“An exploration into the lived experiences of those in receipt of disability benefits”

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An exploration into the lived experiences of those in receipt of disability benefits

DECLARATION
This work is being submitted in partial fulfilment of the requirements for the degree of BSc (Hons) Health and Social Care and has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed: xxxxxx (Candidate)

Date: 03/05/2017

STATEMENT 1
This dissertation is the result of my own work and investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).
Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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Acknowledgments

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Abstract

On average, there are currently 11 million people with a disability in the UK (Gov, 2016). This led to the exploration of individuals' experiences in relation to disability benefits. The current research that is out there that explores this topic is merely focused on disability rather than benefits or if it does relate to benefits the studies are mainly quantitative and do not focus on feelings and perceptions. The lack of research within this area created the ground for this qualitative study to explore the lived experiences of individuals in receipt of disability benefits. This is a phenomenological study, drawing on people’s lived experiences. The study will be inductive which means it will allow the information collected to lead the direction of the study. Participants in this study were recruited through ‘Organisation A’. Data was collected through semi-structured interviews and a thematic analysis was used to extract themes from the data. The study found that participants experienced two levels of stigma; including stigma in relation to their disability and stigma in relation to claiming benefits. Participants felt that media enforced this type of stigma and wanted the media to show true portrays of the hardship they experience on a daily basis. Participants also felt that that the assessment process was daunting, however, were all grateful for the benefits system and would not be able to live without it.
Introduction

The main aim of this study is to explore the lived experiences of those in receipt of disability benefits including those with physical disabilities, learning disabilities and poor mental health. This study hopes to achieve insights into the understanding of a lived experience as a phenomenon. This qualitative study also wishes to explore participant’s experiences through gathering thoughts and feelings. Quite often disabled people have a hidden identity or become a statistic, therefore, this study proposes to let participants discuss their experiences.

The researcher is a volunteer in an organisation and works with disabled people who are claiming disability benefits and was intrigued to explore the lived experiences. The researcher was aware of the mass of media around disability benefits which led to the creation of this phenomenological study. As a result, this study hopes to gauge feeling, experiences and meaning around being in receipt of disability benefit and how it impacts on an individual's lived experiences.

A qualitative approach was chosen for this study as it was found through analysing literature that much of the literature around this topic is quantitative or is merely based on a person’s disability and does not focus on the benefits participants receive.

It is important that definitions and some background on benefits are discussed before the literature is analysed.

Definition of disability

Under the Equality Act (2010) a disabled person is defined as someone who has a physical disability or mental condition that has a significant and long-term negative effect on a person’s ability to carry out normal activities.

However, WHO (2017) suggests that disabilities are broader than this and believes disability is not just a health problem, it’s a multifaceted phenomenon, reflecting the communication between a person’s body and the society of which the person lives.
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Scope (2015) estimates that there are 12.9 million disabled people in the UK. Seven percent of children are disabled, seventeen percent of working age adults are disabled and forty-five percent of pension age adults are disabled.

Currently, there are three main types of disability benefits in the UK. These include Personal Independence Payment (PIP) (replaced Disability Living Allowance DLA), Employment Support Allowance (ESA) and Attendance Allowance (AA) (Gov, 2017).

**Disability Living Allowance**
PIP is gradually replacing DLA for people aged 16 to 64 with long-term ill health or a disability. There are two components to this benefit; the care component – low, middle and high. There is also a mobility component – low and high (Gov, 2017).

**Personal Independent Payment**
PIP is a tax-free benefit for people aged 16 to 64 to help with the extra costs caused by long-term ill-health or a disability. PIP is used to support individuals with day to day activities and to receive support to get around. There is a daily living component and a mobility component for this benefit (Gov, 2017).

**Attendance Allowance**
AA is a tax-free benefit for people aged 65 or over who have a disability and need someone to help look after them. There is a lower rate for supervision at day or night and a higher rate which is supervision day and night or terminally ill (Gov, 2017). The application method for this benefit is a form.

**Employment Support Allowance**
ESA is for people who cannot work because of illness or disability.

To claim these benefits an application form needs to be filled in, unless claimants have a terminal illness they will have to attend a medical assessment. If claimants are not happy with the results of their claim they can ask to attend a tribunal to explain how their illness affects them (Benefits and Work, 2015).

**Change from DLA to PIP**
DLA was established in 1992 for children and adults who need help with care and mobility, it was difficult to claim and was not a way to see if claims remained correct as
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individual circumstances changed (Gov, 2014). In 2013, proposed changes were made for PIP to replace DLA for people ages 16 – 64 (Beatty and Fothergill, 2013).

PIP is built on how a person’s condition affects their life, not the condition they have. It was created to be a more maintainable benefit than DLA, making sure provision continues to spread those who confront the highest challenges in participation of everyday life (Sainsbury and Corden, 2014).

This study will now review the literature on the research topic to allow the reader to comprehend the reason behind this study.
Literature Review

The review of the literature will start by defining and outlining key concepts around the topic area and will then move on to reviewing reoccurring themes within relevant literature.

This study is an exploration of the lived experiences of those in receipt of disability benefits. Therefore, it is important to define some of the concepts that contribute to the research question.

Morris (2016) defined a lived experience as a first-hand account and understanding of an individual’s feelings when they have lived through something. An experience orientates a person’s self-conception around which an individual life organises itself. Marshall and Rossman (2014) believes through ‘lived experiences’ the meaning of a particular history unfolds. This phenomenological research study attempts to understand people’s perceptions, understandings and perspectives of a particular situation (Creswell, 2014).

The benefits system is complex and forever changing (Ham et al., 2012). This study hopes to explore the experiences of those in receipt of disability benefits, it was decided that the study would focus on the three main disability benefits including PIP, DLA and ESA as there are several disability benefits and often a claimant is receiving more than one.

Stigma

The main theme identified throughout the literature was stigma. The word ‘stigma’ originates from the Greek word that in its roots referred to a mark that was cut or burned into the skin. It identified people as criminals, slaves or traitors to be shunned (Heatherton, 2003). Recently, stigma has been defined as a feeling of disapproval that people in society feel about something (Green, 2009). Stigma concerns attitudes and beliefs that lead people to reject, avoid or fear those they perceive as being different (Goffman, 1968).
While stigma is an attitude or belief, discrimination is a behaviour put into action on the basis because those attitudes and beliefs exist. Discrimination occurs when people put their beliefs into action and deprive others of their rights and life opportunities (Thornicroft, 2006).

Examining research articles around disability benefits and experiences, many have identified stigma as the main theme (Garwaithe et al., 2015; Scope, 2012; Turn2Us, 2012). Disabled people continue to face challenges on a day to day basis in every aspect of life, one of them being stigma and the perceptions of others especially in relation to benefits.

In relation to ‘an exploration into the lived experience of those in receipt of disability benefits’ stigma can be categorised as a ‘lived experience’ as it is often something that people on benefits experience due to individual circumstances. However, stigma can be considered complex as individual’s experience stigma relating to their disability as an individual as well as being a disability benefits claimant (Scior and Werner, 2016).

Examining why claiming benefits may be stigmatised, the widespread opinion (Schlesinger, 2006; Spicker, 2011) is that stigma is embedded in standards of reciprocity. Spicker (2011) believes that individuals who fail to repay ‘contributions’ experience social punishments and to a degree benefits are observed as gifts, therefore can be viewed as stigmatising as this group of people are not seen to be ‘giving back’ to society.

Although, Brakel (2006) believes the degree of stigma depends on whether claimants are perceived as ‘deserving’. Oorschot (2000) states that people make deservingness opinions based on claimants’ level of need, claimants who are ‘undeserving’ have a diminished social identity.

Major and O’Brien (2005) argue that stigma may not result in shame when individuals associate intensely with their identity, for example, if individuals regard themselves a deserving claimant and that the stigma relates to undeserving others. This view is recognised in both America (Seccombe et al, 1998) and the UK, as claimants frequently consider themselves as deserving whilst criticising others for ‘scrounging’ (Garthwaite, 2015; Chase and Walker, 2013).
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Stigma can have an intense impact on the ability to maintain the functional capacity to accept the illness or disability. Stigma not only affects self-concept and self-esteem, but it also creates barriers that forbid individuals from reaching their full potential (Goffman 2009). This views disability in light of the social model which suggests disability is caused by the organisation of society and addresses ways of removing barriers that limit the lives of disabled people. Whereas the medical model believes disability is a result of a condition that may reduce the individual’s quality of life. (Davis, 2006).

According to Burke (2008) some additional effects of stigma that disability claimants can experience is that it damages social relationships and social participation as people are ashamed to tell others about their illness and claim disability benefits. This existing stigma can also reduce self-esteem and dignity and due to the lack of control can influence how services are delivered (Albrecht et al., 2001).

Jones (2013) identified three types of stigma personal, social and institutional. Stigma is a feeling held by an individual that claiming benefits is shameful; this can be experienced by claimants and non-claimants. Social stigma is a perception that other people judge benefit claimants (Goffman, 2009). Institutional stigma arises through the process of claiming benefits. Spicker (2011) explains the complex interactions between the three types of stigma. For example, an individual believes that claiming benefits is shameful (personal stigma), they are more likely to expect stigmatising behaviour from staff (institutional stigma). Even if an individual does not personally believe claiming benefits is shameful, the perception that others see it as shameful can be distressing (social stigma) (Scambler, 2009).

The prevalence of institutional stigma is backed up by Finn et al. (2008) who states institutional stigma, particularly at the point of access of claimants is so high due to the lack of privacy. Whether this is being overheard due to lack of privacy in jobcentres or feeling looked down on by benefit staff. Particularly when staff are suspicious about a recipient’s entitlement reinforcing stigma. This could be perceived as surprising as it is a place where society would not expect stigma to exist. Scope’s (2012) large survey of 2,045 people asked disabled people whose attitudes would they like to see change. Nearly half identified the local authority, government staff and health and social care...
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staff as a group where they would like to see attitudes change for the better and to have more empathy and understanding. Social Research (2011) believe this is linked to the idea that the ‘system’ was designed to put people off applying for benefits. However, Morris (2011) argues that the government’s replacement of DLA to PIP was designed to support disabled people.

Jones (2013) put forward that social stigma is the worst type of stigma of the three as it has the biggest effect on how people feel about claiming benefits due to the discrimination of others. Grewal et al. (2002) found that an individual with visible disabilities may experience being patronised, avoided or ignored because of their appearance as a ‘disabled person’. In contrast, Shaw (2012) felt that non-visible disabilities such as poor mental health are more difficult to live with as people cannot see it, therefore not take into account the impairment. In spite of this Nolan et al. (2006) believes people with ‘hidden’ disability could choose whether they want to reveal their disability, as a consequence could face less stigma and are less likely to be patronised by others (Corrigan and Watson, 2012).

This stigma can have a huge influence on an individual’s life experiences (Hannon, 2006). Stigma can leave people marginalised and excluded from their own community. Mckeever (2006) believes stigma can cause individuals with poor mental health to be discriminated against and may even contribute to refusing to pursue help for their disorders which prevents them from getting essential treatments (Corrigan and Gelb 2006). Nolan et al. (2006) believes stigma causes label avoidance and makes it problematic to pursue employment or access services, resulting in low self-esteem.

A number of studies (Disability Rights 2016; Green 2009) have shown that existing stigma can lead to numerous experiences thought to be as a result of an individual’s disability. Scope (2012) used a MORI survey to collect the experiences disabled people had of other people’s attitudes or a behaviour. In extreme cases, some individuals have experienced violent behaviour as a result of stigma. Four percent of participants said they had experienced a physical attack in the previous year and one in six had experienced hostile and forceful behaviour as well as name calling. This is backed up by Grewal et al. (2002) who interviewed 150 disabled people and found that
seventeen percent had experienced subtle jokes about their behaviour, being called names, as well as violence and bullying.

**Media**

Grewal et al. (2002) believe the media has a key role in providing visual and verbal messages informing the public about disability and that this is often negative or stereotypical. A recurrent resurgence of interest is the perception that benefits have become progressively stigmatised due to a media and political discourse of ‘scrounging’ (Baumberg et al., 2012). UK charities have disputed this and argue that this description of benefit scroungers risks stigmatising everyone who has a disability. Claimants have stated that this discourse enforces feelings of stigma (Taylor-Gooby, 2013).

Patrick (2011) believes that the 21st century views disabled people as a part of the ‘scroungerphobia’ problem, with the discourse around ‘disability frauds’ urging the perception that many benefit claimants are selecting a lifestyle on benefits when they could be in paid employment (Piggott and Grover, 2009). A drip feed of negative media stories, uncertain government speeches and an emphasis on the need to get disabled people back into work (Patrick, 2011). These changes signify a move in treatment and classification of disabled individuals, with the history of disabled individuals being regarded as a group who have entitlement to state help.

Multiple studies (McEnhill and Byrne 2014; Scope 2015; Turn2Us 2012) have shown individuals are put off applying for benefits because of the perceived stigma generated by false media representations of “scroungers”. This could imply that many people have been going without money they deserve, depriving them of essentials due to the media’s representation of benefit claimant. Briant et al. (2011) state that the media is creating bad life experiences for those in receipt of disability benefit.

McEnhill and Bryne (2014) also aimed to explore the media in more depth through examining The Sun Newspaper and its articles regarding disability benefit. 85% of articles that discussed disability benefit fraud and dishonesty. Throughout this research, The Sun was seen to characterise disabled welfare claimants as ‘shameful scroungers’. Nevertheless, this study only looked at The Sun Newspaper, different
papers have different values and do not all discuss the same things. Therefore, this study cannot represent media as a whole (Baillie, 2011). Furthermore, there are fears that hardening attitudes perceived from the media have translated into an increase in verbal and even physical attacks on claimants (Turn2Us, 2012). Six charities issued warnings about an increase in resentment and abuse directed at disabled people, as they find themselves being labelled as scroungers (Disability Rights, 2016).

Ross (2011) suggests that television lacks positive images of disabled people and the limited visibility of disabled people contributes to prejudicial attitudes. Grewel et al. (2011) found that disabled characters are included in television programs the character’s disability is the focus rather than have an overall picture of their life. This could be seen as reinforcing the image that disabled people are ‘different’.

Scope (2012) believes that media could be more positive by showing the real lives of people in the media, greater discussions about the issues faced by disabled people and more disabled politicians. However, Hodges et al. (2012) found 53% of 2900 survey respondent said their views had been changed positively by the Olympic games. Although, Wilde (2004) believes that media around the Olympics is not enough as it is only every four years whereas ‘fraud’ media occurs more regularly.

**Application Process**

One of the lived experiences that all benefit claimants would have experienced is the application process which was identified in the majority of the literature found.

Some people may feel relief from finally receiving benefits if they have been suffering or struggling to live (Garthwaite, 2015). However, the application process can be very stressful and difficult adding to the existing disability or illness (Vash and Crewe, 2003).

The application process consists of application forms and medical assessments. Assessment is defined as the act of making a judgement about something or someone (Nardy and Petr, 2002).

Forms are meant to be completed by the person with the disability, however, there is an option for someone to fill in the form on the individual’s behalf including an advocate or family member (Gillespie and Moore, 2015). Arguably, the procedure of
filling in a disability benefit forms requires a technique of self-examination, or even confession (Townley, 2006). Filling in forms involves adopting the criteria and language of the form, and then expressing themselves in terms of that criteria. Claimants reported that DLA application forms are time-consuming and stigmatising (Pudney et al., 2004).

Banks and Lawrence (2005) used questionnaires to explore the experiences of 606 disabled people applying for DLA. Findings from this study found that 97% of participants stated they found the forms challenging, underlining that nearly all the participants struggled to emphasise the difficulty in the experience of applying for benefits.

One respondent stated; “I couldn’t fit my difficulties into a number of times a day, it doesn’t work like that”. This indicates that respondents may find it hard to make their personal situation ‘fit’ the questions, especially individuals with poor mental health or learning difficulties. This could suggest that the forms are more geared towards people with physical difficulties and may not always be suitable for people with poor mental health (Butters et al., 2010).

This is reiterated by Mind (2015) who found that 50% of participants in their survey felt like they were not able to communicate their poor mental health on the form. Individuals were not able to put down the way in which their mental illness impacted their life due to its over-complexity and need to decipher how the descriptors apply to the individual’s mental illness (Callanan, 2011).

However, Gillespie and Moore (2015) argue that individuals with physical disabilities also struggle to explain their disability due to the ambiguity of the questions. Gillespie and Moore (2015) carried out twenty-one interviews with PIP recipients and found one of the questions on the form reads; “Do you fall or stumble as a result of your illness or disability?” One participant in this study said, “I can’t answer that because I stumble all the time but I don’t fall.” This emphasises the difficulty claimants have in describing the effects of their disability in regards to the questions (Oort et al., 2011).

The process of applying for benefits can be worrying for applicants. Salway et al (2007) interviewed 57 adults who reported a long-term health condition and described the
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process of applying for disability benefits complex, stressful and time-consuming; in some cases, referring to the system as a factor of deteriorating the significance of their health condition.

Shefer et al. (2016) also studied the stress involved in being trapped in the cycle of assessment, rejections and appeals being an important lived experience of 20 claimants through face-to-face interviews. This study found that questions were misleading and participants found difficulties putting their disability into words. This highlights that claimants find answering the questions particularly challenging and the need for support to help claimants fill in the forms.

As stated earlier to receive disability benefit the claimants may need to attend a medical assessment. Barr et al. (2015) describe the assessment as an experience in individuals lives which can be daunting. Some participants in the study were offended by the messages suggested by the rejection of their claim as if they were not being truthful. Connected to this was the annoyance felt by other participants, who found it difficult to prove why they were incapable of working because their disability was not physical. This has links to a concept known as ‘invisible disabilities’ which refers to symptoms such as brain injuries, mental health disorders and visual impairments. These are not apparent to the onlooker but can control daily activities varying from individual (Invisible Disabilities Association, 2016). The assessment process can be difficult, as some disabilities are not physical and therefore not always visible and as a result hard to assess.

Shefer et al. (2016) interviewed 25 Mind service users. Some participants felt as though they should try to appear more like the negative stereotype of someone with poor mental health in regards of self-presentation to assure the committee that their case was real. Highlighting that participants felt like they had to play a ‘role’ in order to get a benefit they are entitled to (Barr, 2015).

This has a potential to link to Talcot Parson’s (1951) sick role. Parson (1951) identified three different types of sick roles, unconditionally legitimate sick role is the most relevant here as it the study participants is suffering from illnesses that they cannot do anything to get well, such as schizophrenia, bi-polar or paranoia. Therefore, society
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allows them to occupy the sick role. This relates the participants in the study playing the ‘role’ as they are suffering from an illness which that cannot control and considering to play ‘the part’ to receive the benefit.

This is echoed by Copestake et al. (2014) who found that the assessment process was often insensitive and made claimants feel like they had to ‘prove’ they have an illness again relating to engaging in the ‘sick role’.

Being reassessed for benefits can be stressful having to re-live the nerve-racking experience over again. In 2010 many people were reassessed when moving from DLA to PIP. Barr et al’s (2015) study explored the implications of this move and discovered that local areas where a larger amount of the population were subjected to reassessment experienced a greater rise in three adverse mental health outcomes – suicides, self-reported mental health problems and antidepressant prescribing. Davies (2014) argues that the increase in mental health outcomes are due to the anxiety of money loss or having to go through the whole assessment again, for some reliving the onset of their disability. However, the relationship between reassessment and adverse mental health outcomes in the analysis may be due to unseen factors for example substance abuse. Also, the reassessment procedure was directed in more deprived areas. Mental Health Foundation (2010) stated that poor mental health is more common in areas of deprivation and poor mental health is linked to unemployment, less education and poor living standards. Therefore, it could be said that this study is biased as it focused on deprived areas, it would have been beneficial if it focused on non-deprived areas (Maxwell, 2005).
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**Methodology**

This section will discuss the methodologies used in this dissertation, the sample, the data collection process, the data analysis and also explore the ethical considerations within this research project.

**Methods**

Rugg and Petre (2006) suggest that there are two types of research; primary and secondary. Primary research is research carried out to address specific issues or to explore an identified phenomenon. Primary data collection can include questionnaires and interviews and is collected by the investigator conducting the research (Robson 2002). In contrast, secondary research makes use of information previously researched for other purposes or in the public domain – it could include a study of legislation or newspaper reports. This is known as ‘desktop research’ or a ‘systematic review’ (Gray 2009). A primary data collection method was employed in this study as the researcher used interviews to gather data, due to the limited literature around the specific area of disability benefit and experiences.

This dissertation study is a qualitative research study, Denscombe (2014) states that qualitative research is often undertaken with a smaller sample size with more in-depth or descriptive answers to analyse feelings and emotions as opposed to statistics (quantitative). Qualitative research is used to gain an understanding of lived experiences, opinions and motivations with no hypothesis or question to prove or disprove. It provides insights into a problem or observation and can be used to uncover trends in thoughts and opinions and delve deeper into the chosen phenomenon (Tim, 2011).

Cargan (2007) states that qualitative studies are often inductive, drawing good generalised conclusions from a necessarily limited number of observations. This
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dissertation has taken an inductive approach as its findings will be driven by the data and will explore experiences and feelings.

Paley (2016) states that phenomenology seeks to understand the response of a human being, its aim is to describe or make sense of an individual’s lived experience. This dissertation engages a phenomenological approach to explore, describe and analyse the meaning of an individual’s lived experience: how they perceive it, describe it, feel about it and describe it to others (Marshall and Rossman, 2014).

Crotty (1998) states that interpretivism looks at facts as well as values and how the social world is constructed through meanings. The epistemological approach in this study is interpretivism, as the study focuses on the details of the perceptions behind the scenes of experiences of individuals claiming disability benefit.

Sample

Bryman (2012) states that a sample is a part of a given population, from which data can be collected. Sampling is a technique used to select a portion of the population of interest so that by studying the sample we may generalise our results back to the population from which they were chosen (Trochim, 2008). The sample population used in this study were recruited from Organisation A, service users and volunteers were recruited for this study, most of the volunteers were previously service users and continue to receive disability benefit. However, Dawson (2009) states that it needs to be acknowledged that as a small qualitative sample, it is not possible to generalise as the data cannot make statements about the wider populations, it just provides insights.

When sampling each participant’s wellbeing is vital, sampling must be undertaken sensitively and cautiously (Sydor, 2013). The sample used in this study may be considered as a hard to reach population. Researching into ‘hidden’ or ‘hard to reach’ population focuses on a researching into sensitive subjects. (Bryman, 2008).
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As this topic could be considered as ‘sensitive’ non-probability sampling was used to recruit participants. Non-probability samples are selected without the use of random selection and are based on characteristics and objective of the study (Stommel and Wills, 2004). The characteristics needed for this study were people on disability benefits and volunteer’s/service users of Organisation A. Before recruitment, the method of sampling was thoroughly considered. It was decided that the participants could be recruited through Organisation A who made contact with potential participants and allowed them to decide if they wanted to participate so they did not feel obliged by the researcher approaching them. It is acknowledged that there can be some problems when recruiting from an organisation. Elmir et al (2011) believe that organisations often want to take very active participation in the analysis and discussion which could influence results. According to Ezzy (2013) organisations have been perceived by students as lacking trust in their abilities or as possibly jeopardising the results. Students have concerns about the agencies understanding of the universities ethical procedures that students are expected to follow. In relation to this study, the organisation was made fully aware of the aims and objectives of the research. They were given an information sheet to read and had an opportunity to ask any questions.

Purposive sampling was used in this study as the sample was chosen for the research. Participants were selected with a specific purpose in mind and that the purpose considers the particular qualities of the people or events chosen and their relevance to the topic of study (Denscombe, 2014).

Within a sample, there is often an inclusion and exclusion criteria (Loue, 2000). Inclusion criteria are characteristics that potential participants must have to be included in a study. In contrast, exclusion criteria are characteristics that disqualify potential subject from a study (Card, 2012). For this study, the inclusion criteria were characteristics that relate to the research question and include service users/volunteers who are in receipt of disability benefits.
Data Collection

The data collection method considered most appropriate for this study was semi-structured interviews. King and Harrocks (2010) suggests that interviews in qualitative research are conversations where questions are asked to encourage and guide participants into verbally exploring an experience. Wengraf (2001) states that interviews are useful to obtain detailed information about feelings, perceptions and opinions and allow more detailed data to be collected. However, interviews can be very time-consuming and because of a small sample size, the research cannot represent the whole population (Merton, 2008).

Semi-structured interviews were decided to be the most suitable as Galletta (2013) states they are best used when the researcher will not get more than one chance of interviewing any given participant. See (Appendix 1) for interview questions.

During semi-structured interviews, the researcher has predetermined questions but the order can be modified upon the researcher’s perceptions of what is most appropriate at the time (Watzlawik and Born, 2007). More structured interviews were considered, however, they are not flexible and can be very formal. New questions cannot be asked in response to the dissertation taking place, which can lack depth and detail (Moule and Hek, 2011).

One-to-one interviews were chosen for this research as the participant and the researcher have an opportunity to build a relationship (Bryman, 2008). Using this method means that the participant can express their views and opinions in a relaxed and private space. Denscombe (2014) believes this method can be beneficial for the researcher as it allows one person’s ideas to grasp and can focus on their behaviour as well as their answers.

Focus groups were initially considered as a method of gathering data as Robson (2002) states that they are a highly efficient to collect data since the amount and range of data is increased by collection data from several people at the same time. However, focus groups were disregarded as confidentiality would be problematic as experiences of disability would not be the same (Wengraf, 2001).
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Questionnaires can be used to gather information about sensitive topics that participants would not disclose face to face. However, questionnaires were disregarded for this study as they cannot gauge thoughts and feelings (Bryman, 2008).

**Data Analysis**

Data analysis involves making sense of data that has been collected. Thematic analysis is often used in qualitative research and focuses on exploring themes within data and goes beyond counting phrases or words, it involves identifying implicit and explicit ideas within data (Denscombe, 2014).

Thematic analysis is one of the most common forms of analysis in qualitative research. It is a method for identifying, analysing and reporting patterns within data (Patton, 2014). Themes are patterns across data that are important to the description of a phenomenon and are to the specific research question (Linford and Taylor, 2010).

Thematic analysis was deemed most appropriate in this study as it focuses on the lived experiences of individuals by identifying themes found in the data. With the hope of providing some insights into the lived experiences of disability benefit claimants.

Braun and Clarke (2006) provide a guide to the six phases of analysis which will be used in this study.

**Phase 1: Researcher familiarises themselves with the data**

When employing oral data such as interviews, data will need to be transcribed into a written form to conduct a thematic analysis (Riessman, 1993). Is it essential that the researcher engrosses themselves into the data so they are aware of the intensity and content by searching for meanings and patterns (Parker, 2004).

**Phase 2 – Generating codes**

This phase engaging with the data and producing code from it. The procedure of coding is part of the analysis as the researcher is arranging data into significant groups (Tuckett, 2005).
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Phase 3 – Searching for themes

This phase commences when data has been coded and arranged and focuses on sorting codes into potential themes. Some codes could go on to form the main theme, others may be sub-themes and others could be disregarded (Roulston, 2001).

Phase 4 – Reviewing themes

This phase allows two levels of reviewing themes; one being studying the level of the coded data extracts (Seale, 1999). Meaning that the researcher reads through the extracts and considers possible patterns. The researcher considers the validity of themes in regards to the data and if it reflects the meaning apparent in the data as a whole.

Phase 5 – Defining themes

By defining themes there will be the basis of for the analysis, defining themes means deciding what aspects of the data each theme secures (Charmaz, 2002). It is significant not to just paraphrase the data but to recognise what is interesting about them and why (Braun and Clarke, 2006).

Phase 6 – Producing the report

This is the task of writing up the report and having a set of fully worked themes. Glaser (1992) states that the write up of data analysis is to tell the complex account of the data in a way that persuades the reader of the value, validity and reliability of the analysis. The write up should deliver a demonstration of themes within the data.

There are different positions concerning when the researcher should get involved with the literature related to analysis (Charmaz 2002). Poland (2002) argues that involving with the literature can increase analysis by informing the researcher to more delicate characters of the data (Tuckett, 2005). Consequently, there is no correct way to continue with reading for thematic analysis, though an inductive method would be improved by not engrossing with literature within the initial phases of analysis (McLeod 2001).
Reliability and validity

The use of validity and reliability are commonly used in quantitative research and is now being employed in qualitative research (Golafshani, 2003). Stenbacka (2001) believes that reliability and validity are irrelevant in qualitative studies as reliability and validity concern measurements used in quantitative studies. However, Patton (2002) believes validity and reliability are relevant. In qualitative studies, reliability and validity are conceptualised as rigour, quality and trustworthiness. It is through this association the way to reach reliability and validity of research is to remove bias and the researcher’s belief about the social phenomenon (Healy and Perry, 2000).

Robson (2002) states validity is the extent to which a technique measures what it is intended to measure. In terms of this method, interviews have a high factor of validity as a dependable method which can seize the views of participants in response to the study focus (Moule and Hek, 2011). Klenke (2008) believes interviews are reliable as they provide information through open-ended questions, allowing the participant to talk freely about issues. However, Babbie (2013) states that respondents could restrict the depth of their answer. For example, the Hawthorne effect; restricting the alteration of behaviour by the participants due to the awareness of being observed (Rugg and Marrian, 2006).

This study would have increased validity if interviews were repeated, however, due to the timescale, this is not possible (Gray, 2009). Some techniques that were implemented to increase the validity of this study is making sure that participants are clear on the nature of the research through the participant’s information sheet (Robson, 2002).

Reliability is the extent of which a technique shows the consistency of measurement (Gerrish and Lacey, 2013). Smith (2015) believes that assessing the reliability of findings requires researchers to make judgements about the ‘accuracy’ of the research. Semi-structure interviews are more reliable than unstructured interviews as there are a set of questioned followed and some questions to prompt discussion, if someone was to repeat the interviews in this study as it is likely they would get the same results. However, Carey (2012) states that the priority in qualitative research is
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on feelings and meanings and reliability is not always easy to achieve due to the small sample used.

Moule and Hek (2011) defines bias as an unintentional influence which can occur at any stage of the research process which misrepresents the findings. It could be said as the researcher of this study is a volunteer within the organisation and sees the struggles that benefit recipients have to deal with on a daily basis that there is biased and would want to highlight the negative daily experiences. However, bias will attempt to be avoided, interviews will avoid using leading questions that will influence the respondent's answers (Jacobsen, 2016).

Additionally, as the researcher is a volunteer within the organisation it is important that the sample is not biased. A biased sample might involve choosing participants that the researcher or organisation would perceive as individuals who would say the ‘right’ things (Shi, 2007). To prevent sample bias, the sampling strategy asked all service users/volunteers that meet the inclusion criteria, then narrowing it down by factors such is who is available during the time period (Bryman, 2008).

Ethical Issues

This research study was approved by the Cardiff Metropolitan Ethics Committee, this section will briefly examine the ethics concerned in this research and how risks were minimised.

Ethics are present in research to allow moral principles to inform us of what is right and wrong (Denscombe, 2014). It is vital that the researcher considers who they are working with and not to forget the ethical issues involved in research (Oliver, 2010). Research ethics differ depending on the area of research. In relation to health and social care, the purpose of ethics is to protect participants and protect the researcher from events that may cause harm. Moule and Hek (2011) state the ethical principles separate socially acceptable behaviour that considered socially unacceptable. Ethical principles should be followed all the way through the research process (Somekh and Lewin, 2005).
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Ethical approval is needed for all research undertaken that involves human participants. Bryman (2012) states that in order for research to result in benefit and minimise the risk of harm it must be conducted ethically. Cardiff Metropolitan University ethical guidelines for completing an undergraduate dissertation have been fully met with ethical approval see (Appendix 2) as part of good ethical practice (Oliver, 2010). It is important to state that the title of the study was changed from ‘life experiences’ to ‘lived experiences’ as it better reflects the dissertation and makes no difference to the research. The researcher discussed this with a member of the ethics panel who confirmed it was fine and appropriate to do so.

Consent was also sought from the Head of the Committee Board of Organisation A to recruit participants from the organisation. Although the organisation stated that they would allow this study to use the organisation’s name, to respect the participant’s and the organisation's confidentiality the organisation was referred to as ‘Organisation A’ a false name throughout the study.

Allmark et al. (2009) state that informed consent from participants is essential in research, it relates to participant’s willingness and understanding to be involved in the study. Therefore, informed consent was sought from all participants using the participant's consent form (Appendix 3). All participants were informed of the study and what’s being asked of them including the benefits and risks in order to make a fully informed decision as to their participation (Miller et al., 2012).

Before the interviews participants were given an information sheet explaining the nature of the research, any possible risks and that they can withdraw from the research at any time without reason and any existing data will be destroyed (Appendix 4) (Social Research Association, 2002). The organisation was also given information sheet (Appendix 5).

Potential risks identified for this study were that participants may have felt uncomfortable and become upset when discussing their experiences. This risk was minimised by going through the information sheet before the study, explaining that they could take time out if they needed to and could withdraw from the research at any time (Iphofen, 2009).
Wiles (2013) suggests the confidentiality of the participants is vital as they are voluntarily contributing to a study that engages their experience and feelings regarding a sensitive topic. Cargan (2007) considers that confidentiality in social research goes beyond protecting anonymity, it is about safeguarding the privacy of participants so no harm is produced by the study.

To maintain confidentiality once data had been transcribed recordings were destroyed. Participants remained anonymous as pseudonym was used to identify participants as literature on ethical considerations state the importance of anonymizing participants (Charles et al., 2008).

Organisation A expressed an interest into receiving a copy of the final dissertation anonymity was ensured by not using participant’s names and not saying what part of the service they were from. This was made clear in the participation information sheet (Appendix 4).

Also, as the interviews took place in Organisation A’s office to prevent anyone overhearing interviews were held in a private area which staff members had no access to for the duration of the interview periods.

The next chapter of the dissertation will discuss the findings from the interviews.
Findings

This section will analyse the findings using a thematic analysis to discover reoccurring themes within the data.

Identity

Burke and Stets (2009) state that identity is the fact of being or who a person is. However, Woodward (2003) believes that identity is much more than that. He believes that identities are multiple and changing, reflecting on experiences and integrating them into ‘our story’. Disability identity can be complex, as it involves understanding what circumstances someone chooses to suppress or disclose a disability (Darling, 2013). In effect, disability identity can lead people with disabilities towards what to do and how to behave where their disability stands out, as well as when it is not noticeable (Malhotra and Rowe, 2013).

The claiming of an identity as disabled person has the significant implication of individual’s interactions and well-being; some disabled people find it hard to claim a disabled identity. Identity was a strong theme held within the findings, all participants believed that being a claimant of disability benefit shaped their identity and how they experience day to day living. However, some felt identity to be a stronger part of identity than others:

“Being disabled and receiving disability benefits I feel is a part of my identity, I’ve always received benefits and tell people I have a disability”. – Participant 5

“Being on disability benefits does shape my identity, it shapes my values, my self-worth and confidence. Disability shapes my identity as I am not materialistic, I value the things that are important to family”. – Participant 3

These participants were of those who had a physical disability so did identify themselves as a ‘disability claimant’. This is because their disability is visible to others they believed it is a part of who they are and by other would be identified as ‘disabled’. However, Goffman (1968) deems that disabled people have a ‘mastered
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identity’ thrust upon them that can overwhelm other attributes or abilities. Therefore, he suggests that disability can overpower other parts of a person’s identity.

Other people’s views contributed to participant’s identity, additionally as they have always been disabled and claimed disability benefits they identify themselves as disabled. Erikson’s (1994) theory of psychosocial development believes that this is because during adolescence this is a period most focused on identity and figuring out ‘who am I?’ This is reiterated in these findings as participants who were born with a disability were more likely to regard disability as a primary identity as they have had more time to consider (WHO, 2011).

These participants also felt that identifying themselves as disabled was a relief, as they are entitled to claim disability benefits and there is less pressure to consider working and also consider these benefits as providing financial security.

Participant 2 said:

“It was a relief when I got disability benefits, now I wouldn’t be able to live without them”.

This is reiterated by Corden et al. (2010) whose participants also felt a relief from identifying themselves as ‘disabled’ as the benefits they were receiving boosted self-esteem as they felt that ‘someone cared’.

However, not all participants felt like claiming disability benefits was a part of their primary identity:

“I do not believe my prime identity as being a disabled person on benefits, I see my identity as a wife and a good person” - Participant 4

“Being on disability benefits is a part of my identity but not a big part, as it is not often something I disclose” – Participant 1

These participants felt as though other characteristics were a bigger part of their identity than being in receipt of disability benefits, this may be due to stigma experienced if they were disclosing their disabled identity (Garthwaite, 2015).
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In this study, participants with invisible disabilities felt like being a ‘disability benefits claimant’ took a back seat over other characteristics and would not usually express their disabled identity to others. This belief parallels with the self-identity theory (Tajefel, 1981) which distinguishes between personal identity, skills, likes and dislikes and social identity includes perceived characteristics from a social group. Participants would rather be identified as for example a ‘wife’ than a ‘disabled person’.

Therefore, this ‘coming out’ as a disabled person involves a shift from identification by personal characteristics as a non-disabled person to identification as a disabled person oppressed by barriers (Marian and Sally, 1999). This explained why in this study participant with invisible disabilities tended to identify other characteristics before their disability. Riddell and Watson (2014) states that a disabled identity would supersede other identities a person may have. Baldridge and Swift (2013) believe that individuals with invisible disabilities do not often disclose their condition to avoid being treated differently.

Shakespeare (1996) believes that people with hidden difficulties are less likely to come out as disabled, which was also discovered in the interviews all those with physical disabilities believe that being a ‘disabled claimant’ was a part of their identity whereas for those with invisible difficulties it was not a primary identity and not one they would likely to disclose. Cochrane (2014) believes that individuals would be hesitant to move to a different political identity because it is easier to maintain a ‘normal’ identity.

**Social Stigma**

Social stigma was a theme identified by all participants in this study. Although institutional and personal stigma were mentioned social stigma was discussed by all participants with detailed experiences in relation to social stigma. Park (2013, pp 101) suggests that “social stigma is the disapproval of a person or group of people on the basis that characteristics differentiate them from other members of society”.
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Stigma is a degrading and shameful attitude of society that dishonours a person because of a certain attribute (Barnes and Mercer, 2010). Stigma can abolish an individual’s dignity, which infringes basic human rights. It can reduce the chances of a stigmatised individual achieving full potential (Larson and Lubkin, 2009). Stigma can hinder the happiness and contentment of individuals. People who are stigmatised can be categorised as ‘different’, leading to being devalued and excluded by society (Cox et al, 2015).

In terms of this study social stigma was formed by its participants as the feeling that other people judge claiming benefit to be shameful. If claimants feel a sense of social stigma they may hide or avoid telling people that they claim disability benefits.

All participants stated they had experienced social stigma.

Some participants felt social stigma in terms of their disability.

“I get treated different by other people who don’t know and don’t understand, I don’t get treated the same by other people. I’ve just got a disability” – Participant 1

“People in supermarkets give me dirty looks and abuse as I park in a disabled space” – Participant 3

It was apparent throughout the discussion that participants felt that daily interactions became stigmatising. They expressed that social stigma was becoming a part of their everyday experiences and damaged their self-esteem and made them feel worthless. Participants described social stigma as a process, chipping away at them slowly but surely resulting in a sense of humiliation and indignity.

Corrigan and Watson (2012) also found disabled people felt a significant amount of social stigma by treated differently by others or feeling isolated in certain situations. When participants parked in a disabled bay they would feel a sense of dread getting out of the car in case people made inappropriate remarks or dirty looks. This emphasises that participants acknowledge social stigma on a day-to-day basis, stressing that social stigma due to the individual claiming benefits or that they are disabled, can be classified as a ‘lived experience’.
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The concept of the general public not understanding participant’s illness was explored by Green (2005) who also found that some disabled people sensed social stigma particularly when people did not understand the disability, therefore, participants felt others were hostile within their behaviour towards them.

Other participants experienced social stigma in relation to claiming disability benefit:

“I get stigmatised due to being on benefits, people assume I’m scum and lazy, which is untrue” - Participant 4

“When I say I’m on benefits people assume I’m lazy which is not the case” - Participant 2

Participants experienced social stigma due to receiving disability benefits. Participants felt that people assumed they made a deliberate choice to claim disability benefits. All participants emphasised that they did not want to be a benefit claimant. They felt that this social stigma just adds an unnecessary burden to their everyday life.

The quotes above indicate that participants felt that some people perceived them as ‘lazy’ due to being out of work but seemed insensitive to participant’s illness or disability. Stevenson (2010) describes lazy as unwilling to work or use energy, slothful, sluggish and lethargic. Participants felt extremely annoyed by such descriptions as they stated that this is not the case, they affirmed throughout that did not choose to be a claimant and felt that society struggles to understand this. Stuber and Schlesinger (2007) also found that social stigma was common amongst benefit claimants through 1000 interviews, they found that people perceived claimants to be ‘lazy’, ‘unwilling to work’ and in some cases ‘scum’ which is in correspondence with the feelings experienced by participants in this study. Sainsbury and Davidson (2006) also reiterated the negative views and felt that they were viewed by others as ‘second class citizens’ or ‘scroungers’.

Several participants felt that social stigma affected their self-worth:

“I feel like I am treated differently by other, it affects my self-worth” - Participant 5

“Experiencing stigma is horrific, it makes me feel like nothing, it shapes my self-worth” - Participant 4
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When discussing stigma participants suggested that a major effect of experiencing stigma is self-worth. Due to other people’s attitudes and behaviour participants were made to feel like they were ‘different’ and a segregated part of society. Consequently, this made participants feel that they were less valued as citizens reflecting participant’s confidence and dignity.

Favlo (2005) states that self-worth is a sense of an individual’s own value or worth. Participants felt that their self-worth was been affected because they felt like they were being stigmatised or treated unfairly by others, resulting in low self-esteem and lower levels of confidence. Finlay and Lyons (2000) reiterated that experiencing stigma can create negative feelings.

Often, individuals are confronted with multiple, interconnecting layers of stigma as a result of their illness and other attributes of their identity such as race and sexuality (Goode, 2015). This was demonstrated in this study as participants faced the ‘double stigma’ of being disabled and also being a benefit claimant.

**Media portrayals**

Happer and Philo (2013) suggest that media has a huge impact on people’s opinions. This view corresponds with the theoretical stereotype perspective which suggests that media reinforces the leading view of societies existing opinion and behaviour towards minorities by preserving negative portrayals (Inzlicht and Schmader, 2012). Media can affect the way people act and think and can have an influence on the behaviour of viewers. The media is known to create ‘gossip’ by building up the issues with extravagant words and inciting descriptions, indorsing controversies to get the attention of people (Perse and Lambe, 2016).

Disability Rights UK (2014) suggests that media has become a part of individual’s everyday life. Media is significant in the broadcasting of information to the mass population. Therefore, has a powerful effect on society and reaches many people and shapes attitudes. These portrayals tend to be negative, displaying individuals as having more undesirable characteristics than positive (Jones, 2005).
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In the media, the UK are frequently fed headlines that emphasise the work-shy, lazy and scrounging benefit claimants, expressing that they prefer to live courtesy of all the tax payers (Bresford, 2012).

Participants felt that this was an unfair portrayal:

“The media need to show people the day to day life of people like me, the struggles, the hardship, the sacrifices people make”. Participant 3

“The media portrays people as scum, drinking, smoking, living a life of luxury. When in reality it’s nothing like that, it pays for essential stuff. They need to see real people and see we have nothing”. – Participant 4

Participants in this study were infuriated about the way the media represented disability benefit claimants. They felt it was constantly thrown in people’s faces and splashed across headlines which can create feelings of animosity amongst the general public. Participants felt that this negative media was degrading and an unfair portrayal of the life they lead. Throughout the discussion, participants emphasised the hardship of being on disability benefits and that the media did not represent any of their experiences, which made participants feel frustrated and deceived.

This emphasises that participants want the media to show more of a true portrayal of being on disability benefits as they believed it puts all benefit claimants in a bad light. Participants suggested they want the media to show the challenging life experiences that participants have to face such as the assessments, the pain caused by their illness and money worries. Disability Rights UK (2014) findings correlate with this study as 78% mentioned negative press stories over positive stories and 93% suggested press portrayal was unfair. This was a commonly held belief as Scope (2012) suggests that disability benefit claimants are often portrayed as villains in the media and suggests the media needs to realistic view. Finkelstein (2015) suggest that more disabled role models should be shown in the media and believe this would be influential in transforming societies attitudes towards disabled people.

When participants were asked about media all of them mentioned fraud: Examples of such media is displayed in Appendix 6 -8.
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“Newspaper articles are often around fraud; they portray us all in a bad light”
Participant 1

“The media presents that disability benefits are handed out willy nilly, but it’s not. They make you jump through hoops” Participant 4

Participants stressed their infuriation by the media’s representation of disability benefits and fraud. It was a commonly held belief by all participants that fraud in the media makes it harder for people like themselves who really need it. Participants felt that ‘fraud’ stories made society resent people claiming disability benefits and discussed throughout their desperate demand for the media to demonstrate the hardship they had experienced throughout everyday life.

Scarlet (2012) states that people have widely missed conceptions about the levels of fraud and considers the media to blow it out of proportion, portraying disabled people negatively. In actual fact, the DWP (2011) estimates that as little as 0.5% of expenditure on DLA went on fraudulent claims and 0.3% of incapacity benefit (now known as ESA) went on fraud. This could be considered as a very small percent of the disabled population in the UK but the media is seen to amplify fraud a lot more.

Fear

Harré (2009, pp. 295) defines fear as “an unpleasant emotion produced by the threat of harm, danger or pain”. Fear came up repeatedly throughout the interviews as all participants had experienced fear due to the previous nature of being on benefits or were fearful of a future living on benefits. Facing a fear can have a major impact on an individual’s life and affect life experiences. Nelson (2012) suggests that fear can impact thinking and decision making in negative ways leaving individuals incapable of acting appropriately and can further impact physical and mental health.

Several participants discussed the fear they experienced whilst being on benefits:
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“The tribunal was absolutely terrifying I just broke down; I couldn’t speak I just sat there in tears” - Participant 3

“The assessment was awful it was like being in a Magistrates Court, me on a bench them in front of me large imposing chairs looking down on me it was like being in court” - Participant 5

These findings demonstrate the fear faced by participants when attending assessments. Participants felt as though they were in court being judged as criminals who had committed a crime, which brought on feelings of fright and worry.

The vivid description of the assessment and the participant’s distress explained shows how intimidated the participant felt suggesting this is an experience that the participant would not like to relive again. Lindsay and Houston’s (2013) suggests the formality of appeals, the interrogative nature of the process and the unsympathetic judge made the process very nerve-racking. Shefer et al.’s (2016) research which explores the impact wrongly removing disability benefits corresponds with the findings as participants expressed the fear of appearing assessment panels or appeal tribunals. Some participants found the experience daunting. Scott’s (2015) research explores the disability benefits system through focus groups and interviews also found some participants who attended tribunals felt as they were considered liars and had to face talking about distressing experiences.

Some participants anticipated fears about their future.

“I live in fear of the brown envelope coming through the door. Decisions are made by people who don’t know you and they can make decisions that turn your life upside down” - Participant 4

“I do think there will come a day where the benefit system will end and I couldn’t see any part of my life that wouldn’t be massively negative, I’d lose everything” - Participant 1

Such findings suggest that participants are constantly living in fear of the things outside their control whilst claiming disability benefit. Participants fear that their benefits will stop or the system will come to an end impacting their life in a negative
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Garthwaite (2013) echoed the fear of the ‘brown envelope’ in a qualitative study using interviews with twenty-five participants in receipt of disability benefits. Participants stated they dreaded a brown envelope coming through the door as they felt if they were capable of walking to the door the DWP would assume they are capable of working. A similar worry of the brown envelope was reported by Wolfe (2012) in this study people with myalgic encephalomyelitis who were in receipt of disability benefits, participants also feared that the benefits system may come to an end one day due to anticipated budget cuts also affecting crucial services.

Proving illness or disability

Proving an illness or disability was a common theme throughout the findings. ‘Proving’ something is demonstrating the truth or existence of something with the use of evidence (Stevenson, 2010). In order for a person to receive disability benefits they must ‘prove’ their disability or illness, this can be through the application forms or medical assessments (Shelby et al., 2014). Soldactic et al. (2014) suggest that proving disability to receive benefits involves a test of the individual’s chronic capability and the predictability and synchronicity of the condition. The need to prove entitlement to benefits can be infuriating for individuals and in certain cases can bring back distressing experiences such as the cause of their disability and the effects of their illnesses (Beatty and Fothergill, 2013).

Some participants in this study expressed their concern about the vagueness of the questions in both the physical assessments and the application forms. It was widely agreed that the questions were unclear and hard to understand which may the process a lot more daunting.

“One of the questions was “Are you able to push your wheelchair over 50 meters?” I told them I couldn’t answer that question, there are too many variables. Is it a good day? Is it a bad day? What’s the surface like? Is it uphill? Is it wet?” – Participant 3
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“I didn’t understand the questions if I’m honest. They repeat themselves a lot” – Participant 5

Participants suggested the ambiguity of the questions being asked did not allow for the complexity of an individual’s condition and that participants illnesses and disabilities did not simply fit into a box. It was generally expressed by all participants that people’s abilities can vary day to day and the system was not set up to allow for time. When discussing good days and bad days Charmaz (1991) describes the difference between ‘good days’ and ‘bad days’ and suggests that differentiating good days and bad days in illness reveals a more intensified and focused version of evaluating day generally. Good days and bad days allows the individual to see the limit of self and also reveals images of the self. Sainsbury and Davidson (2006) also suggests that people have difficulties putting into words the way that their lives are affected by a disability or in explaining their illness or disability to others. Participants also felt that the application form questions were repetitive and it was difficult to understand what information was needed. Litchfield (2013) similarly found that questions were misleadingly worded and found that participant’s answers were assigned a different meaning to that which participants had intended.

In addition, participants with poor mental health felt it difficult to fill in forms and felt as though forms were more geared to physical disabilities:

“It’s a case of can you dress yourself, bath yourself, with mental health it’s more diverse” – Participant 1

“I didn’t understand the questions if I’m honest. It’s hard to explain the illness, then having to appear before a tribunal to explain my illness was stressful” – Participant 2

This emphasises the struggle participants with poor mental health have in explaining their illness especially as they felt parts of the form were not applicable to their illness. Butters et al. (2010) reiterated that people with mental health illness seemed to find the forms least tailored to their disorders. The stress of trying to fit a poor mental health into the forms added extra worry to participant’s experience of applying for benefits. Shefer et al. (2016) echo’s this idea and suggests that the process of applying for benefits creates challenges for people with poor mental health. This is due to the
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stress in completing many forms and then having to attend tribunals, again having to prove illness can be unsettling and uneasy. Participants in this study with poor mental health had to appear at a tribunal, further having to ‘prove’ disorder. Weston (2012) suggests that people with poor mental illness are more likely to have to appear in tribunals due to the complexity and subjective nature of mental illnesses.

However, participants with physical disabilities still felt they have to prove their disabilities even though it was visible:

“They thought I could do a lot more than I actually could do. Which meant having to go to a tribunal to prove my disability”. Participant 2

“I felt like I had to prove I had a disability even though it is visible, I am in a wheelchair”
- Participant 3

This highlights that even though an illness is plainly visible to onlooker’s participants still felt like they had to prove something. Disability Rights Commission (2003) findings are comparable as they expressed the insensitivity of the benefit application and assessment process which makes claimants feel they have to prove they have an illness. Gore and Parckar (2010) also suggests that participants continuously felt like they had to ‘prove’ they have an illness even though it was visible and felt like assessors were trying to ‘catch them out’. This also links to Talcott Parson’s (1951) sick role, as participants are playing the ‘role’ of a sick person in order to receive disability benefit.

Although all participants felt that forms and assessment were a struggle and stressful all participants stated that they were grateful for the benefits system and would not be able to live without it.
Challenges in finding employment

In spite of some recent progress, disabled people still have much lower employment rates than those without disabilities, this is known as the ‘disability employment gap’ (Work and Pensions Committee, 2017). In the UK in 2016 48% of disabled people aged 18-64 were in work in comparison to 81% of non-disabled people. Therefore, the gap existed at 33% and has widened since 2010 (Office of National Statistics, 2017).

Although work is not suitable for all disabled people due to various conditions, everyone’s contribution to society should be valued whether they work or not. There are many barriers that prevent disabled people finding employment and keeping their jobs. These include attitudes from employers, inflexible contracts and inaccessible workplaces (Scope, 2017).

Although all participants in the study are in receipt of disability benefits four out of five participants want to get into employment if not now in the future:

“A huge challenge is applying for jobs; it really is a struggle. It’s trying to make sense of the forms, constantly applying and getting blown off basically” – Participant 2

“I want to be like everyone else, I want to work but am reluctant in case I get turned down” – Participant 4

These findings highlight that participants want to work and would prefer the security of a job than being on benefits. There was also an emphasis from all participants about struggling to find employment. OPM’s (2010) research also found that participants felt that employers tend to see disabled people unreliable therefore an uncertain investment.

Barnes and Mercer (2005) reiterated that employers tend to make assumptions about the productivity of disabled people, expecting them to have time off, not be able to do the work to a good standard and need more supervision emphasising why participants are struggling to find employment. Disabled people are reluctant to apply for jobs due to being discriminated against in employment or getting turned down, decreasing self-esteem even more. Participants expressed their difficulty filling in application forms
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and then resulting in getting turned down for a job made them feel worthless.
Robinson et al. (2007) also echoed the struggle of job applications for disabled people and suggests it puts them off applying, therefore there need to be more sensitive job applications and recruitment process and support filling in job applications.

Other participants felt like employers are not willing to give them a chance and feel like they are discriminated against due to having a disability.

“I feel like when I tick the ‘disabled’ box I’m not going to get the job. I know I can’t prove I could do the job; I wish I had the chance to. Employers don’t understand” – Participant 1

“If I the interview they say “Can you guarantee your health won’t get any worse?” I say “no” and the minute you do that the job goes to someone else” – Participant 3

Even with these participants having relevant qualifications and work experience they do not feel like this is enough to take priority over the fact they have a disability. These findings demonstrate that participants feel like they are being discriminated against even though under the Equality Act (2010) employers should not discriminate on the basis of disability, age or race. Hyde (2010) suggests that many employers still fail to recognise the value and abilities of disabled people at a time when low employment should increase demand for disabled people. Scope (2014) also found that participants would most like to see a change in employer’s attitudes due to employer’s not giving them opportunities and underestimating abilities.

All participants emphasised that employers need to have more understanding in terms of disabilities. TUC (2015) use the social model of disability to explain the relationship between employment and disabled people. This is the idea is that workplaces, not workers need to be ‘adapted’. Therefore, employers should make sensible changes to prevent incapacitating workers from particular jobs. WHO (2011) believes a worker with an impairment only becomes disabled when hit by false barriers shaped by workplace, environment and people’s attitudes.
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Conclusions

In conclusion, this study has fulfilled its aimed to explore feelings, experiences and emotions of those individuals who are receiving disability benefits. This study has established that lived experiences of individuals are complicated and their complexity can vary within different circumstances.

Participants felt identity affected their lived experiences as they were constantly managing and negotiating their identity. This study demonstrated that individuals can have multiple identities and have to hide and display these identities under certain circumstances. Participants were reluctant to reveal their ‘disability benefits claimant’ identity due to the fear of experiencing stigma. Highlighting that the ‘scrounger’ discourse does still exist within society as claimants are regarded as not ‘contributing to society’.

It is evident from the research that participants felt like they were constantly having to prove their disability whether it be through forms, assessments or attending tribunals. These experiences were described as daunting and found assessors unsympathetic adding a sense of apprehension to the whole experience. It could be that there need to be policy changes into introducing education at all levels with professionals to ease the process and for staff to have more of an understanding regarding the experiences of disabled people. As shown in this study individuals with disabilities have unique intuitions about their disability and experiences. Therefore, it would be appropriate that when devising and implementing policies and services that individuals with disabilities should be actively involved and consulted.

It was established amongst participants that social stigma was a process, chipping away at them slowly but surely resulting in a sense of shame and indignity. This stigma affected participant’s self-worth and made them feel that they were below everyone else and treated differently by others affecting their lived experience. This study found that individuals can experience multiple forms of stigma as to being labelled as ‘disabled’ and a ‘benefit claimant’. From this, it could be said that further research needs to be conducted as to why these group of people are being stigmatised and discriminated against.
Gathering information on beliefs, knowledge and attitudes on disability can help recognise disparities in public understanding that can be addressed through public information and education. There needs to be a rise in public awareness and understanding of disability. It is important to improve the understanding of disability, challenge negative perspective and stand for disability fairly. This could be done through education; local authorities could make sure that schools and colleges value diversity (WHO, 2011).

Participants expressed that they struggle to find unemployment which is not uncommon, as the employment cap is still present. Participants in this study had relevant experience and suitable characteristics to offer employers but felt that this was overridden by their disability or illness. From this study, it can be interpreted that employers need to have more of an understanding of disabilities and mental illnesses. To do this the government could create a strategy to allow employers to have more training to understand disabilities. There is a lot of support online for employers (ACAS 2017; Disability Action 2011; Gov 2016). However, there seems to be a lack of provision to implement such guidance into work, therefore, employers do not have a knowledge based around this area. However, with a small sample size, caution must be applied, as the findings cannot represent the whole population.

In this study participants felt that stigma and discrimination from others was enforced by the media. This could indicate that the media need to publish stories and create programs that show a true portrayal of being a disability benefits claimant, the struggles they face and the sacrifices they make. Additionally, it would be beneficial to show that claimants are entirely grateful for the benefits system which allow them to live a more ‘comfortable’ life. Also, participants were extremely concerned about the number of stories around fraud in relation to disability benefits which increased stigmatisation. Voluntary organisations, government and professional unions could consider running campaigns to help change attitudes on the stigma attached to disabilities. Such campaigns should involve the media and include positive stories around disabilities.

Additionally, there could more opportunities for people with disabilities, for example, a volunteering placements or internships to create positive interactions with others,
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engage with society and to show employers that disabled people can work and to also gain an understanding.

The dissertation will now provide some limitations and recommendations for improving this study if it was to be conducted again.

**Limitations and recommendations**

This part of the dissertation will examine the limitations of the study and how it could be improved if the research was carried out again. There will be a discussion of the possibilities this study may have for additional research.

It is acknowledged that the sample size of this study was a clear limitation, this means that the findings cannot generalise the who population of claimants in receipt disability benefits. To improve this issue, a larger sample size could have been used to allow generalisation. The sample size was small with all participants recruited from an organisation in Wales, therefore it cannot be considered as a true representation of the population claiming disability benefits. Also, as only one organisation was contacted to recruit participants which could be considered as a limitation as this is not a diverse sample. For further improvement, this study could be repeated in several organisations. Additionally, this study was with people who participated in society through being involved in a charity, therefore, it would be valuable to repeat this study with participants who do not necessarily engage in society.

Furthermore, all participants in this study were under the age of forty which meant that experiences of Attendance Allowance could not be evaluated as the criteria for Attendance Allowance is for people sixty-five and over (Gov, 2017). Also, people of the older generation may have been in the benefits system for a long period of time, therefore, have dissimilar views of those of a younger age. The researcher tried to involve older people, however, due to the timescale, the researcher could not wait any longer to interview participants. Additionally, all participants were of ‘working age’, if older participants were involved they may feel less pressure to feel like they have to contribute to society so answered may have varied. Therefore, a recommendation for
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this study is if there was more time to involve people of all ages to allow a more varied sample.

All participants were white emphasising that this study is not ethnically diverse as it is likely that people from different ethnic backgrounds would have different experiences. A recommendation for this study would be to involve participants from a wide variety of ethnic backgrounds.

Another factor that could be considered as a limitation is that all participants could be deemed to be of a certain social class, therefore, their values and views could be obtained from their social class which may have influenced their answers. As a result, a recommendation could be to include people from a selection of social classes.

Additionally, the current study could be more specific than it currently is. It may have been more beneficial to look at one specific disability benefit rather than generalising several as benefits can have different methods of application. However, due to the timescale, there was a limit of time to find participants. In addition, a recommendation could be to focus on one benefit rather than several under one title.

Through carrying out this study, it has shown that there is a small amount of qualitative research in relation to disability benefits and experiences. Existing research focuses on experiences of disabled people and there is not much emphasis on experiences relating to claiming disability benefits. Additionally, the current research that does relate to disability benefits is generally quantitative. Moreover, future research needs to examine experiences and feelings around being involved in the benefits system.
Reflective learning

I have always wanted to carry out my own primary research but did not think I would have the confidence to. However, this university, the help of my supervisor and being a volunteer at Organisation A gave me the opportunity to be able to do so. Being a volunteer and working with disabled people I had often been left wondering “what are the lived experiences of these people?”. Also, with the vast amount of media around disability benefits led me to establish this phenomenological study.

The experience of carrying out my own research has been extremely interesting, however, it has also been quite challenging. The worry of time was a big challenge as I was carrying out interviews it was hard to arrange interviews at a suitable time. Also, some participants fell ill on the day interviews were arranged which may have caused me to become behind schedule, however, I managed my time wisely and used that time to transcribe previous interviews. Undertaking this project along with other assignments, two voluntary placements and part-time work has been a quite difficult. Nevertheless, I used all my free time wisely to complete this project to a good standard.

Carrying out interviews with people who I had never met before and knowing that they were going to disclose personal information was nerve-wracking to start. With the sensitivity of this study, I was worried that people were going to give minimal responses. However, after the first interview, I felt comfortable and all the participants gave me honest and open answers which I am extremely grateful.

All the information given by my participants was extremely interesting, participants delivered some rich context some of which I could never have predicted before I carried out this research. Although already working with people with disabilities, this study has really opened my eyes to the experiences of those with disabilities. I am proud that I was able to make sense of the research when it came to analysing my data and link with other theories and research.
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If I was to complete another research project, I would consider carrying out a quantitative study to allow me to gain experience in dealing with statistical data and ways of analysing this type of data.

Having carried out my own research, I am thankful to have had the opportunity and I feel that I have achieved something meaningful. I have thoroughly enjoyed learning how to carry out interviews and qualitative research in general, so much so that I have applied to study Masters of Research (Health) here at Cardiff Metropolitan.
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Image References


Appendices

Appendix 1 - Interview Questions

- How did you become involved with Organisation A?
- How did you find the process of applying for disability benefits?
- How does being on benefits impact your life?
- What motivates you to overcome challenges you may face?
- Do you feel that the current benefits are a sufficient amount to meet your day to day requirements?
- Do you believe being on disability benefits shapes your identity?
- If you were to lose your benefits how would this affect you?
- How do you feel about the way in which the media portray people on disability benefits?
- Do you feel there is a stigma around recipients of disability benefit?
Appendix 2 - Ethical Approval

Wednesday, 07 December 2016

cshs/ethics/approved

xxxxxx

BSc (Hons) Health & Social Care
Cardiff School of Health Sciences

Dear Applicant

Re: Application for Ethical Approval: An exploration into the life experiences of those in receipt of disability benefits.

Ethics Reference Number:

Your ethics application, as shown above, was considered by the Applied Community Sciences Ethics Panel on 30/11/2016

I am pleased to inform you that your application for ethical approval was APPROVED, subject to the conditions listed below – please read carefully.

Standard Conditions of Approval

• Your Ethics Application has been given a Project Reference number as above. This MUST be quoted on all documentation relating to the project (E.g. consent forms, information sheets), together with the full project title.

• All documents must also have the approved University Logo and the Version number in addition to the reference and project title as above.

• A full Risk Assessment must be undertaken for this proposal, as appropriate, and be made available to the Committee if requested.

• Any changes in connection to the proposal as approved must be referred to the Panel/Committee for consideration without delay quoting your Project Reference Number. Changes to the proposed project may have ethical implications and so must be approved.
• Any untoward incident which occurs in connection with this proposal must be reported back to the Panel/Committee without delay.

• If your project involves the use of samples of human origin, your approval is given on the condition that you or your supervisor notify the School of your intention to work with such material by completing Part One of the form entitled “Notification of Intention to Work with Human Relevant Material or Human Bodily Material” which must be obtained from the PD (Sean Duggan), BEFORE any activity on this project is undertaken.

This approval expires on 30/11/2017. Please set a reminder on your Outlook calendar or equivalent if you need to continue beyond this approval date. It is your responsibility to reapply / request extension if necessary.

Yours sincerely

Professor George Karani
Chair of Applied Community Sciences & Protection Ethics Panel
Cardiff School of Health Sciences

Tel : 029 20416855
E-mail : gkarani@cardiffmet.ac.uk
Cc: Stevens-Woods, Kirsten

PLEASE RETAIN THIS LETTER FOR REFERENCE
Reference Number: Participant name or Study ID Number:
Title of Project: An exploration into the life experiences of individuals who are in receipt of disability benefits.
Name of Researcher: xxxxxx

Participant to complete this section: Please initial each box.

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I agree to take part in the above study.

4. I agree to the interview being audio recorded.

5. I agree to the use of anonymised quotes in publications.

Signature of Participant Date
An exploration into the lived experiences of those in receipt of disability benefits

Name of person taking consent  Date

Signature of person taking consent
Appendix 4 - Participants Information Sheet

Participant Information Sheet

Project researcher: [Redacted]

Title: An exploration into the lived experiences those in receipt of disability benefit.

My name is Lauren Richards, I am a University student at Cardiff Metropolitan University and I am currently studying Health and Social Care. I am questioning as to you would be willing to participate in a study for my dissertation project, it is a study based on individuals who are in receipt of disability benefits. Before deciding whether you are willing to participate, it is vital that you know why I am interested in researching this topic and what will it involve for you as a participant. Take enough time to read the following information sheet carefully. Take as plenty of time to decide whether you want to take part, if you decide you are willing to participate please sign and date the consent form attached. Thank you for your time.

Purpose of the study
The purpose of this study is to explore the life experiences of those who are in receipt of disability benefits whilst also looking at current literature around this area. In this study I hope to find thoughts and feelings around the individuals who receive benefits. The method of research for this project will be semi-structured interviews, with the hope of between four and six participants. Each interview will be 30 depending on the information shared and there will be around 10 questions.

How I protect your privacy
The privacy of each participant is a very important part of this project, in order for each participant to stay anonymous I will use pseudonym to identify them with instead of their name. Each interview will be recorded on a Dictaphone and the audio recordings will be kept on a laptop secured which only I am able to access. If you withdraw from the project, all the data collected from yourself will be destroyed and will not be used in the research. As the organisation has expressed an interest in receiving a copy of the final dissertation, I will ensure that any locations or names discussed in the interviews will be changed in order to protect your identity.
The possible risks of the project
I am aware that the nature of this project is sensitive and there is a possibility that it may cause upset to individuals talking about past behaviours and situations, as a participant you are in control of the interview. If you feel that you need a break you can at any time without giving a reason.

Do I have to take part?
If you decide to partake in this study it will be completely voluntary. If you decide to take part this information sheet will be yours and you will be asked to sign a consent form. Before starting the interview's, I will ask your permission to begin, and you are able to withdraw at any point without giving a reason.

Why have I been chosen?
I have chosen you because I am aware that you are in receipt of disability benefit and a service user/volunteer at this organisation. Also as stated above I am familiar with the organisation.

Confidentiality
Your name will not be mentioned in the interviews or in the research. Names, addresses and other personal details will be kept separately from recordings and transcribed notes and be stored securely. Such recordings and notes will be used by a coded reference through which I can identify. Once the recording has been written up then the records will be destroyed.
Appendix 5 - Organisation Information Sheet

Organisation Information Sheet

Title: An exploration into the lived experiences those in receipt of disability benefit.

My name is [REDACTED], I am a University student at Cardiff Metropolitan University and I am currently studying Health and Social Care. I am questioning as to you would be willing to participate in a study for my dissertation project, it is a study based on individuals who are in receipt of disability benefits. Before deciding whether you are willing to participate, it is vital that you know why I am interested in researching this topic and what will it involve for you as a participant. Take enough time to read the following information sheet carefully. Take as plenty of time to decide whether you want to take part, if you decide you are willing to participate please sign and date the consent form attached. Thank you for your time.

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The purpose of this study is to explore the life experiences of those who are in receipt of disability benefits whilst also looking at current literature around this area. In this study I hope to find thoughts and feelings around the individuals who receive benefits. The method of research for this project will be semi-structured interviews, with the hope of between four and six participants. Each interview will be 30 depending on the information shared and there will be around 10 questions.

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The privacy of each participant is a very important part of this project, in order for each participant to stay anonymous I will use pseudonym to identify them with instead of their name. Each interview will be recorded on a Dictaphone and the audio recordings will be kept on a laptop secured which only I am able to access. If you withdraw from the project, all the data collected from yourself will be destroyed and will not be used in the research. As the organisation has expressed an interest in receiving a copy of the final dissertation, I will ensure
An exploration into the lived experiences of those in receipt of disability benefits

that any locations or names discussed in the interviews will be changed in order to protect your identity.

**The possible risks of the project**
I am aware that the nature of this project is sensitive and there is a possibility that it may cause upset to participant talking about past situations. If the participant feel that they need a break they can do so at any point without giving a reason. I will let the participants know before hand they can stop the interviews when ever they need to.

**Do I have to take part?**
If you decide to partake in this study it will be completely voluntary. If you decide to take part this information sheet will be yours and you will be asked to sign a consent form.

**Why have I been chosen?**
This organisation has been chosen as I am familiar with the organisation.

**Confidentiality**
The names of participants will not be mentioned in the interviews or in the research. Names, addresses and other personal details will be kept separately from recordings and transcribed notes and be stored securely. Such recordings and notes will be used by a coded reference through which I can identify. Once the recording has been written up then the records will be destroyed.
Appendix 6 - Front page of the daily mail stating the 75% of incapacity claimants are fit to work

Source: Daily Mail (2010)
Appendix 7 - Daily express front page stating that 75% who are on sickness benefits are skiving

Source: Daily Express (2012)
Appendix 8 - Front page of Daily Mail implicating that claiming disability benefit is as easy as filling in form

Source: Daily Mail (2012)