutions within the person. It could be argued that it is inappropriate to ignore the context of someone experiencing psychological distress due to external influences such as changes in their benefits and related hardship (Waldegrave et al., 2003). Instead, a more contextualised, socio-politically aware approach can locate the causes of the distress within the discursive, societal or community level, allowing an individual to position themselves in relation to public discourses, changes in society and experiences within their communities. This research suggests that we should ask about our client's physical health, home situation and benefits status in our initial primary and secondary care psychological assessments, as these are likely to affect their mental health. Within our teams, we can use our skills in formulation to help other professionals to understand the links between an individual's context and their mental health presentation. I hope that these practices would remind us of the additional resources required to cope as an individual with physical health needs, and thus normalise the need in accessing benefits, which may contribute to reducing stigma surrounding claiming benefits within our teams. As claimants find the system difficult to

understand, Psychologists may also have a role, as professionals in a position of relative power, to support and to act as advocates for benefit applicants in navigating the benefits system. This might include supporting benefit applications with formal letters and attending benefits assessments with those who would like an advocate.

Narrative therapy, where difficulties can be placed within their context and causes of distress can be externalised (Epston & White, 1990) is an example of one therapeutic approach that allows such a contextualised position. Haugaard (2015) argues that narrative therapy may function as a form of activism, as it involves resisting dominant cultural truths (White, 2004, in Ord 2013), and Findlay (2015, p78) stated that “‘therapeutic’ narrative practices are also ‘political practices’”. Therapist and client may work together to ‘return the normalising gaze’ (White, 2002), to deconstruct what it means to be ‘normal’ in society (Hutton, 2008) by questioning taken-for-granted discourses. Together they can unpack the dominant discourses impacting on the client’s distress, for example the ‘scrounger’ discourse. They can explore the meanings and historical and cultural origins (Ord, 2013) of these discourses, such as the constructions of disability over time or the context of welfare reform, and consider the values informing these meanings. This allows the client to consider whether these are values they wish to align themselves with or distance themselves from. Through such a process of collaborative deconstruction and processing changes in one’s sense of self and others’ reactions, clients can co-construct a meaningful understanding of their difficulties and align themselves with their preferred identity and values. This would restore a sense of the continuity of self (Denborough, 2005) within the context of the hardship they are experiencing.

Another example of a therapeutic approach that allows for a contextualised position

is Acceptance and Commitment Therapy (ACT, Hayes, Strosahl & Wilson, 1999).

This approach supports clients to be mindful of and present within their current situation, rather than avoidant of their experiences. ACT aims to help clients to clarify their personal values and to move towards building a life that is meaningful to them, despite their day-to-day difficulties. Use of these approaches might facilitate empowerment and hope.

Critical psychological theory (Holzkamp, 1992) challenges mainstream, one-to-one therapy as a route to treat psychopathology, and looks towards social change as a means of preventing mental health difficulties. One of its main criticisms of conventional psychology is that it fails to consider the way that power differences between groups can affect mental and physical wellbeing, as it tends to explain behaviour at the level of the individual. Although some types of therapies, as described above, can address power differences, Psychologists can also work at a broader level. Community psychology (Kloos, Hill, Thomas, Wandersman & Elias, 2011; Levine, Perkins & Levine, 1997), working with wider systems to enhance and promote wellbeing, is a further approach that enables Clinical Psychologists to helpfully respond to the distress experienced by those experiencing benefit cuts or changes. Rather than a reactive, treatment-based approach, community psychology takes an active role in identifying, challenging and changing the societal structures that perpetrate psychological distress. Clinical Psychologists may become involved in community-led approaches to mental health that strengthen communities and their resources (SCDC/CHEX, 2012), or community empowerment of local groups to impact local decision making, which has been found to be beneficial for health (Rappaport, 1977). Therapists may support clients to find or create meaningful peer

support networks, such as the social media networks indicated by participants in this study. These approaches could assist disabled people experiencing welfare changes to support one another, thereby undermining the social isolation described by participants in this study by increasing connection with others. They could also help disabled people to work together to oppose the impacts of benefit changes at an individual, and potentially a collective, level.

In conclusion, I feel that Psychologists have a role in mitigating the impact of welfare reform as described by participants in this study, both with individuals and in prompting change and understanding at community and political levels. This might include supporting individuals and collaborating with communities who are experiencing difficulties, and researching the impact of policy changes and disseminating the findings. I hope that this research will add to existing voices highlighting the significant impacts of welfare reform to academics and practitioners in the healthcare and benefits system, and to policy-makers in government.

#### **4.3.3 For policy makers**

The participants in this research gave a number of suggestions for how to improve the benefits system to make it more empathetic and less dehumanising. They told us about the importance of having assessors and decision makers who are trained about how particular disabilities affect people. However, if this is too difficult to implement, then perhaps the system could employ advisors who are expert on different conditions so that assessors could seek help to understand their impact on people's lives. In fact, many participants spoke of their desire for a system where their own medical professionals, who are experts in their health, would assess their

suitability for benefit support. Although this would add to medical professional's time commitments and paperwork, it might reduce the time and cost of the assessments, as they would already be familiar with the claimant and the nature of their conditions.

Another alternative, suggested by participants, would be to have only one assessment for all disability-related benefits. The current arrangements of multiple assessments for different benefits are considered to cause claimants additional stress and confusion, and must cost more to carry out. This therefore doesn't seem to be a worthwhile or sensible approach.

Participants would also prefer an assessment where they had the opportunity to discuss their individual needs and is not points-based. In particular, they felt that a points-based system is unsuitable for people who have fluctuating or degenerative conditions. In addition, although home assessments are sometimes available, it seems that the decision-making process for who may receive a home assessment should be reviewed in order to better accommodate participants who are too unwell to travel. This would prevent them from being requested to attend assessments or to participate in work-related activities outside of their own homes.

Many participants spoke of their difficulties in understanding the application forms or finding them too long, and some mentioned finding a paper form difficult due to their physical disabilities. Adjustments to the form could include having shorter forms with clearer wording, and providing these in alternative formats, such as electronic as well as paper options.

Confusion seemed to be caused by frequent and un-notified changes in eligibility criteria for particular benefits and the complexity of finding information about these criteria, so improved communication, for example a website with all of this information held in one place in clear language, would benefit claimants and professionals alike. In addition, stress was caused by long waits for decisions on assessments followed by sudden changes to individuals' benefits. Claimants would therefore benefit from a speedier decision-making process, with clearer communication and more advance notice of decisions, particularly when the decision might involve a significant reduction in income. A guaranteed maximum period for the notification of the outcome following an assessment would considerably improve this situation, and reduce stress for claimants.

Furthermore, it seems that the media and the government play a huge role in perpetuating the stigma and negative narratives surrounding people with disabilities and benefit claimants. It would be positive to see more training on disabilities for politicians and professionals who work in this area, so that they may understand some of the complications of living with a physical health condition and some of the difficulties with the benefits system from the perspective of someone with long-term ill health.

In the area of the media, I would also like to see some moderation of the television programmes which discuss the lives of those on benefits, and the production of some more empathetic programmes which show the real difficulties of disabled

people on benefits. This would counter many of the programmes where unemployed benefit claimants are shown as having chosen that way of life, and might help to destigmatise the claiming of benefits.

This research is important for the DWP, members of the government, commissioners of television programmes and editors of newspapers to take note of and respond to thoughtfully. I hope the findings will encourage them to consider the impact of the way that they speak about disabled benefit claimants. I also hope it will encourage the DWP to make changes to improve the current benefits system to make it more effective and appropriate to the needs of disabled claimants.

## **4.4 Evaluation of the research**

### **4.4.1 Strengths**

This study has a number of strengths. It fills a gap in the literature regarding experiences of recent and ongoing welfare reforms, as much published research draws on data prior to 2010. This is important because research in this area is quickly outdated, and tightened benefits criteria can create higher anxiety and risk of poverty (deWolfe, 2012). Another strength is that it uses first person accounts, rather than those of professionals. This helps us understand the experiences of individuals, whilst giving voice to those who often go unheard and may not normally have the power or opportunity to share their views (Lister, 2004). Furthermore, this study focuses on disability benefits, rather than a range of benefits or on other topics such

as poverty or health, as in a number of studies in the literature review. This means that we can make more informed conclusions about the experiences of disabled people, who have different needs to other benefit claimants or people living in poverty.

The rationale for the research is strong and the study was methodologically rigorous, implementing most of Elliott et al. (1999)'s guidelines for qualitative research, as discussed in section 2.7. The use of grounded theory allows for findings to be grounded in the personal accounts of participants, and grounded theory methods, including constant comparison of data and theoretical sampling, allow for a rich, thorough and robust analysis. SU consultation allowed for the research question to be relevant and the research to be conducted in a way that would be acceptable to those living with benefit changes.

The study sample comprises a diverse population across cultures, socio-economic status, education levels, age, types of disability, and geographical area. As grounded theory seeks to gain a wide variety of experiences within the sample, these variations were advantageous. The diverse sample adds richness to what we can understand of people's experiences in relation to this phenomenon. As a result, the conclusions drawn from this study are not limited to a particular sub-group of the UK population. The sample was also large enough for categories in the model to have been saturated.

After recruitment of the majority of participants, it was noticed that the sample comprised mostly of people with invisible disabilities. One of the benefits of using

grounded theory was that theoretical sampling could be used to explore the experiences of people with visible disabilities, and compare them to people with invisible disabilities, and then to incorporate these into the model.

It is hoped that this study topic is interesting and emotionally engaging for readers. It gives Clinical Psychologists, and other mental health professionals, an opportunity to consider their position in relation to 'welfare reform', as well as the political role and responsibilities of Psychology.

#### **4.4.2 Limitations**

The study has a number of limitations. It may be that those who were motivated to participate in the study had poorer experiences of the benefits system or were more politically engaged. The grounded theory model presents how participants fought to retain their preferred identity; perhaps people who did not participate may not have found ways to fight the impact of a negative ascribed identity. As much recruitment occurred through disability charities and a Facebook benefits support group, the study may exclude those who are isolated from other disabled people. Additionally, there are limitations to recruitment through social media (Morris, 2013), which means this study may not represent the views of those in extreme poverty who cannot afford Internet, or those who have disabilities which limit access to the Internet. Therefore the results may under-represent some groups of disabled people. However, recruitment through various methods helped to mitigate this.

The sample only includes English speaking people, possibly due to the recruitment methods. It also includes fewer males than females, and we do not know whether a more equal sample would yield different data, although the two genders did not voice differing views. I wonder whether this was due to a gender bias in willingness to discuss distressing experiences. The sample only included participants who had experienced concerns about their benefits, which means that the results may be biased against the benefits system. However the diverse sample shows that the experiences reported were not limited to one sub-section of the population, and it is important to voice these experiences, even if they do not necessarily represent the views of all disabled people.

For these reasons, the model's ability to provide insight into all people who experience changes in their disability benefits is limited, and therefore more research is required.

#### **4.5 Suggestions for further research**

This study explored the experiences of people primarily with physical health difficulties and for that reason it excluded many people who claim disability benefits. This was necessary in order to draw clear conclusions from the data, but it would be useful to undertake similar research with people with mental health problems and cognitive or learning disabilities. It would also be interesting to research the experiences of children of disability benefit claimants, which were mentioned by some participants.

This study provides examples of how participants internalise a narrative of not being deserving, and of attempting to pull away from this. This has been reported previously, but less well explored than other experiences in the benefits system. Future research could explore this further.

Although many disabled people have appealed benefit decisions and some have spoken out about the system, this has not been regularly framed as acts of resistance against impacts of the benefits system. There has been little research exploring the experiences of those who performed public acts of resistance and how they countered the stigma of being disabled and a benefit claimant to enable them to speak out, so it would be beneficial to explore this. Hypotheses from this research might relate to strength of determination and moral duty, level of education, and experience with disability charities, in political activities and/or media.

Social media and online peer support groups have a role in including and enabling people who are unwell or less mobile to socialise with peers (Morris, 2013). In this study, they enabled solidarity with peers, sharing of experiences and knowledge, and as such collective resistance. However, the study also highlighted the possible negative influence of hearing about others' struggles on individuals' anxiety. There is also the potential for criticism and harassment online from non-disabled people (Alhaboby et al., 2016). Research into this relatively new area would further our understanding, including to what extent online support helps or hinders disabled people.

This study contributes to filling a gap in the literature regarding the experiences and identity of disability benefit claimants. Future research would develop our understanding further.

#### **4.6 Study reflections**

Critically considering the lessons learnt from any research project should be combined with reflexive examination from the perspective of the researcher (Vernon, 1997). This enables consideration of their own values, interest and assumptions and how these influence their work (Charmaz, 2014). Considering my position was crucial given my role as both interviewer and primary data analyst.

The main problem I encountered was in navigating the intensity of my personal responses to the data, including sadness and anger. I was surprised by how many individuals had been affected by welfare reform and the extent of participants' financial and emotional struggles was truly shocking. This made it more difficult to remain rigorous in the research framework and could have affected my curiosity about certain aspects of the data, for example searching for data that fitted my own expectations. My supervisors held similar opinions about the topic to me, so I continually reflected on our biases. In order to maintain methodological rigour I used a reflective diary (Appendices M & N), regular research supervision, peer and supervisor coding checks, and line-by-line coding, which forces systematic attendance to all the data.

I found it difficult to understand welfare reform, and my supervisors felt this was because there have been many changes in a short period of time. I am therefore not surprised that participants were often confused about the benefits system. In constructing the grounded theory model, I also found it confusing initially to separate the categories I had formed, as there was significant overlap.

Through listening to the recordings and transcribing data, I have developed confidence and skills in interviewing, for example using follow-up questions, probes or summaries to obtain further examples. Some participants held concerns about conveying strong opinions, and I endeavoured to put them at ease by reiterating confidentiality and explaining that I valued their opinions. The flexibility of using an interview guide gave me scope to be responsive to participants' comments. It was a privilege to listen to their experiences and I wanted to remain close to their accounts. Therefore, I spent considerable time on line-by-line coding, used in-vivo codes to stay close to the data, and continued to code thoroughly even after I had a draft model. Memo-ing helped in gathering my thoughts and linking ideas together, but I found it difficult to decide on the grounded theory model which evolved during the study.

I have developed as a researcher and as a reflective practitioner throughout this project. The experience of reflecting on my values and epistemology, where this comes from and how this might affect my work will assist me in future research and clinical practice.

## **4.7 Conclusion**

This study has made a contribution to the limited research on the responses of people with physical health conditions to changes in disability benefits. The findings are consistent with previous research regarding difficult experiences of the benefits system and stigma in society. It emphasises the significant impact of welfare reform on both mental health and physical health. It is the first study to draw together the ideas in a visual model, and one of a few to frame responses as issues of identity. It advances our understanding of the social processes involved in living as a benefit claimant. These findings are important for Psychologists, as well as SUs and the wider professional community, particularly in a time of ongoing welfare reform.



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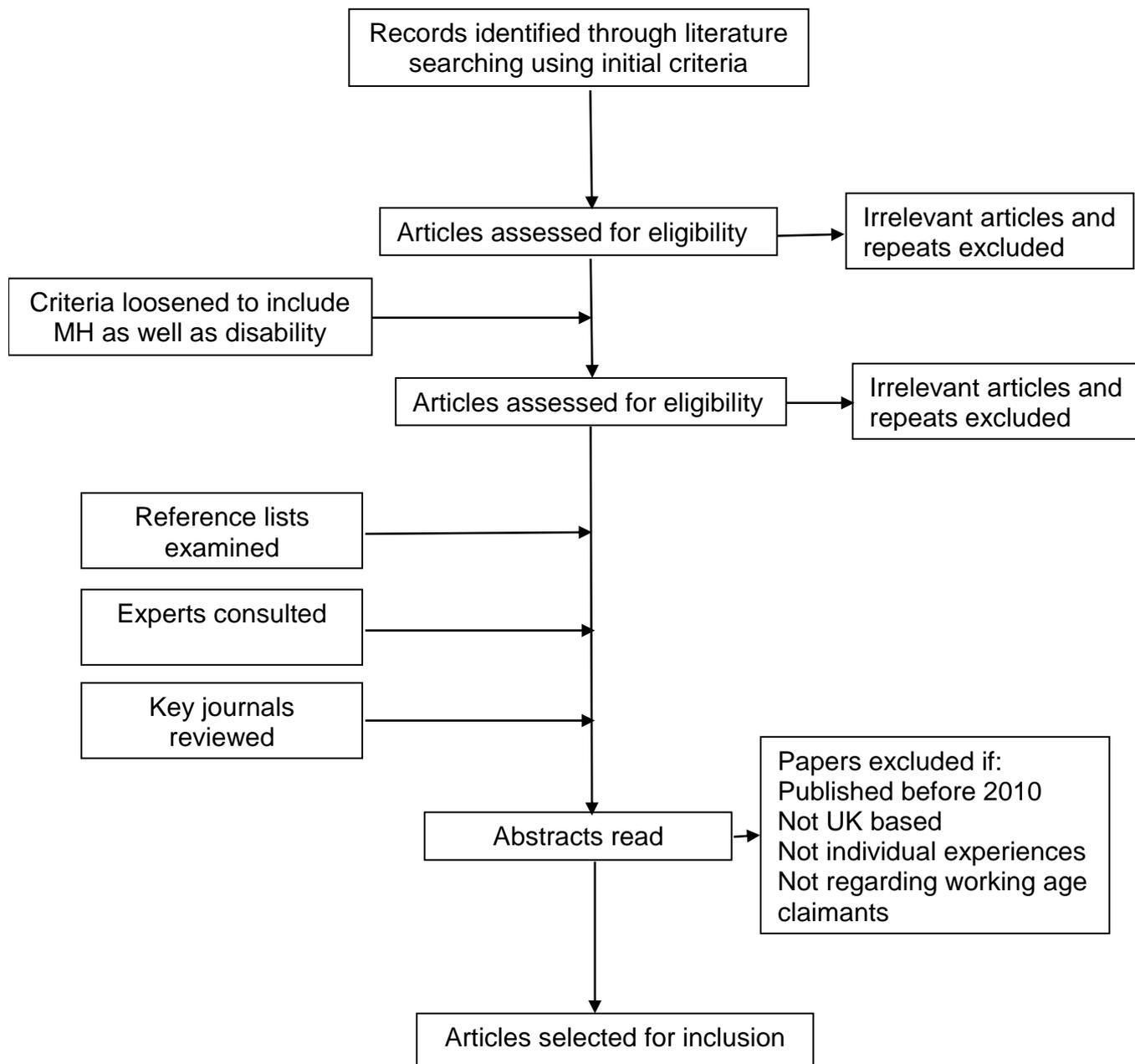
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## **Appendices**

## Appendix A: Literature search strategy



**Appendix B: Quality assessment of literature using Elliott et al. (1999)**

**guidelines**

Authors	Guidelines Shared by Both Qualitative and Quantitative Approaches										Guidelines Pertinent to Qualitative Research						
	Explicit scientific context and purpose	Appropriate methods	Respect for participants	Specification of methods	Appropriate discussion	Clarity of presentation	Contribution to knowledge	Owning one's perspective	Situating the sample	Grounding in examples	Providing credibility checks	Coherence	Accomplishing general vs. specific research tasks	Resonating with readers			
Clifton et al. 2013	✓	✓✓	✓✓	✓	X	✓✓	✓✓	✓✓	X	✓✓	X	✓✓	✓	✓✓			
Curl & Kearns 2015	✓✓	✓✓	✓✓	✓✓	✓✓	✓	✓✓	N/A	N/A	N/A	N/A	N/A	N/A	N/A			
de Wolfe 2012	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓	✓✓	✓✓	✓	✓✓	✓	✓✓			
Garthwaite 2014	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	X	✓✓	✓✓	✓	✓✓	✓	✓✓			
Garthwaite et al. 2014	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	X	✓	✓	X	✓	✓	✓✓			
Garthwaite 2015	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	X	✓✓	✓✓	✓	✓	✓	✓✓			
Moffatt & Noble 2015	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	X	✓✓	✓✓	X	✓	✓	✓✓			
Morris 2013	✓✓	✓✓	✓✓	✓	X	✓✓	✓✓	X	✓	✓	X	✓	✓	✓✓			
Patrick 2014	✓✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓	X	✓✓	✓✓	✓	X	X	✓✓			
Patrick 2016	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	X	✓✓	✓✓	✓	X	X	✓			
Patrick 2017	✓✓	✓✓	✓✓	✓✓	✓✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	X	✓			
Pemberton et al. 2016a	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	X	✓✓	✓✓	X	✓✓	✓	✓✓			
Pemberton et al. 2016b	✓✓	✓✓	✓✓	X	✓✓	✓	✓✓	X	✓✓	✓✓	X	✓✓	✓	✓✓			
Porter & Shakespeare 2016	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	X	✓✓	✓✓	X	✓✓	✓✓	✓✓			
Shefer et al. 2016	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	X	✓✓	✓✓	X	✓✓	✓✓	✓✓			
Wright, 2016	✓✓	✓✓	✓	✓✓	✓✓	✓	✓✓	X	✓	✓✓	X	✓	✓	✓			

Key: X – does not meet criteria    ✓ – partially meets criteria    ✓✓ – fully meets criteria    N/A - not applicable

## Appendix C: Ethics Approval Notification



UNIVERSITY OF HERTFORDSHIRE  
HEALTH AND HUMAN SCIENCES  
**ETHICS APPROVAL NOTIFICATION**

**TO** Jessica Saffer  
**CC** Lizette Nolte  
**FROM** Dr Richard Southern, Health and Human Sciences, ECDA Chairman  
**DATE** 15/8/16

---

Protocol number: **LMS/PGR/UH/02419**

Title of study: The impact of a loss of disability benefit on people with physical health problems, on their sense of self and their perceptions of disability

Your application for ethics approval has been accepted and approved by the ECDA for your School.

This approval is valid:

From: 15/8/16

To: 31/10/17

**Please note:**

**If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete.**

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

## **Appendix D: Participant information sheet**

### **Title of study**

The impact of a loss of disability benefits on people with physical health problems, on their sense of self and their perceptions of disability

### **Why have I been given this information?**

You have been invited to take part in a piece of research being conducted by Jessica Saffer, Trainee Clinical Psychologist.

Before you decide whether you are happy to take part in the research, it is important that you understand why this research is being conducted and what your involvement will include.

Please take your time to read the following information carefully. It aims to answer any questions that you may have about the research. Please feel free to contact the researcher if you have any questions or if you are unclear about any information on this form - details are given at the end of this document.

### **What is the research about?**

This study aims to explore the impact of a loss of disability benefits on people with physical disabilities. The research will focus on people's quality of life and on perceptions of people with disabilities.

The views of participants will be used to develop a model that could help organisations think about ways of supporting people who are going through this experience, and perhaps to encourage policy makers to structure the system differently so that adverse consequences may be avoided.

### **Do I have to take part?**

It is up to you whether or not you decide to take part in this study. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason.

### **Are there any restrictions that may prevent me from participating?**

The study is open to all adults (aged 18+) who have at least one life-limiting physical health condition, disability or impairment. People who have additional difficulties or mental health problems will not be excluded.

### **What will I have to do?**

If you decide to take part in this research, you will be asked to meet with Jessica Saffer, Trainee Clinical Psychologist. She will contact you to arrange a convenient time and place for the meeting. During this meeting, Jessica will speak to you about the research and make sure that you understand the information on this sheet. You will have the opportunity to ask any questions. You will be asked to sign a consent form that shows that you are willing to participate. Jessica will then ask you some questions about your views and experiences of losing disability benefits. The interview will last between 45 minutes and 1.5 hours and will be audio-recorded to allow it to be transcribed afterwards.

### **What are the benefits of taking part?**

The interview will give you space to discuss issues relating to disability benefits that worry you. You may find it interesting to talk about this, although it may not benefit you directly. Jessica will not be able to provide support about individual benefit concerns although she may be able to direct you to someone who can help you. The information we get from this study will help us to think about ways we can support people who receive benefits or who experience benefits changes in the future.

### **What are the possible disadvantages of taking part?**

There are no dangers involved in taking part, although it is possible that you could get upset when talking about something you find difficult related to your experience. If this occurs, you will be able to take a break at any time in the interview or decide not to continue with the interview. If you do find the interview upsetting, Jessica can provide information on people to provide you with support.

### **How will my taking part in this study be kept confidential?**

The recordings of the interviews will be kept on a password protected computer. Any papers will be stored in a locked filing cabinet. Only the researcher will have access to these. Following the study, the recordings will be deleted. All identifying information will be removed from transcripts to protect confidentiality. Anonymised transcripts will be viewed by the research supervisory team and examiners. Extracts will form part of public documents, including a research thesis and published papers in peer reviewed journals. All care will be taken to ensure that no one can be identified from such extracts.

If Jessica has any concerns about your safety or wellbeing or that of someone else following the interview, she will have a duty of care to respond to this. In this case she would discuss this with you.

### **What will happen to the results of the study?**

When the study is completed Jessica will write up the findings as an academic thesis that will be submitted as part of the requirements of her course. In addition, she will write up an article for publication in a journal.

These publications might use quotes from our interviews, but she will ensure the quotes will not identify you to ensure your privacy. If you say something during the interview that you do not want to be used, you can ask her to remove this from the transcript.

### **Who has reviewed this study?**

This study has been reviewed by The University of Hertfordshire Health and Human Sciences Ethics Committee with Delegated Authority. The approval protocol number is LMS/PGR/UH/02419.

### **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with the researcher by phone or by email. Alternatively you can contact the research supervisor, Lizette Nolte. Contact details are provided below.

Principal researcher  
Jessica Saffer  
Trainee Clinical Psychologist  
Tel: 07732 270 860  
Email: [j.saffer@herts.ac.uk](mailto:j.saffer@herts.ac.uk)

Research supervisor  
Dr Lizette Nolte  
Clinical Psychologist  
Tel: 01707 286322  
Email: [l.nolte@herts.ac.uk](mailto:l.nolte@herts.ac.uk)

**Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar.**

**Thank you very much for reading this information and giving consideration to taking part in this study.**

## **Appendix E: Consent form**

**Title of research:** The impact of a loss of disability benefits on people with physical health problems, on their sense of self and their perceptions of disability

I agree with the following statements (please tick if you agree):

- I confirm that I have read and understood the information sheet provided.
- I understand what my participation in the project involves. I have had any questions answered to my satisfaction.
- I understand I can withdraw at any time without giving reasons and that I will not be penalised for withdrawing nor will I be questioned on why I have withdrawn.
- I understand that I can decline to answer any questions that I am not comfortable with.
- I understand that any information obtained will be kept confidential, unless the researcher is concerned for my safety or the safety of somebody else. When such concerns are raised these will be discussed with me.
- I understand that the interviews will be recorded using audio recording equipment and that these recordings will be destroyed once the interviews have been transcribed.
- I agree that research data gathered for the study may be published and if this occurs precautions will be taken to protect my anonymity.
- Contact information has been provided should I wish to seek further information from the investigator at any time for purposes of clarification.

In addition, please consider the use of your data for future studies. This choice will not prevent you from being involved in this study.

- I am happy for my data to be kept securely to be used in future studies.

**Participant name:**

**Participant signature:**

**Date:**

**Researcher's name:**

**Researcher's signature:**

**Date:**

## Appendix F: Demographic information form

Name: \_\_\_\_\_

Gender:  Male  Female  Transgender  Other: \_\_\_\_\_

Date of birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_\_

Ethnicity:  White / White British  Mixed / multiple ethnic groups

Asian / Asian British  Black / African / Caribbean / Black British

Decline to answer  Other ethnic group: \_\_\_\_\_

Marital status:  Married  Widowed  Single  Other: \_\_\_\_\_

Employment status:  Employed full-time  Employed part-time  Unemployed

Benefits history: (please describe)

## **Appendix G: Debrief sheets**

### **Appendix G1: Debrief sheet**

Thank you for giving your time to take part in this research project. Hopefully this research will help us to think about ways we can support people who receive benefits or who experience benefits changes in the future.

The information that you have provided will be kept confidential and the recordings will be destroyed after the interviews have been transcribed and analysed. If you wish to withdraw your involvement in the research, you can do so at any time.

If you would like further support, please find below the details of some organisations that may be useful:

#### **Your GP**

Please consider contacting your GP if you are feeling low or anxious.

#### **Psychological therapies**

If you think that you may benefit from engaging in a talking therapy (such as cognitive behavioural therapy), then you may wish to consider self-referring to your local psychological therapies service, or asking your GP to refer you.

To find your nearest service, you can search on the NHS choices webpage:  
[http://www.nhs.uk/Service-Search/Psychological-therapies-\(IAPT\)/LocationSearch/10008](http://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008)

Please note this is not an emergency service – please attend A&E in an emergency.

#### **Samaritans**

This is a confidential helpline for anyone experiencing any emotional distress.

Freephone: 08457 90 90 90

Website: [www.samaritans.org](http://www.samaritans.org)

If you have any further questions or would be interested in being informed in the outcome of this study, please contact the researcher, Jessica Saffer, by email ([j.saffer@herts.ac.uk](mailto:j.saffer@herts.ac.uk)).

If you have any complaints about the study, please contact Lizette Nolte by email ([l.nolte@herts.ac.uk](mailto:l.nolte@herts.ac.uk)).

**Thank you again for your participation and support.**

## **Appendix G2: Debrief sheet – for charity**

Thank you for giving your time to take part in this research project. Hopefully this research will help us to think about ways we can support people who receive benefits or who experience benefits changes in the future.

The information that you have provided will be kept confidential and the recordings will be destroyed after the interviews have been transcribed and analysed. If you wish to withdraw your involvement in the research, you can do so at any time.

If participation in this research caused you any distress, please discuss this with a representative from **CHARITY NAME**.

Telephone: XXX

Email: XXX

If you would like further support, please find below the details of some organisations that may be useful:

### **Your GP**

Please consider contacting your GP if you are feeling low or anxious.

### **Psychological therapies**

If you think that you may benefit from engaging in a talking therapy (such as cognitive behavioural therapy), then you may wish to consider self-referring to your local psychological therapies service, or asking your GP to refer you.

To find your nearest service, you can search on the NHS choices webpage:

[http://www.nhs.uk/Service-Search/Psychological-therapies-\(IAPT\)/LocationSearch/10008](http://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008)

iCope provides this service for people in Camden and Islington.

Camden Referrals: 0203 317 6757

Islington Referrals: 0203 317 7252

### **Samaritans**

This is a confidential helpline for anyone experiencing any emotional distress.

Freephone: 08457 90 90 90

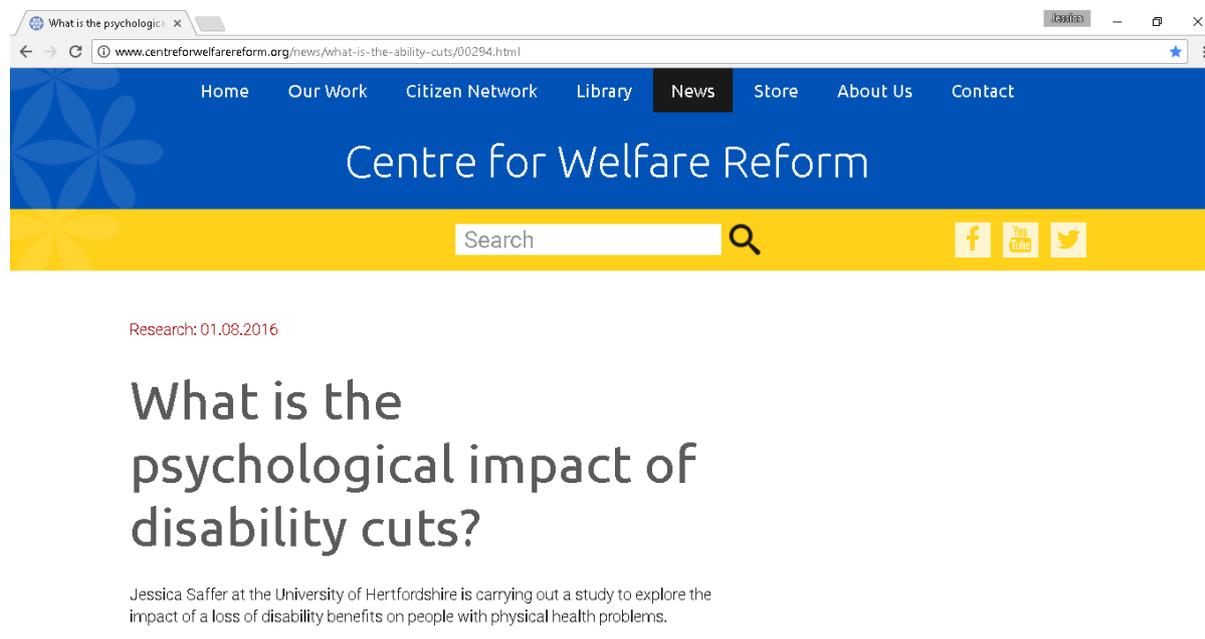
Website: [www.samaritans.org](http://www.samaritans.org)

If you have any further questions, or would be interested in being informed in the outcome of this study, then please contact the researcher, Jessica Saffer, by email ([j.saffer@herts.ac.uk](mailto:j.saffer@herts.ac.uk)).

If you have any complaints about the study, please contact Lizette Nolte by email ([l.nolte@herts.ac.uk](mailto:l.nolte@herts.ac.uk)).

**Thank you again for your participation and support.**

## Appendix H: Study information shared via social media



Full text:

### ***What is the psychological impact of disability cuts?***

Jessica Saffer at the University of Hertfordshire is carrying out a study to explore the impact of a loss of disability benefits on people with physical health problems.

This study will explore how losing money related to helping people with a physical disability affects people, including their daily functioning, sense of self and perceptions of disability.

### ***Are you willing to be interviewed?***

Jessica is looking for people who are willing to be interviewed about their experiences. She is looking for people who meet both the following criteria:

- You have lost a benefit, entitlement or allowance in the past few years, and may (or may not) have appealed this decision.
- You are aged over 18 years and have at least one life-limiting physical health condition, disability or impairment (and you may also have additional difficulties or mental health problems).

Ideally Jessica is looking for people who live in Hertfordshire or London in the first instance, but it may be possible to meet in other locations.

### ***What does the study involve?***

You will be given more information about the research and an opportunity to ask any questions before consenting to take part.

If you decide to be involved, we will arrange to meet at a convenient location. You will be asked a number of questions about your views and experiences of losing disability benefits. This will last between 45 minutes and one and half hours, and it will be audio-recorded to allow it to be transcribed afterwards.

You will not be provided with support about individual benefit concerns but the interviewer may be able to direct you to someone who can help. You are free to withdraw from the study at any time without giving a reason.

### ***What will happen to the findings?***

The data will be kept on a password protected computer. The data will be used to develop a model that could help organisations think about ways of supporting people who are going through this experience, and perhaps to encourage policy makers to structure the system differently so that negative consequences may be avoided. Extracts of the transcripts will form part of public documents, including a research thesis and published papers in peer reviewed journals. All identifying information will be removed from transcripts to protect confidentiality.

### ***Who can I contact?***

If you may be interested in being involved or would like further information, please contact the researcher Jessica Saffer by email on [j.saffer@herts.ac.uk](mailto:j.saffer@herts.ac.uk)

### ***Official details***

This study has been reviewed by *The University of Hertfordshire Health and Human Sciences Ethics Committee with Delegated Authority*. The approval protocol number is LMS/PGR/UH/02419.

## **Appendix I: Interview guide**

### **Initial questions**

Can you tell me a little about yourself and the disability you live with?

Prompts: I wonder whether there was a particular reason why you wanted to take part in this research?

When did you lose your disability benefits? Would you feel comfortable sharing with me how much less well-off you are now?

Prompts: Which benefits?

How has your life changed since a loss of disability benefits?

Considerations: practical / daily functioning / physical health, mental health/ mood, relationships with friends and family, ability to engage in local community, sense of self, ability to work/ study/ volunteer, socialising / hobbies

Prompts: Anything else? / Can you give an example of that?

Anything negative / anything good that has come from losing benefits?

Is this changing over time? Does it seem to get more difficult? Easier? Anything unexpected / surprising about impact of losing benefits?

How has losing your benefits changed how others feel about you?

Prompts: Friends, family, people who don't know you / society, media (TV, radio, social media) Can you give an example of that?

As we come to the end of the interview, is there anything you wanted me to know about your experiences of having a disability and losing your benefits that I did not ask you about? What key points do you want me to take from talking to you?

How did you experience taking part in this interview? Any questions?

### **Additional questions for people with visible disabilities:**

Give overview and ideas from model. Is that your experience or would you say that people with a visible disability feel any of this less? Does the model apply same amount to you?

People were talking about what it was like to lose a sense of themselves, or who they thought they were until they developed an illness or lost their benefits. Does this resonate with you?

Prompts: What it was like when could work, weren't ill, weren't fearful.

People spoke about how people with disabilities are perceived in the benefits system or society, e.g. 'scrounger'. Do you feel this less because you have a visible disability?

People have spoken about ways they try to live a good life – what kinds of things do you do to keep you going?

Prompts: E.g. Fight, seek support

## Appendix J: Examples of memo-ing

### E.g. 1 - Hierarchy of impairment

Participant C - "disabled people against other disabled people saying oh gosh well I'm more worthy than that one there" - even setting up disabled people against each other

Levels of disability:

Visible physical health - in a wheelchair, using a stick

Invisible physical health - fatigue, pain

Mental health - perhaps levels in severe e.g. psychosis vs depression /anxiety - not mentioned yet in interviews

Some people with visible physical health problems may be functioning well, albeit without use of legs or back, but perhaps not in pain or not in shock /low mood /anxiety about their condition. For example interview B had accepted her condition and was quite blazé about it, maybe because it was congenital and not acquired, which may involve a process of acceptance rather than acceptance from birth. In comparison to someone with an invisible disability (physical health or mental health), they may be (not necessarily) struggling less, in less physical or emotional pain, have fewer current challenges to deal with, such as treatment or ongoing pain. However someone in a wheelchair is iconically disabled, and everyone can see it- a person in a wheelchair is the international symbol for disability, even though most disabled people don't look like that. This means they may be given a space on a train - they take priority over a pushchair for example on a bus. Few people will doubt their disability. Conversely, they are disabled by society, in that they can't access some restaurants, some floors of museums / offices etc. This makes me ANGRY. No lifts in train stations makes me fume. So I sign petitions or I help people with their bag (*if they look frail*)...but I must be missing helping those who don't have a visible condition. They must be stuck at home because no-one will help them because it isn't obvious they need help. People who look unwell /distressed or speak to themselves in public will be seen as drunk or crazy, not as people to be spoken to (and this must be to some extent from experience, in case they are drunk and they lash out). But we do not know who has an invisible disability. For example, some days I may want a seat on the train because I feel exhausted or overwhelmed, I guess this could be seen as emotional pain, or on a scale of mental health need (if I extend my logic quite far!), but few people can see that (and people don't look that closely at each other!)...unless I cry...and then people offer tissues or a seat or ask if I am ok (perhaps because I am a white female).

Is this fair? Clearly not. Although I can't see what we can do aside from write 'feeling ill today' on our heads...which may not be helpful!

I understand it's harder to see someone's invisible illness so it's harder to judge how much support they need...which translates to disability assessments (although

doesn't explain the rude nature of the assessments or assessors, who are assuming that people lie or over exaggerate to get money). But how come people with different needs have different value or worth?

Feeds from: media, stigma, scapegoating disabled people, hate crime, power of government and workers including assessors, services being unable to help?  
Feeds into: low mood, anxiety, stress, internalising stigma on board?, feeling low worth, doubting validity of own illness, having no voice, and if decision for no money then feeds into everything to do with loss of money including leaning on family support, low mood, going out less  
Links to: not being heard

Not sure where mental health sits in the hierarchy ...sometimes this is seen as more valid than illnesses such as chronic fatigue, sometimes there's an attitude of pull yourself together or it's all in your mind. None of the participants doubted the validity of mental health issues, none were really embarrassed (but I'm a Psychologist so their answers may not represent how they present to others), and all were clear on mental health consequence of benefits loss and in most cases due to their illness too, for example when going out less due to mood, and in all cases (so far) mental health worsened illness in a vicious cycle.

Participant A - invisible, ongoing mental health  
Participant B - visible, resulting mental health  
Participant C - invisible in an office of visible disabilities, ongoing mental health  
Participant D - invisible, resulting mental health  
Participant E - invisible, resulting mental health  
Participant F - invisible physical health, resulting mental health (not worsened physical health although fatigue so interlinked)

### E.g. 2 - Climate of fear

Waiting for the hammer to fall

Anticipating future changes and feeling out of control

The fear of changes to one's own benefits prevents people from complaining about the disrespect they have received or are receiving. A fear of an almost omnipotent organisation which can take away your money and therefore your livelihood and even your life, even if you have little social or financial support. Ongoing uncertainty makes people worry (and feel low). Participant C was worried she would be forced to work additional hours, even though she feels too unwell, so this organisation does not take health into account when allocating people to benefit groups. Participant E was worried something would happen if the powers found out she had a cat!

Participant G: 'because of course we all know that work sets us free' - this sounds like Nazi propaganda...it stinks of concentration camps and disability cleansing, or

non-disability supremacy (although I'm not sure how many people would be left!).  
Links to government rationale.

### E.g. 3 – Seeking or relying on support

Seeking family, or peer, support has many aspects. People are grateful that they have family, friends or colleagues / charity members that they can rely on and receive support from. But there is another layer of wanting to be independent, of not wanting to rely on support. As well as being aware not everyone has family support (for example), many people who do have this excellent resource, feel guilt or shame at needing to rely on this support. They may feel like a burden. The family or friends may not understand the full extent of the issues and it may be tiresome to explain this to them (B).

Support can be divided into social-emotional and financial, which may relate to differing levels of guilt, although not always - as with interviewee A there was a huge amount of feeling like a burden for the levels of emotional support received, and embarrassment at needing this, particularly from one's children, and even I noticed there may be some shame at crying to one's sister.

With friends, peer support is tricky - how much can people be trusted with the full information about one's needs? How is best to balance telling people due to wanting to talk vs. not wanting them to bring the violin (C) or pity out, and without them thinking you are asking for financial support not just socialising or emotional support?

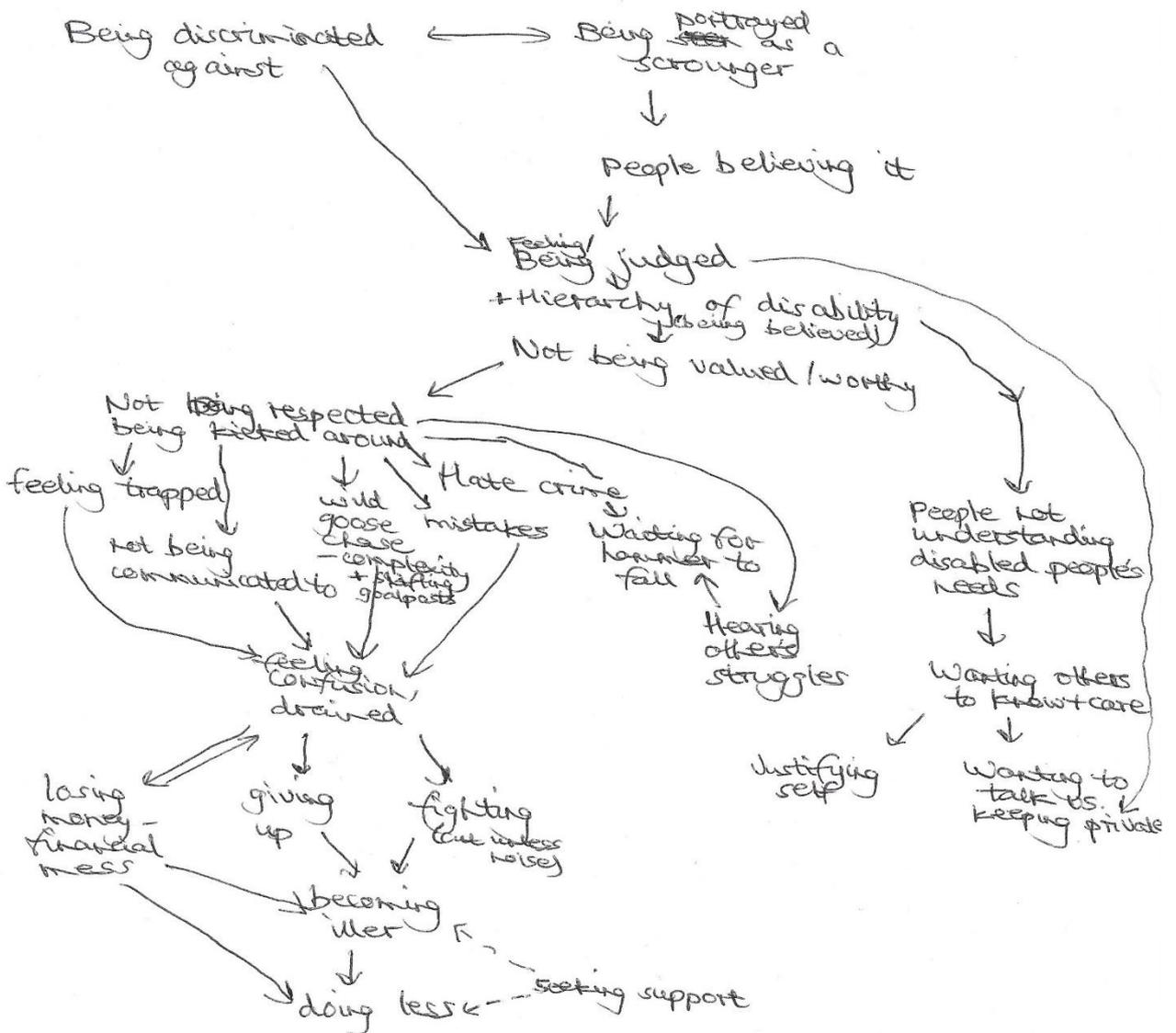
On the one hand, participants wanted people to understand, to know about their issues and to care, but on the other hand they were influenced by the stigma of claiming benefits, and were afraid or shy to tell people the full details of their experiences, perhaps because others may not have the context in which to understand and listen. They did not want to be judged by others, or for others, especially neighbours, to make comments on how disabled they actually were (F) as opposed to how they felt or their medical professional's assessment (can't rely on DWP assessment though!). Sometimes it was best to keep quiet (A), even from close friends or neighbours, even when one felt safe, because people might not want to know, might not believe them, or might later use this information to compare it to their own or family or friend's situation and might judge them for getting more family emotional support or more benefits than them.

This last section links to perceptions of disability, the questioning of how disabled someone actually is including hierarchy of disability, and also the stigma of being a benefit 'scrounger' (which links back to policy and media portrayal of benefit recipients).



Appendix K: Examples of diagramming

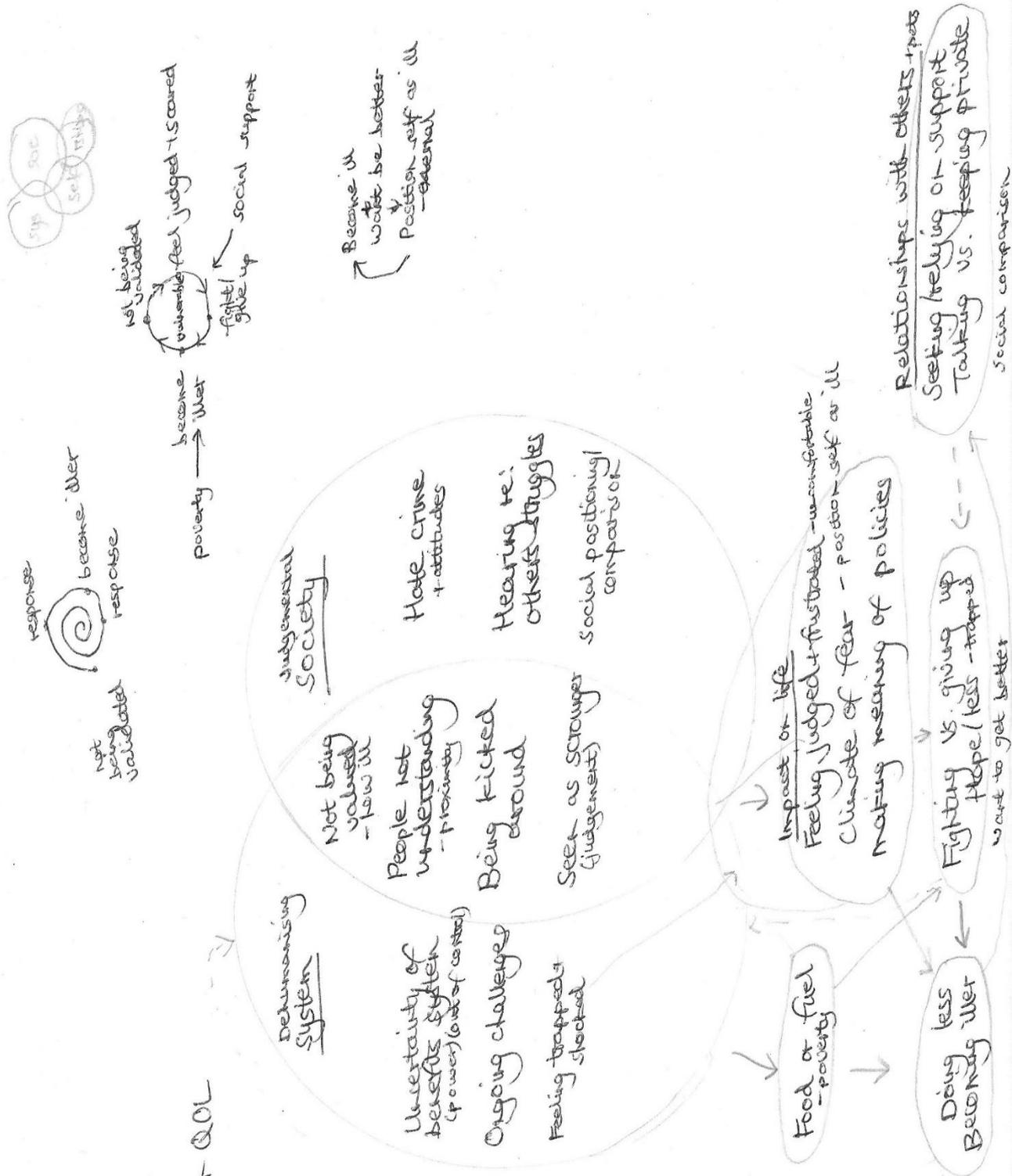
04/12/16



context - none of us choose to be disabled do we? want equal playing field  
 - cost of living raised

21/01/17

Context:  
Being ill  
Needing extra for QOL



## **Appendix L: Extracts from reflective diary**

31<sup>st</sup> August 2016

Reading paper re: reflective journal (Ortlipp, 2008 - Keeping and Using Reflective Journals in the Qualitative Research Process) – did I put too much of myself into interview? But how could I get participant trust to talk to me and be honest with me if they didn't know I was anti-austerity measures and the negative impact on people with disabilities? They might otherwise have thought I was on the side of the government and spying on their actual abilities! I wouldn't be doing the research if I wasn't trying to share the impact of the cuts with a wider population.

'The interviewer's thoughts, feelings, fears, and desires impact on the interview, but they are not visible in the data or the transcriptions' ....so I must share my reflective diary in thesis. So I should write it more often!

I'm wondering is it ok to share self in interview, as long as I'm transparent in my thesis about this? It might help interviewees be more at ease with me, and therefore more honest about difficult experiences ...

1<sup>st</sup> September 2016

Whilst out running I thought again why aren't we doing anything to help? Why are people carrying on with their lives (middle-class types) and not helping?

The GUILT is overwhelming, as I live my sheltered life, complaining about the building works at home, whilst some people have no homes, no food, and no escape by going out to dinner or to a hotel, or even a friend's house if they have no friends or family... I am so lucky.

11th October 2016

Have I done enough? I'm sure I haven't, yet it's not clear how to go forwards and what would be most helpful for people who are, and who will and who have been, suffering – at the whims of our government and its welfare state which is intended to safeguard those people. People have died because too few people cared, or were aware, or those people who cared had too little power to change the policies.

I have spoken to people (interview E) who have difficult, traumatic histories and who, despite the pain, have cared for their children, in some cases alone and with little support. How can these people deserve nothing? How can their honest requests for support (now, so late!) be ignored or batted away? For what? Who benefits from this? How can we help people who want to work back into work without patronising them (if I lost my job as a postgraduate academic, I wouldn't want CV support, I'd want tips on where the jobs are that would accommodate me!). And for those who

want flexible work, how can we guide employers and how can we make this economically sensible? For those who volunteer, how can we start to appreciate this as beneficial for the wider community? And for those who are simply unable to work, how can we change attitudes towards them?

Disability is proximal to everyone. It could happen to anyone, anytime. I don't like to imagine life with a chronic illness or pain condition, never mind something more severe. Being in a wheelchair with a back condition (for example) would mean I couldn't be independent, I couldn't get to my bedroom in my lovely new house and there'd be a bump down into the kitchen. I couldn't prepare food, I couldn't drive (without adjustments). My whole life would change. I pray that if this were to happen to me or anyone I know that they would be supported and have the funds to make adaptations to their homes and work or study environments. And I pray that friends would be supportive...forever...it's a big commitment. It's easy to see how friends might bring food for a few weeks if I was ill and then it slow down...I'd hate to rely on people. I'd want to do things that could do before myself. I'd need aids to do this.

People have their own stories. We should respect them for their efforts. And support them to be as strong as possible. Support them to have as healthy mental health or wellbeing as possible so that they can continue with their lives. Not intimidate them, allow them to drown in a culture of fear. Until, they, give, up.

25<sup>th</sup> November 2016

I acknowledge that:

a) I have never been on benefits, never been poor, never even lacked money for unnecessary items that I would like. I haven't even been hungry, except on a religious fast day.

b) I adamantly believe that poverty is not the fault of individuals, nor the responsibility of those individuals. I believe that it is the responsibility of those who have more than enough to provide the basics or the support to get the basics needs met for those who do not have enough to eat / shelter. I am influenced by my religious upbringing, my parenting, my education, including Clinical Psychology training, and I think also my humanity in this respect.

Therefore I can feel angry, I can feel furious but I will be highly unlikely to ever know what it is like to be in the position of someone with a severe physical health condition who has no money. I have savings and a supportive family who I would not feel too guilty to lean on, and hope they would lean on me in similar circumstances. I know that disability could affect anyone, and it does, but I will never have lived a life of poverty. I am also educated, have many educated, and even journalist, friends, and some familiarity with the benefits system, so I could fight any benefit cuts to myself and my family. However I'm not sure I would be able to do this if I was depressed,

and I appreciate that long-term frustration, anger and stuckness might lead to depression if I was in the participant's situations.

## **Appendix M: Extracts from reflections on data analysis**

### 28<sup>th</sup> October 2016 - Constructs or dichotomies

It feels like many of my sub-categories (or however you call them) are on a scale, where people are trying to balance their desires for one thing and manage their other impulses at the same time.

- For example, trying to do your best at life including going out as much as possible and doing as much as possible, but also showing yourself to be as ill as possible to get benefits. I've heard stories of assessments being a test, where if you can't get there you're damned and get no money but if you can get there then you're able and could be classified as fit for work. Often my interviewees / people in news articles have had to ask someone to assist them to get to assessments, which cannot be arranged at the last minute or would not be possible on a regular basis.
- Another idea is wanting to strive to do your best and being determined versus feeling very unwell or low.
- Dwelling versus striving or being proactive - is this due to personality, based on level of social support or how ill you are?
- Competing with other people for benefits so trying to prove self as worse off versus wanting to help others and recognising others deficits and feeling sorry for others. Links to visibility of disability and worthiness.
- Annoyed and fear of complaining about mistreatment. Power seems to be important here.
- Being patronised when you're an adult.
- Wanting to talk to friends & family versus not wanting pity ("getting violin out").
- Asking for help versus not wanting to ask for help (and not being helped).
- Professionals "on side as it were" versus forced to do their job and meet targets.

### 23<sup>rd</sup> December 2016 – Thoughts on categories

If I were to choose top categories / concepts now, after analysing 6 interviews and doing 6 more... I realise this may change, a lot, as I go forwards with my analysis.

- Being disrespected / kicked around by benefits system, waiting for hammer to fall, shifting goalposts, wild goose chase, climate of fear, media portrayal as a 'scrounger'. Anomaly – feeling grateful – link to comparison to others
- Stress or process, and fighting, causing further illness
- Public not knowing or understanding, fear of telling, hate crime - relational
- Guilty until proven innocent - disabled people not being valued, hierarchy of disability, leads to stigma of claiming benefits and keeping details private, feeling judged, justifying self, being discriminated against, internalising these societal values and questioning others

? Context – government who want to save money

Context: needing more money, support or resources to get same quality of life as non-disabled

## Appendix N: Analysis audit trail

### Appendix N1: nVivo Coding Examples

In nVivo, codes are named 'nodes'. Initial codes can be grouped underneath focused codes, as shown here. The sources column indicates how many data sources contain the code. The reference column indicates how many sets of data have been coded under the node. The plus sign next to a code indicates this code can be expanded to show where earlier initial codes have been grouped together.

#### Sub-category – Suffering from maltreatment

Nodes			
Name	Sources	References	
Being kicked around - disrespect	12	146	
Being discriminated against	3	9	
Being tortured	7	72	
Being wronged	8	25	
Not being believed	7	20	
Not being cared about	3	4	
Not being listened to	7	16	

#### Sub-category – Being overwhelmed by fear

Climate of fear - waiting for the hammer to fall	8	62	
Anticipating future changes	4	16	
Being affected by others experiences	4	13	
Fear others dobbing you in	1	3	
Feeling scared	6	26	
Not complaining	1	3	

**Appendix N2: Extract from interview B transcript with line-by-line coding**

Interview B

	Reflective comments	Interview	Line-by-line coding	Clustering
1		Interviewer: So can you tell me a little bit about yourself and the disability that you live with?		
2		Client B: Errrrr. In what way?		
3		I: Well I guess a bit about how your disability affects you.		
4		B: So well I have like what's called a 24/7 care package. Cos I need like high levels of personal assistance with pretty much everything really yeh.	getting care requiring support	
5		I: Mmm. And was there any reason you wanted to take part in the research?		
6		B: I can't remember now to be honest with you. I think did *Chris contact me initially?		
7		I: Yeh...		
8		B: Yeh it was about... cos I've had some interesting times with Access to Work in the last 18 months or so, so I think it was sort of about that.	more humour / downplay British increasing	
9		I: So he thought that you'd be interested in telling me?	experiencing difficulties with benefits	
10		B: Yeh.		
11		I: Is there any reason you might be interested in telling me?		
12		B: I think it's cos I think it's good for people to know about this kind of stuff is going on really yeh.	wanting to share experience	feeling invisible
13				
14				
15				
16				

existing vs. living - inherent ability to live fully  
 knowledge how may it reduce cuts? optimistic positive  
 if ppl knew the truth, there would be outrage - physical appearance  
 evocative

17			
18	Yeh. And why would you want people to know and what kind of people would you want to know?		
19	B: I would want as many people to know cos the problem is it tends to be only those that are immediately affected that know about it and therefore care whereas if other...if more people knew in general then quite possibly these cuts wouldn't take place in the first place.	wanting others to know (raising awareness)	
20	Yeh. So in order to prevent the cuts taking place more people would... what kinds of people would be helpful? I mean, if I were to publish anywhere, what would be helpful do you think?	wanting others to care	
21	B: Tory voters	preventing cuts - knowledge may reduce cuts	
22	Laughs. Tory voters		
23	B: Well, in a way, because I think they don't believe, you know they don't. Because they thought Cameron was helping disabled people and all the rest of it where as actually what he was doing was quite the opposite.	wanting to be believed	
24	Yeh. So as many people who vote as possible?	intending to help	
25	B: Yeh. To be honest it's not the right-on lefties that need to know, it's everybody else really. Yeh.	misunderstanding needs	
26	Hmm. The general population.	wanting others to know	
27	[Dictaphone issue!]		
28	Could you...would you be able to tell me a bit more about your disability?		
29			
30			
31			
32			
33			
34			
35			
36			
37			

38	B: It's a congenital thingy which means I'm very small (for people you can't see me on tape) and I've very restricted mobility and strength. Yeh.	congenital	
39	Do you mind telling me what it's called?	power - maintain her	
40	B: It's a latin-y thing. It probably won't mean anything to you.		
41	No, no, it probably won't mean anything to me. Ok.. so tell me... you said Access to Work benefits, tell me about that benefit.		
42	B: Well it's a ...Access to Work is a scheme that's there to support disabled people who are in work. So in the past I was able to apply for funding from them to...aid for support workers to assist me at work. So it's slightly different from my PAS who provide all my personal care. Support workers will do the more practical things needed whilst...cos I'm a <u>freelance writer and performer</u> . - <u>identity not as disabled person</u>	supporting people to work apply for help ownership	money!
43	Performer?		
44	B: So yeh so like when I've been in shows, in productions in the past, it's little things about being on hand to take notes if needed, or open doors, assist with costumes, all that kind of thing. And it's always been ok. And then about 18... well getting on for 2 years ago now actually, I applied. I had a, I was gonna be doing a performance of my own work as part of a festival. And I applied to Access to Work for funding for some support work hours. And they <u>turned me down</u> .	'little things' getting practical support feeling confident in receiving help in the past applying for ATW preparing for work rejecting support	
45	Ohh.		
46	B: Because they said I hadn't paid enough.. class NI 2 contribution.	not qualifying for support that outweighing enough?	
47	Ok.	previously no problem not eligible	
48	B: And previous to that it had never been a problem. But all of a sudden this new ruling came in. So all of a sudden I wasn't eligible.		

justapastion little things vs if only ppl knew they would be outraged

using others more readily to demand own rights  
community people who need support

60	So there was some kind of policy change.		
61	B: Yeh, there was and there wasn't because actually it was more that the workers didn't understand the change.		policy change not understanding policy change
62	Ok		
63	B: So they were giving out the wrong information. They were turning down people's claims when they shouldn't have been. They were misinterpreting the guidelines cos they were given enough guidance basically. So yeh.		receiving wrong info rejection claims misinterpreting guidelines workers not enough guidance
64	So did that mean you didn't have any support for that show?		
65	B: It meant I had to pay for it myself. And now they've re-investigated my eligibility for Access to Work. So I have actually been paid some compensation money and we are trying to get them to refund what I ended up paying out.		supporting self reinvestigating support / being compensated fighting for refund
66	Ok. So what the impact on that show?		
67	B: Well I did it cos there was no way... I mean this was the thing. I had enough resources to be able to pay for those support hours myself. But another individual in my situation might not have been able to do that and they would've lost that gig.		carrying on supporting self others couldn't support self
68	Sure. Yeh. And how did it feel..?		unfair system take power, quit?
69	B: Well I was just really shocked cos it didn't make any sense. Because it had never been a problem before. And it was like all of a sudden you know, shop was shut kind of thing. And I just got loads of confusing information as to why and what I needed to do and yeh.		feeling shocked feeling confused not knowing what to do
70	What was the conflicting information you were receiving?		
71			
72			
73			
74			
75			
76			
77			
78			
79			
80			
81			

memo - abrupt change  
shock, surprise, confusion conflicting information info  
lady trying to work  
drive - waiting people to know & hope for change vs. sadness / shock

### Appendix N3: Example codes about anticipating change

Name	Name	Coded Text
Anticipating a fight for funding	Interview B	But I know it's gonna be such a bloody fight.
Anticipating future casualties or real figures	Interview F	It's just to me, it's all, an awful lot has happened that has not even probably been revealed but I think it... it will eventually I can tell from what she was asking.
Anticipating future changes	Interview B	
Anticipating future changes	Interview B	but she rang me this morning asking certain questions and I know it's because they are going to challenge whether I need assistance but you know I know it I know it is. And that's not paranoia
Anticipating future changes	Interview B	Cos I know from other people's experience that that's what happens
Anticipating future changes	Interview B	In four years time we don't know you see.
Anticipating future changes	Interview B	So I don't end up an isolated individual at home revolving around 15 minute calls.
Anticipating future changes	Interview B	There's always something around the corner. Yeh.
Anticipating future changes	Interview B	Well because you're always waiting...it always feels like there's something hanging over you, like you're always waiting for the hammer to fall kind of thing cos you don't know what they're gonna cut next or how Well I am really worried that they'll just say you don't really need a PA at night.
Anticipating future changes	Interview B	well they do at the moment
Anticipating future changes	Interview C	So I don't know. That's why it's... cause I know quite a few people who've had to go and claim for PIP so I don't know whether that's why it seems to be taking longer with me. Nobody's bothered contacting me about Yeah, I'm really worried now because I'm thinking oh my goodness, they've cut that, are they gonna cut this now? You know.
Anticipating future changes	Interview C	And the other thing I forgot to mention was Damien Greene's Green Paper, which I believe is just a rehash of IDS's White Paper where he was going to set out how he was going to mitigate the ESA WRAG cut but resigned instead. For me it is yet more conscious cruelty especially as I think the policy has already been pretty much written by the Reform Think Tank. It's them that have pushed the idea of disability payments incentivising us to remain sick an disabled and the work as cure gumf. But if I was living in fear before I know I'm going to be terrified after.
Anticipating future changes	Interview G	I can't see anything other than all people being required to complete a distance from the jobs market assessment and then have 'agreed' plans of moving us all nearer to it. I think that there will be a flat rate JSA level

		<p>payment with top ups for jumping through hoops, we won't have to submit to 'counselling' starting with alcoholism and obesity as Cameron wanted instead we'll be made to 'agree' to CBT where the shift will be our psychological unwillingness to work because of course we all know that work sets us free....</p>
Anticipating future changes	Interview G	<p>So I suppose what I'm saying is the psychological impact of the cuts is not just about what has happened and is happening but what I feel will happen in the future and as far as my research has led me to believe it is only going to get much much worse and I expect it to have a detrimental affect physically, mentally and emotionally. I also expect that the government through the DWP will go for the low hanging fruit first i.e. the bad back and CFS malingerers brigade which is pretty much me.</p>
Anticipating not being believed	Interview E	<p>But yes they won't believe me.</p>
Anticipating not getting benefit	Interview B	<p>So that's it, isn't it, but if you don't, if you are just stuck at home, you know constantly worrying about whether your care package is gonna..</p>
Anticipating not getting benefit	Interview B	<p>That'd mean I'd have to be on my own at night. And I can't, this is it, when I'm in bed I can't sit myself up let alone get myself out of</p>
Anticipating not getting benefit	Interview E	<p>Because, well the appointment was in *A which is, how far away is that?, fifteen, there's an hourly bus service, it was pouring with rain and I still went there, and if I went there without any aids, no walking things, because I'm not going to do that until its time. But yes they won't believe me.</p>
Anticipating not getting benefit	Interview E	<p>Heh, well there's not a chance.</p>
Anticipating not getting benefit	Interview E	<p>To try, yes.</p>
Anticipating not getting benefit	Interview E	<p>Yes. I don't expect they'll give me any, but it's worth a try wasn't it?</p>
Anticipating not getting benefit	Interview H	<p>I think that at the moment I am a bit frightened but if I were to get poorly again you know who would look after me? Because as they cut my benefits so much, or even with it, I don't know that I could afford the help that I need. You do have, you do have to, these days you do have to buy any equipment that you want. It is not provided. So you need that money for that. I have had to pay out for a bed side, you know a rail to stop me falling out of bed, a leg lift, all sorts of different things. A stand that swings, all those sorts of things you have to buy yourself whereas you used to get help with it.</p>

Anticipating not getting benefit	Interview H	Interviewer: So did you have someone to help you dress before this change in benefit?  H: No because I was worried. When I knew that I'd got to apply for this PIP, I sort of put it on hold. (Int: ok). But last year certainly and this year, when I go out I have to just go out in bare feet. I don't mean bare feet so I have to put my shoes on but no socks.
Anticipating not meeting criteria	Interview B	But I very much doubt I'm going to score points on that medical list that they have.
Anticipating not meeting criteria	Interview B	they'll just say you don't really need a PA at night

Appendix N4: Example codes from interview D

## Interview D nodes

Name	Coded Text
a tightening up of benefits.	a tightening up of benefits.
a tightening up of benefits.	I had claimed it in 1997 and I was refused it but I went to appeal and when I went to the appeal the lady doctor was very nice, she understood what I was talking about and she actually took on board what I was talking about. And I won my appeal and I got it since 1997 to 2007. Then of course they were getting tougher on the benefits and when I went for...oh no I had to fill a form in. and I filled in just like I would've done before but this time I failed to get it. And I went to appeal and I failed in the appeal as well and that was, I just left it at that didn't I. I didn't agree too much about that one
Acknowledging socialising helps mood	But because of the depression coming on periodically er I wasn't actually trying very hard to get out there and be sociable. And so it's a kind of catch 22, you get stuck..
Acknowledging socialising helps mood	It's only recently I've started to try and push myself to go out and mix with people. It does help your mood but I find it very difficult to do that.
Acknowledging there are some fraudsters	I mean you do have folk pulling the system
Acknowledging there are some fraudsters	And there's only 0.7 percent of fraud in the system. But yet they would make you believe that's it's 99% fraud in the system.
Appeal not taking into account current circumstances	It should've been based on what is happening since that day I would've thought.
Appeal not taking into account current circumstances	when I went to the appeal in the February I wasn't to mention that, I was only mention how it was on the day. So I think that the appeal was a bit err one-sided.
Assessing doctor prioritising job over health	But they were trying to get me into something that would help me get into a job. That was how they were interested in, they weren't interested in my health.
Assessment being flawed	And the assessment is just a computer based yes / no answer and that doesn't cover fully ? conditions, you cannae get a full reading of it, how somebody's condition is by just asking yes or no. and you cannae answer anymore, you can't expand anything. They didn't listen to you.
Assessment being flawed	This doctor at the assessment kept, er the appeal, kept saying 'but you should've tried' kind of style, I should've tried that. And then there was talk about a wheelchair. You know I couldn't see the relevance of a wheelchair, I can walk, why would I want a wheelchair?
Assessment company being fraudulent	Er to me it's a fraudulent exercise. Err the company that came up with the assessment have been done for fraud in New Zealand, have been done for fraud in America yet our government choose to employ a bunch of fraudsters.
Assessment company being fraudulent	Well the company that the tory government employed was unum and if you ever want to look up about unum then you'll get a lot of bad reports on google. And they were associated with Atos. Now atos has been kicked out of doing the disability, they've been taken off the job of doing incapacity benefit assessments now because they were making so many mistakes.
Assessment company being fraudulent	Yes. Everybody knows it's a scam. Because everybody that goes get zero points. Nobody gets any points. And when you go to an appeal everybody seems to get six points. So it's just, it's just err playing games with the people that are hurting the most.
Assessment doctor not knowledgeable about condition	I mean even the doctor at the appeal, I mean to me he was... he was an orthopaedic doctor that should know what my condition was but he didn't seem to know what my condition was. The only thing that he could keep telling me was have I had a second opinion.
Assessment doctor not knowledgeable about condition	This doctor at the assessment kept, er the appeal, kept saying 'but you should've tried' kind of style, I should've tried that. And then there was talk about a wheelchair. You know I couldn't see the relevance of a wheelchair, I can walk, why would I want a wheelchair?
Assessment not being suitable	I mean even the doctor at the appeal, I mean to me he was... he was an orthopaedic doctor that should know what my condition was but he didn't seem to know what my condition was. The only thing that he could keep telling me was have I had a second opinion.

Responses of people with physical health conditions to changes in disability benefits

Name	Coded Text
Being recipient of rudeness	and when I went to the job centre the person there who I saw was really rude to me
Being recipient of rudeness	He just said, do you want to speak to my manager or not? And just said like.
Being recipient of rudeness	He was, he just threw a piece of paper at me and told me to sign this, sign this
Being recipient of rudeness	His patronising, condescending attitude towards people who don't have any money, they're not really well, and you've got to go and face that. You know, who wants to... What is this horrible way of treating people like this? You know, how dare they or he, or whoever, you know.
Being recipient of rudeness	You know speaking to me in that manner. You know I thought it was absolutely awful.
Being seen as a scrounger	she holds the perception that other people are scroungers.
Being seen as a scrounger	I think it is and that the way they are portrayed as not being genuine, you know, recipients of benefits
Being seen as a scrounger	You know, for everything in society all these cuts that are happening. It's like, you know, oh disabled people are scroungers. You know, they don't want to work
Being told what to do	"Never mind, what you have to do is just sign this now".
Being told what to do	And in there, it was just basically telling me what to do, you know.
Being told what to do	And then I was told to sign on for jobseekers allowance
Being told what to do	He was, he just threw a piece of paper at me and told me to sign this, sign this
Being unable to work more due to health	and I'm limited to what I can do
Being unable to work more due to health	because I can't work more than what I work at the moment due to my conditions.
Being unable to work more due to health	I can't do any more work than I'm doing at the moment
Being unable to work more due to health	I'm already doing eleven hours and that's all I can do at the moment.
Being unable to work more due to health	I'm doing eleven hours cos that's all I can do and erm so I didn't do it
Being unsure what others think	but I say that they've been supportive but I don't know because I don't know what they think, you know
Being validated	she said you're already working you know, you don't need to do that and if that's all you can do at the moment then that's fine
Being vilified	I think, I just can't believe how people are treated and just vilified because, you know, it's just awful and everyone's treated so badly.
Being vilified	and vilifying people for claiming benefits, and they, they quite often use the worst examples as well of people, you know
Being vilified	Oh you know like up north where they're all on disability benefits like someone came in and said that.
Being without money	Now just imagine if I didn't have this, little, you know this job. I'd just be without any money.
Being worse off than friends	They're all really comfortable. A lot of them have partners. They're all quite, they've got a good bit of money.
Benefit docked-stopped	and erm then eventually they said to me that erm it hasn't been awarded and
Benefit docked-stopped	and erm they just stopped my benefit.
Benefit docked-stopped	And then just got stopped.
Benefit docked-stopped	And then, when they make that decision to stop your benefit, I think they should give you notice and maybe they should give you two weeks money, say right after these two weeks, then it's going to be stopped.
Benefit docked-stopped	I've just, I just got the letter... so from I think they said the 8th of July that the benefit was cut and I just got a letter the other day. So was what that, about a month?

Responses of people with physical health conditions to changes in disability benefits

Name	Coded Text
Benefits being interdependent	Yeh so if you're receiving, well for me anyway, if you're not receiving that benefit then you know don't automatically get council tax or housing benefit
Carrying on	I literally said, right just leave it because...
Carrying on	But I'm just gonna leave it
Causing financial mess	So it kind of threw me into this financial mess
Causing financial mess	You know, so anyway, yeah, it was just all a big mess so I've ended up in debt and overdrawn and everything.
Change causing depression	cause my moods really gone really low down
Change causing depression	And it just kind of threw me into this depression
Changing therapy	And that's why, you know, about the CBT is now, instead of doing it to cope with my anxiety and panic disorder, it's about just my low mood and just feeling really overwhelmed with everything.
Changing therapy	And where I was working towards getting over my anxiety and panic disorder through CBT, I've now had to focus on more of a talking therapy
Charity losing funding	So they also do that. We used to do it but we no longer have any funding so...
Charity losing funding	Well it was a grant. It was lottery. But I think if that *I council gave us more funding we'd be able to provide that service, you know.
Chasing decision	But I wasn't, I had to kind of chase it up. So I didn't know what the decision was after the assessment and I kept on calling them
Checking eligibility for benefit	I said do you realise I've just come off ESA, that I have some health conditions and I do actually work at the moment. Just a few hours, what I can do so I'm wondering if it's worthwhile.
Checking eligibility for benefit	And because I work eleven hours erm I wanted to find out if I'd be entitled to jobseekers, if it was worth my while
Checking eligibility for benefit	but then when I said look I'm not too sure on the telephone about whether I'm entitled to it because I explained I was doing permitted work,
Checking eligibility for benefit	So I wanted to find out if I was actually entitled to one job seeker's allowance
Checking eligibility for benefit	You know and I said, well I'm not too sure whether I'm actually entitled to it.
climate of fear	I was really stressed out about that and I was just really worried. And I thought, oh no then they might just stop making my life more difficult and say oh yeah then you have to pay back that money because your son made a contribution towards housekeeping.
climate of fear	So, you know, they kind of hold you in this, like, fear, you know. So...
climate of fear	No it was just awful.
climate of fear	Yeah and I think as us disabled people, but we're kind of held in this climate of fear, so you don't complain, cos you just wana get your benefits back in place.
Comparing self to others	They're all really comfortable. A lot of them have partners. They're all quite, they've got a good bit of money.
Considering consequences of losing money	you think oh my gosh the way everything's going I could lose my home, or, you know
Considering if policy calculated	And I think that's what they rely on. That's the whole, you know, that's the object to this changeover, just to wipe loads of people off.
Considering if policy calculated	I know that sounds like a bit paranoid but it could possibly be.
Considering if policy calculated	Is it someone behind that saying well let's make all these awful programmes about people
Considering if policy calculated	Sometimes I think is it that measured?

Responses of people with physical health conditions to changes in disability benefits

Name	Coded Text
Proximity to disability	And a lot of the folk down south they're having quite a nice life. Everything's going hunky-dory, it's not until something happens to you, you realise that you need a welfare system to back you up. And if the welfare system is demolished like it's happening at the moment, everybody gonna be ?happnd by it.
Proximity to disability	And in fact some of the people that voted tory this time, there might be a time that comes when they suddenly become ill, and they'll find it then, that what they've voted for will come back and hit them
Proximity to disability	No, no. they just look at, other people that don't know anything about disabilities or benefits or anything,
Public believing media	And folk are starting to believe it.
Public believing media	And folk start, if you say something enough times, folk starts believing it.
Public believing media	And they're believing everything this lot tell them. They (?) can't be that wise.
Questioning staff ability	So I kind of fell out with the assessor because I asked her I says, you're a nurse, I says do you know anything about er depression? She says ' I'm a professional'. She just kept telling me that she was a professional but wouldn't answer the question. Well if she had any knowledge of err depression or no. Well that kinda got my back up so I started saying to her 'do you not read the things in the papers?'
Questioning the system	And what I can't understand is how the BME, British Medical Association, hasn't pulled these doctors and nurses that work for these organisations up. Because what they're actually doing is er they're failing their contract they sign, when they sign up as a doctor they sign up to put the patient first. But when they're working for the government and working for ATOS they're not putting the patient first, they're putting the government first and the patient comes last. And to me they're going against their oath. And they should be reported.
Rationale for policies	It's because the tories never did like the welfare system and because of the bank crash, it's. it was their excuse for bringing austerity in which was never needed in the first place. There's no need for austerity – most of the top economists in the world tell you that. It's just a way, just an excuse to get rid of the welfare state. The tories never liked it.
Receiving benefits advice	I mean I've been told to reclaim, to fill out a form, but I feel I don't want to do that
Receiving medical support	And ive been on the medication all the time (tearful).
Receiving medical support	He has been through a variety of painkillers through the years but now he deals with it himself and is not taking painkillers."
Receiving medical support	He was treated for depressive disorder in 2005. He still gets a bit stressed at times.
Receiving medical support	I saw another doctor and he changed me onto something else and I was much worse. And he said' you should never change your anti-depressants because once we find one that seems to work, you're better staying on the one, and no changing to anything else'. And although the one that I'm on sometimes doesn't help me very much, it's still better than changing to something else.
Reciprocal relationship health and mental state	A few weeks before, it must have been march I had a chest infection and er then all of a sudden I was feeling really depressed and I never slept for 3 weeks. The chest infection affected my mental state as well I think and er I never slept for, not even for 2 minutes.
Reciprocal relationship health and mental state	Well I suppose it's a combination of everything. I read about chronic pain and chronic pain can actually have an adverse effect on your, on your err mental state, and vice versa. The mental state can have an adverse effect on the chronic pain, so it's it kinda builds up. It's kinda like 2 things coming and hitting each other and it's building up.
Reflecting on Tory policy or rhetoric	And this is all the rhetoric of the Tory government, spreading myths and lies.
Reflecting on Tory policy or rhetoric	And when the Tories came to power they made it sound like the something for nothing crew.
Reflecting on Tory policy or rhetoric	because their Tory line since they came to power has basically been that.

Responses of people with physical health conditions to changes in disability benefits

Name	Coded Text
Taking medication	And I changed my anti-depressants but that was the wrong thing to do according to the doctor that put me on the original ones. I saw another doctor and he changed me onto something else and I was much worse. And he said 'you should never change your anti-depressants because once we find one that seems to work, you're better staying on the one, and no changing to anything else'. And although the one that I'm on sometimes doesn't help me very much, it's still better than changing to something else.
the majority of people are genuine	but very little compared to the amount of people that's on benefits.
the majority of people are genuine	the majority of people are genuine
the suns shining but all you see are dark clouds	and you cannae see any way out of it and it's kinda like being in a pit
the suns shining but all you see are dark clouds	the suns shining but all you see are dark clouds
the suns shining but all you see are dark clouds	You can see the sun shining up above but you cannae get up to have a proper look at it, you just feel stuck..
Ugh so angry	It was them that was doing it when I went through it. That's another thing that gets me, they were taken away off that job because they weren't doing it properly yet I'm still classed as fit for work.
Ugh so angry	So I was a bit angry when I started.
Ugh so angry	The reason I wanted to take part in the research was, it's kind of like getting it off my chest because I've been quite angry person since this has happened to me
Ugh so angry	Well that kinda got my back up
Use of language to spread rhetoric	About, somebody like George Osbourne who would say things like err we've got to stop this something for nothing brigade, the ones that wake up and see somebody next door with the curtains drawn, all this kind of language. This is the kind of lanaguge that's been spreading since they came to power in 2010.
Using humour	well that's a lot of folk in Scotland, well there's not really a lot of folk in Scotland (humour)
Want return to old system	Oh I dunno. Well er you haven't asked me if I thought, I suppose you know by now I don't think it's fair, but you haven't asked me er do I think that the assessment and other these policies should be reversed?
Want return to old system	unless they change the system and do away with the assessments already and go back to the other system where your doctor had the authority over you. Your doctor knows you best, not some government department that has no idea what illness you've got or how it affects you or anything.
Wanting to be happy	And I knew it would take a long, I mean I wanted to be instantly happy again. But I knew that wasn't going to be possible
Wanting to fight back	It's still carrying on. It's not just for myself, it's for everybody out there that err is in the same position.
Wanting to fight back	because how do you fight back against, how can you fight back when nobody listens, takes any notice of you?
Wanting to fight back	Well I wanted...I would like to have fought it in the courts but I don't have the money to do it.
Wanting to get rid of welfare state	It's because the Tories never did like the welfare system and because of the bank crash, it's. it was their excuse for bringing austerity in which was never needed in the first place. There's no need for austerity – most of the top economists in the world tell you that. It's just a way, just an excuse to get rid of the welfare state. The Tories never liked it.
Wanting to support others	It's not just for myself, it's for everybody out there that err is in the same position.
Welfare system being demolished	welfare system is demolished like it's happening at the moment
well I'd get a second opinion but then whose opinion do I believe? Do I believe the first man's opinion or the second man's opinion? you know people go under	well I'd get a second opinion but then whose opinion do I believe? Do I believe the first man's opinion or the second man's opinion? and er it was as if I couldn't live another day feeling the way I did. That's what was going through my head at that time (tearful).