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Redistribution and recognition:

A critical examination of the citizenship of people with learning disabilities

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A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for the degree of Doctor of Philosophy

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Abstract

People with learning disabilities (PWLD) are a vulnerable group who frequently experience exclusion within society generally, do not often participate in research, and are usually left out of citizenship theorising. Observing the position of PWLD through a citizenship lens is useful in both highlighting the injustice suffered, the flaws of normative understandings of a concept that promises universal inclusion, and asks what form of citizenship do PWLD consider valuable.

This thesis provides a narrative account of a group of PWLD perceptions and experiences of normative understandings of citizenship. Independence and participation in this normative sense are juxtaposed with the findings that the participants valued feelings of autonomy and inclusion above such normative acts, which are aligned with neoliberal assumptions whereby self-sufficiency, economic contributions and a normative conception of independence are revered.

The citizenship of PWLD is in need of both recognition and redistributive address. The recognition of difference, positive representations, and the need for institutional respect for PWLD are found to be required on the one hand, and redistributive measures addressing economic marginalisation and being in a position where, as a group, PWLD are unable to achieve goals in line with a neoliberal value system.

The thesis concludes that in order for PWLD to experience true inclusion it is necessary to remove discussions of citizenship from expectations in relation to the economy and the ability of the individual to meet neoliberal goals. This is a radical assertion, however, the research findings indicate that a focus on redistribution is central to the true inclusion of PWLD.

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Chapter 1: Introduction

1.1 Introduction

This thesis explores the citizenship of a group of people with learning disabilities (PWLD). Current hegemonic discourses frame a successful citizen as an independent, contributing individual who participates in society in normative ways. I sought to understand how far the individuals involved in the study valued these normative ideals, how far they experienced the independence and inclusion valued by this conception of citizenship, and how citizenship could be used as an inclusionary tool in relation to PWLD specifically.

The research is set within a wider context of contemporary challenges to citizenship rights in relation to excluded minorities, whereby considerations of justice interrogate how far citizenship can be used to facilitate inclusion in contemporary society. These challenges come in various forms but can be divided into two areas: (1) those who see recognition of difference and/or a focus on identity as a necessary addition to citizenship rights in order that excluded minorities can experience inclusion; and (2) those who seek this recognition of difference/identity focus alongside considerations of redistribution. Notably, Nancy Fraser's (2003, 2010) conception of justice is employed to analyse the data as this conception of justice, alongside the preliminary need to address 'representation' (i.e. how far a group are 'seen' politically), sees both recognition and redistribution as in need of address.

Both theoretical and empirical research in relation to the citizenship of PWLD is minimal. Where learning disability has been considered in relation to citizenship theories, PWLD often contradictory position in terms of the expectations of a citizen in a neoliberal age have been highlighted. The present research interrogates the meaning of normative conceptions of independence and participation to those involved in the research, asking how far these understandings are valued and experienced.

This introductory chapter details how I became interested in contemplating the citizenship of PWLD, situates the researcher within the wider research context and gives an overview of the thesis. I detail my previous research experience and working as a support worker at the organisation where I conducted the research in relation to their influence on the present research. These experiences led to an interest in the area and an awareness that the citizenship of PWLD was an under researched area. Although currently on the increase, this is the case in relation to research with PWLD as participants generally. This is followed with a brief outline

of the research context with reference to current constructions and understandings of learning disability in relation to hegemonic neoliberal discourses, and the potential of citizenship to be used as an inclusionary tool. This leads on to an overview of the research contribution with reference to the aims of the research and the niche that they aim to address. An overview of the thesis follows.

1.2 Research inspiration

My Masters research, entitled 'Emotion and professional identities: A comparative study of professionals in Further Education and learning disability support services' (Byrne, 2011) found the perceived underlying ideology to policy was a concern amongst professionals supporting PWLD. Those interviewed were concerned that normative independence was considered a blueprint for success. The promotion of independence was further understood to be detrimental to the current personalisation agenda. For example, the general consensus amongst participants was that when moving people from residential homes into independent living, this must be done with equal focus on what the individual wants as well as what they are capable of. Support workers concerns that truly personalised care was not being provided led me to contemplate the effects of this on the PWLD being supported.

Conducting the research for my Masters allowed me insight into the organisation, leading me to believe I would enjoy working there. I worked as a support worker from July 2010 to December 2014, starting work there 10 months after commencing my Masters research. My working there provided further drive for the present research. As I discuss in greater detail in Chapter 4: Methodology and Methods, I inadvertently carried out participant observation during my time working at the organisation, which I see as beneficial to the research as this fuelled my desire to interrogate the citizenship of PWLD and allowed me to form a rapport with the future participants, many of whom I do not believe I would have gained data as rich from had I been unknown to them.

The concerns highlighted by the staff were compounded by my own experiences of not only attempting to facilitate normative ideals, but also seeing instances where these ideals were not desired. An example of this was the experiences of an individual who had been moved into independent accommodation. He had lived in a residential home all his life before this. This move was in line with hegemonic discourse of independence and organisation goals – the support staff had facilitated independence. However, he was not happy living alone, he was

lonely and would eagerly await the bus each morning to take him to the day centre. This is just one example of many experiences I had and stories I was told that exemplifies a clash of valued outcomes and desires of the individual.

1.3 Research context

The lived experience and perceptions of learning disability have varied to a great extent throughout history, with people with learning disabilities (PWLD) experiencing an array of treatment and constructions, including demonization, euthanasia, segregation, medicalization, 'normalisation', integration, and inclusion. These are not mutually exclusive and continue to affect the lives of PWLD in the present (Neugebauer, 1978; Digby, 1996; Kay, 2003; Gilbert et al, 2005; Goodley, 2000; 2016; Race, 2007; Kevles, 2009; Duffy, 2010; McClimens and Richardson, 2010).

These various constructions of PWLD are discussed in relation to the individual model of disability, normalisation theory, and the social model of disability. The individual model of disability exists in opposition to the social model of disability (Oliver, 1983), understanding an individual to be limited by their impairment; disability is an individual Pathology – the 'problem' of disability belongs to the individual alone. The social model of disability calls into question these understandings of impairment and disability. The limitations which impairment often entails, rather than being discussed as an individual Pathology, is attributed rather to the way in which society is structured (Oliver, 1983). The individual model is a combination of 'personal tragedy theory' alongside the medicalisation of disability, whilst the social model understands the cause of disability to be society failing to take into account the needs of people who are disabled (Oliver, 1990). Whilst useful as a lens through which to understand the experiences and constructions of learning disability, these models of disability grew from a distinction made by the Union of the Physically Impaired Against Segregation (UPIAS, 1976) between 'impairment' and 'disability', explicitly excluding learning disability from this discussion. These models are discussed in detail in Chapter 2: Background and Policy where I consider the use of the social model when contemplating constructions of learning disability, highlighting the problem of understanding disability as caused solely by society's inability to provide adequate support for individuals. This has the potential to overlook impairment, thus overlooking the realities of learning disability (Shakespeare and Watson, 2001; Redley and Weinberg, 2007).

Discussions of the individual and social model of disability run alongside those in relation to the personalisation agenda, a current hegemonic discourse used by government and care providers (Needham, 2011). This agenda is described as a needs based approach to social care services, generally understood to involve individual budgets, direct payments, an ethos of 'person centred care', with the stated aim of facilitating greater inclusion of PWLD in society (Duffy, 2010; Needham, 2011). It has continued as part of successive government strategy (DoH, 2001; 2007; 2009; 2010; 2012; 2014; Emerson et al., 2011), recently evidenced in The Care Act (DoH, 2014). Government goals of 'independence', 'inclusion' and 'participation' are sought in normative, contributive terms, such as participation in education and employment, implying inclusion in these areas will result in both PWLD feeling part of society and fulfilling their social responsibilities (Lewis, 1998; Turner, 1997; Oldman, 2003; Gilbert et al, 2005; Vorhaus, 2005; Redley and Weinberg, 2007; Redley, 2009; Fisher, 2011; Hale, 2011; Ferguson, 2012).

Such goals illustrate adherence to a neoliberal ideology – identified as an ideological undercurrent of governments since 1979 – whereby values in relation to market centred goals dominate (Harvey, 2005; Somers, 2008; Hall, 2003; 2015; Donaldson and Harris, 2015). In terms of neoliberal economics, a free market is seen as a fair and natural ideal, social welfare expenditure should be kept to a minimum, public services privatised, competition is understood as a defining characteristic of human nature, and citizens are seen as consumers (Harvey, 2005). It therefore does not acknowledge coercion within markets, such as domination by large corporations, nor the support and regulatory role of the state in facilitating this domination (Wright, 2003). Wright explains the importance of understanding that the distribution of wealth and income within society is not only the result of the choices made by free acting individuals, but is determined by the rules of the state in relation to the market.

Following from this, a neoliberal ideology, or ''culturalist' approach to political analysis' (Rustin, 2015 p. 88) sees neoliberalism as dominating cultural assumptions, values and aspirations, with the competitive, self-sufficient, contributing individual being the ideal citizen (Driver and Martell, 1996; Harvey, 2005; Somers, 2008; Hale, 2011; Hall and Massey, 2015; Rustin, 2015). Taking this adherence to neoliberal ideology into consideration leads to questions in relation to present conceptions of citizenship. This has been identified as a dangerous situation for PWLD as it means individuals may be seen to fail in fulfilling their responsibilities as citizens if they are not able – because of impairment or lack of opportunity

– to participate in valued ways (Shakespeare and Watson, 2001; Redley and Weinberg, 2007). Those who do not achieve valued goals, which centre on economic self-sufficiency and independence, may be framed as deficient and deserving of their quality of life (Owen, 2012).

Citizenship has long been used as an inclusionary and exclusionary mechanism (Lewis, 1998); all UK citizens are subject to the same rights, although having these rights does not necessarily mean that they are felt by the recipient or granted in practise (Marks, 2001; Lister, 2007). Those theorising in relation to the citizenship of PWLD have highlighted the potentially contradictory position of PWLD in relation to expectations of a citizen in a neoliberal age; expectations of productivity and self-management are juxtaposed by PWLD being potentially unable to achieve these goals, being seen to fail if they do not meet their obligations (Gilbert et al, 2005). In line with others who have interrogated the inclusionary potential of citizenship rights in relation to marginalised minorities (Meekosha and Dowse, 1997; Pakulski, 1997; Shakespeare, 2000; Stevenson, 2001; Hoffman, 2004; Kymlicka,, 2004; Moosa-Mitha, 2005; Yuval-Davis, 2006; Lister, 2007) I therefore contemplate citizenship as a facilitator of the inclusion and exclusion of PWLD.

1.4 Research contribution

Although on the increase, the voices of disabled people are often overlooked in research (Meekosha and Dowse, 1997; Pakulski, 1997; Shakespeare 2000; Stevenson, 2001). This has also been recognised specifically in relation to PWLD (Kiernan, 1999; Kellett and Nind, 2001; Walmsley, 2001; Gilbert 2004; Tuffrey-Wijne et al., 2009; Crook et al., 2015). Involving PWLD in the research as participants, the present research questions hegemonic discourses whereby normative independence and inclusion are valued, contemplating PWLD's limited access to these valued outcomes. As central goals of government policy in relation to PWLD (DoH, 2001, DoH, 2009; DoH, 2014), I therefore wanted to explore understandings and experiences of independence and inclusion, adding to research exploring the citizenship of PWLD (Digby, 1996; Goodley, 2000; Gilbert et al, 2005; Redley and Weinberg, 2007; Bollard, 2009; McClimens and Richardson, 2010).

The present research therefore sought to explore how far normative understandings of 'independence', 'participation' and 'inclusion' were valued and experienced by the participants. This led to the first research aim:

(1) Develop an understanding of participant's perceptions and experiences of 'independence' and 'inclusion' as normatively understood.

This questioning of the idealisation of normative understandings of independence and participation within government policy led to theorising in relation to how far citizenship serves to include and exclude PWLD. Disability theorists have incorporated discussions of citizenship in their theorising, but it is rare that citizenship theorists include reference to PWLD (Lister, 2007). Relatively speaking, there is much research in relation to the citizenship of other marginalised minorities whereby the potential of citizenship as both an inclusionary and exclusionary tool are highlighted, the citizenship of PWLD remaining relatively minimal in comparison. The second research aim therefore to:

(2) Contribute to the development of a citizenship theory in relation to PWLD.

Finally, whilst the methodology and number of participants limits the potential to generalise or make significant policy recommendations, the third aim is to:

 (3) Explore the necessary changes indicated by the empirical research to support the inclusion of PWLD in society.

Whilst I sought to provide a platform for the opinions of the PWLD who agreed to take part in the research, I came to the research with ideals and opinions that I could leave outside of the interview environment more easily than I could leave outside the research project as a whole. For example, what did I see as a just world? What did I think of the idealised goals of inclusion and independence in the way that they are currently understood? An advocate of normalisation theory, for example, would have a very different position to those favouring the social model. Research carried out in the context of normalisation theory would focus on how people needed to change in order to reduce stigma, 'normalising' them, rather than changing society. In contrast, someone approaching the research as an adherent to the social model of disability would likely have the political goal of changing the structures in society in order that disabled people are able to be included. It is important to highlight that the contribution I make will be affected by my own values, assumptions and understandings; an area I will discuss in detail in Chapter 4: Methodology and Methods.

1.5 Terminology: why learning disability?

With reference to the term 'learning disability' there are two points which must be covered: (1) a definition of the of the group of people I am referring to when I employ this term; and (2) why I chose to use the term 'learning disability' as opposed to 'learning difficulty' which is the term currently championed by various UK advocacy movements, disability activists and theorists (e.g. People First, n.d.; Goodley, 2001).

Learning disabilities are usually the result of one of the following: problems during pregnancy and birth, such as the mother being ill or the baby not getting enough oxygen; the baby developing certain genes; or illness in early childhood. In relation to UK terminology, 'mental sub normality' was replaced by 'mental handicap' in the 1970s, and subsequently 'learning disability' replaced 'mental handicap' in the early 1990s. Learning disability corresponds with the term 'mental retardation', the term used in both of the standard internationally used classification systems: the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10 version: 2016), produced by the World Health Organisation (WHO, 1993), and the Diagnostic and Statistical Manual of Mental Disorders 4th Edition (DSM-IV), produced by the American Psychiatric Association (APA, 1994). Within these classification systems all health problems are assigned to a unique category and given a code. ICD-10 defines 'learning disability' as:

> A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition. (WHO, V, F70 – F79)

Classifications of learning disabilities are based on intelligence quotient (I.Q.) tests and scales assessing social adaptation being used to evaluate an individual's intellectual functioning. Classification is dependent upon how far a person falls from the 'normal distribution'; how far they differ from the general population. There are six classification categories ranging from 'mild' to 'profound', as well as 'other' and 'unspecified'. The Valuing People (VP) (DoH, 2001) policy states:

> …people with learning disabilities are people first. We focus throughout on what people can do, with support where necessary, rather than on what they cannot do. Learning

disability includes the presence of: a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development. (p.14)

I have chosen to employ the term 'learning disability' in line with UK government usage (DoH, 2009), as well as this being the term used by leading learning disability charity, Mencap, and both the organisation where I conducted the research and the participants involved in the research. Mencap, in explaining their use of the term learning disability as opposed to learning difficulty state that 'learning disability is often confused with dyslexia and mental health problems. Mencap describes dyslexia as a "learning difficulty" because, unlike learning disability, it does not affect intellect.' (Mecap, n.d)

I note debates regarding terminology. 'Learning difficulty', is the term advanced by advocacy group, People First (n.d), as well as by theorists and activists in the area (e.g. Goodley, 2001). People First explain:

…we believe that people labelled as having a learning difficulty are disabled by society. We choose to use the term 'learning difficulty' instead of 'learning disability' to get across the idea that our learning support needs change over time.' (People First, n.d)

Making reference to people with learning disabilities as one homogenous group is potentially problematic as the severity and manifestations of learning disabilities are innumerable and differ vastly, however, it is because of this very nature of learning disability that it would be difficult to attempt to categorise people further, or to avoid categorisation altogether, discussing people's needs on an individual basis. I discuss how definitions of this group have changed over time and the influences upon definitions in Chapter 2: Background and Policy. The inclusion of a historical trajectory of the treatment and constructions of PWLD demonstrates the varied conceptions of learning disabilities and the effect of these on PWLD. I then go on in Chapter 3: Citizenship and Justice to discuss the positives and negatives when grouping individuals together.

1.6 Thesis outline

Chapter 2: Background and Policy observes the various conceptions and treatment of PWLD throughout history, focussing on the industrialisation period onwards, in order to frame the

present as well as contemplate how past assumptions continue to affect the present day experiences of PWLD. Following a discussion of the industrialisation period which demanded speed and efficiency of the workforce, I move through discussions of the eugenics movement of the late 19th century; the post Second World War era which is linked to the creation of the welfare state; the disability rights movement of the 1970s; the social and individual models of disability and the 'normalisation' agenda; finally I explore present day hegemonic discourse in relation to the continuing 'personalisation' agenda. This agenda, which is generally understood to stem from disability rights social movements and community care reform (Brookes et al., 2015), has continued to receive cross party support since it's official introduction by the New Labour government in 2007 (DoH, 2007), most recently evidenced in The Care Act (DoH, 2014).

I move on within this second chapter to question how far personalised support, which is set within a dominant neoliberal ideology, whereby a successful citizen is framed as someone who is able to carry out certain performative competencies, can be positive for PWLD (Digby, 1996; Goodley, 2000; Gilbert et al, 2005; Redley and Weinberg, 2007; Bollard, 2009; McClimens and Richardson, 2010). This is discussed in relation to the current neoliberal social settlement which sees citizens judged in relation to their ability to contribute in valued ways centring on independence, self-sufficiency and economic contributions (Harvey, 2005; Somers, 2008; Hall and Massey, 2015; Rustin, 2015). Fraser explains that when a person does not contribute in these valued ways they are seen as '… comparatively unworthy of respect.' (Fraser, 2003 p. 27). These discussions of the historical context, models of disability, government agenda and a neoliberal climate, are followed in Chapter 3: Citizenship and Justice with questions concerning the citizenship of PWLD. The sources of noted exclusion are contemplated alongside understandings of citizenship in relation to this marginalised group.

Chapter 3: Citizenship and Social Justice introduces the concept of citizenship, giving an overview of historical uses of citizenship as both an inclusionary and exclusionary tool; from its exclusionary role in Ancient Greece where women, slaves and people with impairments were not considered to be citizens by law, to the present where theorists have used the concept to challenge the exclusion of marginalised groups (Turner, 2007). In the present, although an individual may be classed as a citizen, their exclusion in various ways sees their citizenship wanting (Lister, 2007; Stevenson 2001; Pakulski, 1997; Moosa-Mitha, 2005). This is followed by a discussion of universal and particularist rights in line with recommendations by the above

theorists that differentiated approaches to citizenship better suit those who hold marginalised positions in society. Universal rights are problematic for those who do not or are unable to adhere to accepted knowledge and achieve normative valued outcomes (Turner 1997), such as PWLD. On the surface, universal rights do not appear exclusionary with their equal treatment of all; however, I discuss here the pros and cons of this philosophy and the problems that may arise when differences between individuals are overlooked. Being in possession of rights is not considered to be enough when hierarchical power structures negatively affect minorities (Simon, 2001; Bollard 2009, Gilbert et al., 2005).

Theories of recognition and identity are discussed at length alongside theories of redistribution and materialist inequalities in this chapter in relation to the citizenship of PWLD. Theorists advocating the need to consider both in tandem state that amidst the widening socio-economic gap, identity politics and theories of recognition alone cannot remain the focus of theories of citizenship (Fraser, 2003, 2010; Somers, 2008; Piketty, 2014).

Chapter 4: Methodology and Methods justifies employment of a narrative methodology in relation to my ontological and epistemological understandings, as well as in relation to carrying out research with PWLD, and with regards my decision to use a thematic approach to data analysis. The practicalities of the research are covered, including access and recruitment methods, the substantial issues in relation to the consent process, the process of data collection, data analysis, and a reflection on the research process. A central concern in relation to the methodology and methods was that they facilitated the inclusion of the participants in the research; adaptability was therefore an essential. Efforts in relation to carrying out research that led to the participants being included in the research, is therefore a central point of discussion in this chapter.

Narrative methodology fits with the goals of my research as it can be used as a tool with which to challenge taken for granted discourses, and is a process by which agency is afforded to the participants; the voices of the marginalised can therefore be heard and empowerment facilitated (Gilbert, 2004; Baldwin, 2008; Lesseliers et al., 2009). It therefore fits with the goals of this research. This emancipatory potential was evidenced throughout the research process, pertinently by a number of the participants who expressed their appreciation and surprise that their stories were the subject of the research.

I carried out eighteen semi structured interviews with PWLD from the organisation where I once worked as a support worker. To different degrees, I knew all of the participants prior to carrying out the research. I wanted to gain an understanding of PWLD perceptions of independence, participation and inclusion and explore what they valued in relation to these concepts. For example, did they value independence in the way policy assumes? Investigations of perceptions are recognised as a difficult task, especially when coupled with my third aim of exploring the necessary changes indicated by the empirical research to support the inclusion of PWLD in society (Silverman, 2013). Such a goal involves the interpretations of the researcher to be made into practical suggestion. The exploratory nature of this research means I do not aspire to be able to generalise the findings, rather, I wish to justify the conclusions I have drawn and contribute towards a body of work that supports the greater inclusion and understanding of PWLD.

Chapter 5: Independence and Autonomy, Chapter 6: Participation and Inclusion, and Chapter 7: Redistribution, Recognition, Representation detail the research analysis. The research process can be best described by Holliday (2007) who explains that qualitative studies involve '…an unfolding story in which the writer gradually makes sense, not only of her data, but of the total experience of which it is an artefact.' (p. 122) I found that independence and inclusion are often not understood and/or desired in the same terms as have been identified over an extended period in policy and rhetoric (Pateman, 1989; Gilbert et al., 2005; Harvey, 2005; Clarke 2005; Redley and Weinberg, 2007; Seymour, 2010; Hale 2011; Hall, 2015; Rustin, 2015). The analysis made clear it would be useful to discuss the normative understanding of independence in conjunction with the concept of autonomy. As such, I developed two separate analysis chapters in relation to the first research aim: (1) Independence and Autonomy and (2) Participation and Inclusion.

In Chapter 5: Independence and Autonomy I explain that although 'independence' and 'autonomy' may be used as synonyms, I use them here in exclusive ways as it became clear that the participants desired the opportunity to make decisions about their lives – which I term autonomy – above normative definitions of independence which, as I have discussed, are understood here as aligned with economic imperatives (Hall, 2003; Somers, 2008). A continuing government agenda refers to the ideal that PWLD be independent, particularly in relation to living independently and working, at the same time as advocating the ability of PWLD to be autonomous and make decisions about their lives (DoH, 2009). In line with others

(Oldman 2003, Fisher 2011, Somers 2008), I question the ability of these hegemonic discourses to positively affect the lives of PWLD.

Chapter 6: Participation and Inclusion goes on to juxtapose these two concepts as the research findings illustrated that whilst policy espouses the need for PWLD to participate in society in order that they feel a sense of inclusion, the participants valued feelings of inclusion above acts of normative participation. The areas of participation identified in the data were: family, school, work, and community. In the same way that independence does not equal a sense of autonomy for the participants, and a sense of autonomy is rarely equated with independence in the normative sense, the data indicates that nor do acts of participation equal a sense of inclusion. The findings here are also linked to those in the previous chapter as a sense of autonomy affected how far acts of participation were valued – did they choose to participate in society or were they directed by support workers and family, for example. The data discussed in both chapters 5 and 6 therefore illustrates the necessity to differentiate between an action (i.e. independence and participation) and a feeling (i.e. autonomy and inclusion).

In relation to Chapter 7: Redistribution, Recognition, Representation, as the analysis developed it became apparent that the degree to which material factors played a role in how far the participants were able to live their lives in the way they chose. In addition it became clear that opportunities for inclusion within society were affected by structural barriers, as well as factors relating to recognition and agency. The research therefore reinforced the necessity to look at the macro as well as the micro; structural inequalities are not addressed in policy with the same weight with which the individual is focussed on. The policies focus on the micro, with the macro addressed only in terms of the opportunities that are provided for PWLD. Participation in society is largely framed as an individual issue once the opportunities for participation have been granted. The interviews highlighted the need to look at the bigger picture. As such, the findings detailed within the first two analysis chapters focussed closely on identity and recognition based theories, and appropriately so, but did not sufficiently address materialist understandings. Fraser (2003) notes that there has unfortunately been a general move away from materialist based understandings, towards identity based models amongst theories of justice and citizenship (Fraser, 2003). This chapter therefore culminates in the inclusion of materialist discussions in relation to the citizenship of PWLD in line with those who strive to return to materialist alongside post-socialist considerations (Young, 1990; 1997; Fraser, 2003; 2010; 2013; Somers, 2008), as the findings indicated that the participants both desire and

require a combination of recognition and redistribution to facilitate inclusion in society in both a way that they desire and a way that is just.

Finally, Chapter 8: Conclusion draws the present research to a close and indicates the possibilities for future research and theorising in relation to the citizenship of PWLD. This chapter includes a summary of the main research findings; details the empirical, theoretical, philosophical, and methodological contributions to knowledge; discusses the limitations and recommendations for future research; and details my final thoughts. The chapter discusses the main research findings in relation to citizenship's capability to facilitate both inclusion and exclusion. The exclusionary effect of a lack of resources are the focus here, being identified as a barrier to both autonomy and inclusion – areas valued by the participants – as well as the normatively valued areas of independence and participation. Resources are discussed as in need of separate address from theories of recognition, which differentiated citizenship theories predominantly advocate. The contributions to knowledge include an address of the exclusion of PWLD within citizenship theorising and within research generally; a critique of normative assumptions; it adds to a discussion of the ethicality of informed consent, arguing the need for this to be a process that continues throughout the research; and finally, it adds to a critique and expansion of narrative methodology in relation to participants with communication difficulties. The limitations of the research are discussed alongside recommendations for future research, which leads to the final section where I advance the need to include discussions of the potential for a 'universal basic income' as a remedy for the social injustice and exclusion experienced by the participants.

Chapter 2: Background and Policy

2.1 Introduction

In order to understand the contemporary position of PWLD it is essential to address the wider historical and policy context that has framed them over time. This chapter observes the various conceptions and treatment of PWLD throughout history, focussing on the industrialisation period onwards, in order to frame the present and contemplate how past assumptions and treatment have affected the present day lived experiences of PWLD. I observe various points throughout recent history which I consider to have significantly shaped the present. The aim of this chapter is therefore to contemplate current expectations of an individual in relation to economic realities and cultural assumptions, in relation to the ways in which PWLD experience inclusion and exclusion. This leads on to theorising citizenship in Chapter 3: Citizenship and Social Justice and how PWLD could experience greater and more meaningful inclusion in society.

The first section involves a brief look at the treatment and understandings of learning disability pre-industrialisation. I then take the point at which industrialisation came into effect in the early 19th century as the main point of departure from to begin relating the past to the present. This period saw PWLD being forced out of work as the demands of industrialisation meant workers who were fast and efficient were required. I then go on to look to the Eugenics movement of the late 19th and 20th century; this movement had dire consequence for PWLD, resulting in segregation, sterilisation and genocide. The period following WWII is noteworthy; the events of the war led to a focus on human rights, and legislative changes followed.

In the second section I look at the disability rights movement of the 1960s and 1970s, which saw people with physical impairments in particular calling for their rights to be addressed. This movement is discussed in relation to the Social Model of Disability and Normalisation theories which emerged at this time. These theories, whilst markedly different in their theoretical foundations, both sought the greater inclusion and address of wellbeing of those with impairments. This theoretical discussion leads to a focus on how such theories of inclusion have been related to PWLD in recent policy in the UK. I identify the dominant application of normalising strategies to PWLD. The Social Model and Normalisation theories, I argue, whilst useful in their focus on wellbeing are inadequate when applied to PWLD because of their failure to address impairment as a feature of an individual.

The third section discusses the impact of neoliberal ideology. Neoliberalism is understood to have infiltrated government policy and values since the Conservative government of 1979. It has contributed to wide common sense assumptions that the free, independent, competitive individual that contributes economically to society is the ideal, and those who fail to meet these criteria are regarded as failing in their duties as citizens (Harvey, 2005; Clarke 2005; Seymour, 2010; Hale 2011; Hall, 2015; Rustin, 2015). It is my contention that the challenges and lived experiences of PWLD cannot be fully understood without addressing this wider ideological context.

2.2 Historical trajectory

2.2.1 Pre-industrialisation

The treatment of people with impairments has varied across time and place, highlighting how understandings of disability are fluid and socially constructed. These constructions have been influenced to differing degrees – depending on theoretical position – by the individual's impairment, historical context, current socio-cultural circumstances, and dominant hegemonic narrative (Finkelstein, 1980; Stiker, 1997). An example given by Stiker (1997) of differences across space was that in Sparta, a state in Ancient Greece, the law stated a baby was not considered a child until seven days after it was born, meaning infanticide could be carried out if a baby had a noticeable physical impairment. In Sparta this infanticide of those with visible disabilities was carried out as a matter of course, whereas in other parts of Ancient Greece at the same time this was practiced for economic reasons alone – when a family had more children than they could look after.

Late Medieval and Early Modern English history indicates on the one hand that those considered 'insane' – which would often have usually included PWLD alongside those with mental health conditions – were subject to cruel treatment, the subjects of witch hunts, and blamed for bringing diseases such as the plague upon a community. However, evidence also shows a move during this time to the employment of naturalistic criteria, such as physical and mental health assessments, in the evaluation of those believed to be mentally ill or learning disabled, followed by humanitarian efforts to make provisions for their wellbeing (Neugebauer 1978). Neugebauer explains that this change in treatment is often said to have influenced by the Age of Enlightenment whereby scientific investigation was gaining prominence, however,

other evidence indicates in some jurisdictions, such criteria was used as early as the 14th century.

These examples are intended as a brief highlight of the ever changing multiplicity of treatments and understandings of learning disability that have existed both across time, place, and in parallel within a society. It is necessary to briefly discuss the position of people with impairments before the Industrial Revolution in order to illuminate the changes which occurred in terms of the position of PWLD following this point in history; changes which have continued today (Oliver, 1990).

2.2.2 Industrialisation era

The Industrial Revolution brought changes to the working environment and understandings of work that were to continue to the present day (Oliver 1990). Oliver explains how an ideological shift at this point meant people with impairments were to be assigned the position of the 'other' as a result of having greatly reduced opportunities to take part in working life. Industrialisation resulted in both the pace at which one was expected to work, and the separation of home and work – whereby factory settings became the norm – leading to PWLD having little opportunity to be part of the work force.

Generally speaking, whilst before Industrialisation the treatment and understandings of learning disability varied considerably, PWLD were not excluded from work as a matter of course. In contrast, following industrialisation they were excluded both physically and ideologically (Finkelstein, 1980). Industrialisation and capitalism established a hegemonic narrative of individualisation which distinguished between those considered 'able-bodied' and those who were not (Oliver, 1990). If a person was not able-bodied, this was considered an individual Pathology. It was the individual impairment that excluded them from the workplace not the failure of employers to accommodate their disability, as the social model was later to expose.

The 1834 Poor Law Amendment Act was important in relation to PWLD and others, such as people with mental health issues, who were experiencing reduced opportunities to take part in employment as a result of industrialisation. This act resulted in those considered 'idiots' or 'lunatics', who had been forced out of the labour market following the commercialisation of agriculture, being placed in workhouses as the act resulted in provision of poor relief being given only via the workhouses in an effort to deter individuals claiming relief that they did not

need. This change resulted in those unable to financially sustain themselves being viewed as 'deviants' (Wright, 2010). Such 'deviants' included PWLD; the criteria required for a worker to be capable had shifted with the ever increasing rate of production forcing many out of the labour market (McClimens and Richardson, 2010).

In 1845 the Asylums and Lunatics Act stipulated that the pauper 'insane' were to be sent to asylums, furthering the creation of a separate social group. However, there was a loophole in the Act which meant it was only the 'violent' or 'unruly' who were admitted, whilst others remained at home or in workhouses. By allowing people to remain in the workhouses the government saved money, as they did not have to invest as much in the asylum system (McClimens and Richardson, 2010). McClimens and Richardson explain that this, combined with the medical establishment's mixed beliefs about whether those with incurable 'lunacy' were appropriately placed in hospitals, meant the establishment of separate hospitals was delayed until early twentieth century when the Minority Report of the Poor Law Commission (1909) and the Mental Deficiency Act (1913) were published.

In relation to this, later in this chapter, I will discuss the theoretical position of Mike Oliver (1983; 1990; 2013), a prominent disability rights activist and theorist in the field of disability studies. Oliver (2013) represents a number of disability theorists, such as social model pioneer, Vic Finkelstein (1980; 2001), who have analysed the perceptions and experiences of disability though a Marxist lens, explaining disability as a consequence of materialist conditions whereby the mode of production is concomitant with the hegemony of individualist discourses of disability.

2.2.3 Eugenics and the medicalisation of learning disability

This individualisation of impairment, alongside the rise of the eugenics movement in the late 19th/early 20th century, changed the role of the medical establishment and the 'professional' with regards PWLD, increasingly leading to the 'medicalisation' and segregation which continues to the present day (Richardson, 2005). 'Medicalisation' sees medical understandings of – and power over – natural experiences and issues that were once not a medical concern (Foucault, 1963; Illich, 1976). Examples of medicalisation include childbirth (Oakley, 1987), aging (Skrabanek, 1995), and disability (Schwartz Cowan, 1972; Kevles, 1999), all of which are not the result of illness, but are often under the control of a medical authority and viewed in medical terms.

The term 'eugenics' is derived from the Greek words, 'eu', meaning 'true or noble', and 'genos', meaning 'to give birth'. The term was conceived by Francis Galton, cousin of Charles Darwin, in his book entitled 'Human Faculty' in 1883. Galton (1907) acknowledged his contribution to the founding of the eugenics movement, explaining he had '...kindled the feeble flame that struggled doubtfully for a time...' (p. 7). He believed that his aim to improve the racial qualities of mankind was ahead of its time and thus he had to wait for popular opinion to also recognise the need.

Galton believed that if the parents are afflicted with some form of 'degeneracy', then the children would be affected. The question of how far the children would be affected was held to be easily determined when certain facts were collected. He makes reference to the maxim: 'It is better that many guilty should escape than that one innocent person should suffer' to which he follows with the belief: 'But that is not the sentiment by which natural selection is guided, and it is dangerous to yield too far to it.' (1907 p. 14)

He saw the involvement of emotion in human action as a hindrance, citing it as one of the reasons eugenics based policies may face barriers in their implementation:

> Human nature is such that we rarely find our way by the pure light of reason, but while peering through spectacles furnished with coloured and distorted glasses. (1907 p. 24)

He advocated the need for reformers, such as himself, to overcome the influences of customs or prejudices, and promote the inclusion of eugenics in society. Explaining that the: '…enlightenment of individuals is a necessary preamble to practical Eugenics...' (p 24). He goes on to acknowledge that the arrival of eugenic practices may be perceived as drastic and there will be worries about its acceptance in society, however, he believed public opinion was often more advanced than private morality and the former would lead to the latter, noting that: '...whenever public opinion is roused it will lead to action, however contradictory it may be to previous custom and sentiment.' (1907 p. 29).

This conviction that once public opinion was roused then the implementation of eugenics policies could occur, is addressed by Kevles (2009) who states: 'Eugenics fell squarely in the mainstream of popular and scientific culture' (p. 86); it came to fruition during a time when concerns were being raised about the hindrance of the poor and 'degenerative' upon society. Kevles (2009) makes an important contribution not just to our understanding of the eugenics

movement, but our understanding of learning disability in the present, with the statement: '...we need to bear in mind that science is in any day what scientists do and defend.' (p. 86).

In relation to this warning, the eugenics movement was pioneered by those seeking to reform Western Europe and North America, at which time the 'feeble-minded' and those whose genes were said to dictate them to be paupers and criminals were blamed for the social problems in society (Race, 2007).

In the USA there were fears that the believed racially inferior Eastern Europeans – believed so in part because they were disproportionately represented in the 'degenerate' sections of society – who were migrating to the country at the time, would affect the quality of the Anglo-Saxon American gene pool, considered racially superior. There were fears that in the event that the Eastern Europeans were to procreate at a faster speed, they would eventually outnumber those who considered themselves Anglo-Saxon descendants (Kevles, 1999).

Whilst in the UK, the practice of eugenics was motivated by the need to reproduce upper-class values, therefore reducing the amount of 'degenerates' in society. This grouping included poor people, criminals, those considered 'social degenerates' – such as prostitutes, and the physically and intellectually disabled (Ekberg, 2007). Even after the science behind the eugenics movement had been shown to be flawed, The Eugenics Society continued a successful campaign for voluntary sterilisation, focussing on the poor (Mazumdar, 2002). The infanticide of Ancient Greece was replaced with sterilisation for those unable to support their families financially, and PWLD, if not already incarcerated, were sterilised as part of the poor class.

Observing eugenics practices by country illustrates political goals dictating to whom they were applied; in the USA, Eastern European immigrants, the mentally ill and those with impairments were targeted as they were considered the biggest threat; in the UK the poor were the focus (Kevles, 1999). The Nazi Holocaust was preceded by the sterilisation and murder of 400,000 and 70,000 disabled people respectively (Ekberg, 2007). These are just some examples.

Although eugenics were recognised as a 'farrago of flawed science' (Kevles, 1998 p. 164) by the late 1930s it was still pursued by 'reform eugenicists' (Kevles, 1998). The decline in scientific support did not seem to alter its application, and as Schwartz Cowan (1972) notes; 'Science dominated by political ideology is one thing, but science stimulated by political theories and directed toward social goals may be quite another' (p509). Eugenics neither rose nor fell based on its scientific credibility, appearing to be a social, rather than scientific

movement, the social context instead determining its course (Allen, 1999). Allen explains; 'The problem comes when we pretend that science is in fact not culturally situated and therefore fail to examine which cultural biases or ideas help and which hinder our understanding of the phenomenon...' (p10). Further to this, Kliewer and Drake (1998) suggest the scientific basis for state institutions is based 'not [on] science, but an ideology of segregated control' (p. 98). They refer to the creation of professions in relation to disability as 'Technical Rationalism', which they describe as 'evoking an illusion of objective science to support particular practices in the tradition of segregation while squelching dissenting voices' (p. 96). Arguably then, state institutions needed eugenics in order to claim objectivity and thus rationalise their controlling of the populace; the term 'Scientism' is used by Hunter (1990) to describe the use of such language in order to hide an ideology of segregated control.

It is difficult to dispute the claims of Kliewer and Drake (1998) that; 'The science of segregation, originating with eugenics, supports the notion that difference must be stigmatised, contained and eliminated from the community' (p107). This is especially true when we consider programmes founded on the practice of eugenics were continued even after the science behind them was disputed or shown to be false.

In relation to PWLD in the UK, the eugenics movement led to increased incarceration as eugenicists called for the government to create institutions with the purpose of preventing procreation negatively influencing the gene pool (Goodley, 2000; Kay, 2003; McClimens and Richardson, 2010). Learning disabilities came to be considered increasingly in medical terms; if PWLD came into contact with medical agencies it was usually the case that they would be incarcerated. McClimens and Richardson (2010) explain that '…the mesh of scientific discovery, of increasing industrialization, of medicine and political theory were all combining to alter the relations of the individual to the society they inhabited.' (p. 23). These observations are relevant to the present concern regarding the inclusion PWLD as they illustrate the way in which social issues can be constructed and managed when justified by science. Such points in the history of learning disability are not mutually exclusive. For example, the influence of eugenics have not disappeared and are now evident in more subtle ways, such as the continued, albeit under a different guise, institutionalisation of PWLD, and the deprivation which they continue to experience in policy (McClimens and Richardson, 2010).

2.2.4 Post-World War II

The Holocaust saw the mass murder of Jews alongside other minority groups, including disabled people, who did not fit the 'Aryan' prototype. This persecution turned public and political opinion away from eugenic ideas as they witnessed the horrors it could result in, and led to the Universal Declaration of Human Rights (UN General Assembly, 1948) in order to protect and ensure all individuals had access to the same human rights (Emerson and Ramcharan, 2010; McClimmens and Richardson, 2010). This was followed in 1971 by the United Nations Declaration on the Rights of Mentally Retarded Persons (UN General Assembly, 1971), in an attempt to ensure the human rights of those with 'mental disabilities' were protected.

Although the period after the Second World War has been linked to a period of 'normalization' (McClimens and Richardson, 2010), the actual treatment of PWLD remained very much the same as the pre-war days (Race, 2007). Following the establishment of the National Health Service (NHS) in 1948, the control of the institutions, in England referred to as 'colonies', was moved from local to central government. The main change to affect the lives of PWLD was the added credibility that the welfare state and medical profession gave to the establishments – now called 'hospitals' – in which PWLD were placed (Race, 2007; McClimens and Richardson, 2010). Learning disability was thus 'medicalised' further; PWLD were viewed through a medical lens, with all aspects of an individual's life being monitored by the medical establishment (McIntosh, 2002; Goodley and Tregaskis, 2006).

As discussed earlier, McIntosh (2002) observes this medicalisation in relation to the period following industrialisation and during the rise of eugenics when PWLD were incarcerated in institutions. McIntosh contends that very little has changed in the present as PWLD experience the same surveillance and control but different methods are now employed to carry this out:

> Emancipated from institutions, PWLD now undergo assessment of their strengths, capabilities and weaknesses. Every deficiency is logged and plans are drawn up to correct this…lives and thought are explored, interpreted, and broadened to a wider audience. Sexual orientation and practices of the individual are observed, judged, monitored, restricted and discussed in 'open' forums such as case conferences and psychiatric consultations as to their appropriateness. The lives of people with learning disabilities are played out publicly. (McIntosh, 2002, p.73)

This medical authority – be it those on the front line of care, or the medical establishment itself – Foucault (1984) explains, is a disciplinary power which defines how a person should experience their own bodies. Foucault's understanding of power relations between the individual and the medical establishment involve lives being experienced through hegemonic medical discourses. Foucault observes both the positive outcomes of medical discourses dominating understandings of the body (i.e. treating illness) and the negative (i.e. individuals understanding their bodies in subscribed terms). Foucault's understandings of the medical establishment's power has been critiqued as overlooking individual agency (Lupton, 1997). For example, for a lack of acknowledgement of any potential for these dominant discourses to be challenged and altered by the people whom they subjugate as well as those who are a part of the medical establishment. However, Foucault's understanding is particularly pertinent when contemplating the medicalisation of PWLD, as this is a group of people whom we can observe as having been historically subjugated and denied agency through practices of institutionalisation. This historical overview has highlighted the various ways that PWLD have been denied agency, institutionalised and excluded from society in order to view the present historically. The lives of PWLD continue to be dominated by medical discourses, their existence and experiences understood in medical terms.

2.3 Theories of disability

2.3.1 Disability rights, normalisation and the social model of disability

Social movements are a means by which groups of people collectively seek and bring about political and cultural changes (Staggenborg, 2016). Tarrow (2011) discusses these movements as a 'cycle of contention', whereby collective action spread from one group to another. The Civil Rights Movement of mid-1950s – late 1960s USA, with its promotion of a universal vision of human rights, and questioning structural and cultural exclusion of minorities, is identified as the catalyst for many subsequent movements, including gender equality, sexual equality, and the disability rights movement (Staggenborg, 2016).

Two major events occurred during this period in relation to disability rights: (1) the Union of the Physically Impaired made a distinction between 'disability' and 'impairment' (UPIAS 1976). This was the foundation for the Social Model of Disability whereby an individual may have an impairment, but their disability is socially constructed by the way society treats the person (Oliver, 1983); and (2) the concept of 'normalisation' emerged, the aim of which was

to integrate PWLD in society. This involved two strands; PWLD being portrayed positively in order that they are perceived in a positive manner, resulting in their acceptance by mainstream society; and by their holding respected social roles, which would meant they were then valued by society (Wolfensberger, 1982; Wolfensberger, 1980; Wolfensberger and Tullman, 1982). In summary, the social model sought changes in order that society accommodates the individual, and normalisation sought ways in which the individual could be allowed to participate in society as it stood.

The social model of disability exists in opposition to that which is termed the medical or individual model of disability (Oliver, 1983). This model understands an individual to be limited by their impairment, rather than being disabled by society's barriers and perceptions; disability is an individual pathology. The Social Model of Disability, is a pivotal theory whereby understandings of impairment and disability were called into question in a way that was to affect the way in which disability was to become to be understood (Goodley, 2001). The limitations which impairment often entails, rather than being discussed as an individual pathology, was attributed rather to the way in which society is structured (Oliver, 1983). The Social Model understands society to be the cause of physical and cultural barriers, with changes to which resulting in the individual having greater opportunity to participate and be included in society. Although the social model was not founded in relation to PWLD, but specifically physically disabled people, the model has since been used as a theory from which to contemplate the inclusion of PWLD (Chappell, 1998; Goodley, 2001). The question of 'what is disability' is therefore discussed as a structure-agency debate – to what degree is disability caused by societal oppression and to what degree is it the result of individual impairment (Thomas, 2004).

Normalization, also called 'social role valorisation', is a theory of integration whereby people with disabilities are helped and encouraged to live life in a way that is in line with the way the majority of those in society do. For example, holding valued social roles and participating in community life, as well as having a routine in line with the rest of society, such as having a working week and weekends (Wolfensberger, 1980; Wolfensberger and Tullman, 1982).

The Independent Living Fund (DOH 1988) is an early example of policy in line with Normalisation theory and illustrates a continued alignment with the Individual Model of Disability. This policy sought deinstitutionalization, aiming to enable disabled people to live in the community, rather than in residential homes as was predominantly the case previously.

In terms of progress, Normalisation, like the Social Model, was positive for the welfare of disabled people as it pushed for a focus on quality of life (Race, 1999), and '...paved the way not only for more inclusive policies, but for more inclusive research' (Walmsley and Jamesson 2003, p 48). However, this model also reinforced a dichotomy between 'normal' and 'abnormal', resulting in attempts to integrate people into mainstream society, instead of the creation of a more inclusive and accepting one (Oliver, 1996b; Marks, 2001). Instead of allowing for, and accepting, difference, this understanding held the non-disabled as the ideal.

Oliver (1983; 1990; 2004; 2013), as founder of the social model of disability, has been consistent in his critique of normalization theory. Oliver states that both the UPIAS's Fundamental Principles of Disability, and the social theory underpinning Marxism, are far more useful and appropriate to the improvement of the lives of disabled people than functionalist practices of normalization could ever be, stating: 'normalization…is…at best a bystander in these struggles, and at worst part of the process of oppression itself.' (Oliver, 2004 p. 81).

In 1993, the United Nations General Assembly's resolution provided further evidence of societal alignment with the individual model in their definition of disability. Without mention of any need to examine the influence that social structures have upon an individual's experiences, they state:

> The term "disability" summarizes a great number of different functional limitations…People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature. (Paragraph 17, UN Enable 1993)

Also in adherence with an individualist understanding of disability, The Disability Discrimination Act (1995) defined disability as 'Either a physical or mental impairment, which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities' (HMSO 1995: section 1.1). Continuing this theme, the Equality Act (2010) in their 'Key Concepts' section, discussed disability without reference to material, structural or identity related barriers, defining disability as an individual pathology:

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

normal day-to-day activities. (2) A reference to a disabled person is a reference to a person who **has** a disability.' (my emphasis)

The terminology is important here. In relation to the quote above, to 'have a disability' implies that this is static and stems from the individual. Whilst referring to someone as a 'disabled person' implies a possibility for change – they may be disabled *by* something. Both quotes above problematically conflate 'disability' and 'impairment'.

In terms of success of the social model of disability and the disability rights movement, the late 20th century saw a move towards the 'personalisation agenda'. This agenda was hailed a triumph due to individual budgets, direct payments, an ethos of 'person centred care' being seen to represent individualised care and looking to the specific needs of the individual (Duffy, 2010). The personalisation agenda is evident in the *Community Care and Direct Payments Act* (DoH, 1996) and *Valuing People* (DoH, 2001), being officially introduced by the New Labour government in *Putting People First: a shared vision and commitment to transformation of adult social care* (DoH, 2007). This agenda has since continued to receive cross party support (Needham, 2011; Brookes et al, 2015; Durkin and Gunn, 2017). Most recently this is in the form of the The Care Act (DoH, 2014). However, this personalised support is understood to be set within a hegemonic neoliberal ideology evidencing contractual goals (Hale 2011). Despite the discourse of 'personalisation' over the past decade being discussed in relation to a focus on individuals rights, choice and needs, there has been a movement towards rights being framed as earnt (Shakespeare, 2000; Oldman, 2003; Hale, 2011; Fisher, 2011; Reindal, 2009; Needham, 2011; West, 2013). West (2013) contends that the 'ideological efficiency' of personalisation serves to silence critiques of austerity by framing such positions as inherently paternalistic and anti 'choice and control'.

2.3.2 The social model and learning disabilities

PWLD are often left out of Oliver's (1983) social model, with the focus being on those with physical impairments (Chappell et al., 2001). This is understandable with its focus on the need to remove the disabling physical barriers in society, which the acknowledgement of impairment – essential when discussing PWLD (Shakespeare, 2013) – would seemingly confuse. However, in relation to both those with physical impairments and those with learning disabilities, I am aligned with those who call for impairment to be acknowledged as an aspect of an individual, being neither seen as potentially negatable by the removal of structural or cultural barriers (in

line with the Social Model), nor seen as the sole reason for a person experiencing exclusion (in line with the Individual Model) (Abberley, 1987; Shakespeare and Watson, 2001; Gilbert, 2004; Redley and Weinberg, 2007). Shakespeare and Watson (2001) explain:

> …the British social model has been an excellent basis for a political movement, but is now an inadequate grounding for a social theory. This social model was a modernist project, built on Marxist foundations… We believe that the claim that everyone is impaired, not just 'disabled people', is a far-reaching and important insight into human experience, with major implications for medical and social intervention in the twenty-first century. (p. 23)

In relation to such critiques of the social model of disability, Thomas (2004) looks at case studies of prominent sociologists, observing a noted divide between theorists working in disability studies and those working in medical sociology. Contemporary disability studies theorists typically understand disability as '…centrally structured by social oppression, inequality and exclusion' (p. 570), whilst medical sociologists understand disability as '…caused by illness and impairment and entails suffering and some social disadvantage.' (p. 570) For PWLD it seems that both require acknowledgement.

Drawing on the social model, Digby (1996) examines learning disability historically, noting similarities between the 'hospitals' and 'colonies' of the past, and the more recent care in the community settings emerging in the 1970s. The majority of social problems suffered by those in institutions were the same as those apparent in Digby's study of more recent community care settings. She found inadequate funding, stigmatisation and the positioning of PWLD as objects, as issues which have not been overcome simply because the environment in which they live has altered. Digby calls for 'a reinventing of social perceptions' (p. 18) alongside the addressing of structural conditions.

More recently measures introduced to aid the inclusion of PWLD in society, and enable them to live more independent lives (DoH, 1988; DoH, 2001; DoH, 2009), continue to frame them as deficient and unable to take part in 'normal' society (Chappell and Gifford, 2011). Ultimately, it appears that the apparently opposing objectives of inclusion and integration arise; to accept people as they are and attempt to change structures and understandings in order that they are better placed to participate in the world, or normalise them. If the latter, then PWLD

will remain a marginalised group. Structural barriers, as well as culture and perceptions, must be altered (Digby 1996, Oliver 2004). Learning disability must be;

> ...resocialized, culturalized and politicized; regained from individualistic, psychologising and medicalizing discourses which have maintained its essentialist difference and deficiency… (Goodley 2000, p. 36)

The current goal of empowerment within recent government agenda – explained as PWLD shaping and having real choices regarding their lives and the support they receive (DoH, 2009) – strives to enable individuals to participate in normative activities such as education and employment. As discussed above, whilst such practices in the 1980's can be considered a move forward in terms of disability rights (Race 1999; Walmsley and Jamesson 2003), as they brought the wellbeing of disabled people into question, the epistemological foundations upon which the theory was founded are questionable (Goodley, 2001; Oliver, 2013). We need to ask what it is that we understand disability to be, what we understand a just society to be, and whether this is in line with the approach being subscribed to in our goal of a more inclusive society (Fisher, 2001).

Fisher (2011) discusses government assistance for children who are disabled and their parents so they can partake in normative citizenship – the 'normal' behaviours that are expected of them. This could be the government providing opportunities for parents to go back to work; childcare in order that they are able to do so; and skills training for their children in order that they will be able to partake in mainstream education, and thereby mainstream society. Fisher explains that the provision of such opportunities results in an individual being framed as deficient if they fail to succeed in making use of them. The present research asks similar questions in relation to the expectations placed on PWLD to take part in normative citizenship, contemplating the consequences of this going unachieved.

2.4 Neoliberal ideology

Neoliberal ideology is underpinned by the assumptions that a free market is a fair and natural ideal, social welfare expenditure should be minimised, public services privatised, competition is depicted as a defining characteristic of human nature, and citizens are primarily consumers (Harvey, 2005). It therefore does not acknowledge coercion within markets, such as domination by large corporations, nor the support and regulatory role of the state in facilitating this domination (Wright, 2003). Wright explains the importance of understanding that the

distribution of wealth and income within society is not only the result of the choices made by free acting individuals, but is determined by the rules of the state in relation to the market. Neoliberal theory therefore values the independent, competitive individual (Stevenson, 2001), being '…grounded in the 'free, possessive individual', with the state cast as tyrannical and oppressive' (Hall, 2015, p. 14). Since 1979, the UK has seen a '…drive to subject all of social life and the public sphere to market mechanisms has become the prevailing ideational regime' (Somers, 2008 p. 2), with Thatcher's Conservative government of 1979 being understood as the point at which the welfare state was forced into decline and the market was allowed to dominate government policy (Hall, 2015). All governments since 1979 are understood to have been compelled to fall in line with the global neoliberal project to some degree (Harvey, 2005; Seymour, 2010; Rustin, 2015). To emphasise this point, although identified as the party since 1979 whose values had to alter most in order to embrace neoliberal theory (Rustin, 2015), New Labour – and Clinton's New Democrats in the USA simultaneously – were understood to be constrained to such a degree by free market globalisation that '…they could not help but sustain the process of restoration of class power even against their own better instincts.' (Harvey, 2005 p. 62) Blair stated that it is not possible to reverse or stop the process of free market globalisation and that it must be embraced alongside a social democratic agenda (Seymour, 2010); the 'Third Way' was therefore an attempt to combine the two (Driver and Martell, 2002; Hale, 2011). Blair stated: 'no country is immune from the massive change that globalisation brings. …What globalisation is doing is bringing in its wake profound economic and social change…' (Blair, 1999 p. 48).

Such considerations of a consistent, if varied and/or unwilling adherence to neoliberal theory lead to the key question of whether, in a globalized world, a single state has the power to decide whether they are willing or able to opt out of what Hall (2015) refers to as a 'hegemonic project' (p.30), or whether they must submit to the dominant global status-quo (Harvey, 2005; Rustin, 2015).

In relation to the present research, neoliberalism is understood as more than an economic system. It has '…become hegemonic as a mode of discourse…it has become incorporated into the common-sense way many of us interpret, live in, and understand the world (Harvey, 2005 p. 3). Somers (2008) explains that it is therefore necessary to discuss neoliberalism when contemplating contemporary identity politics and materialist circumstances and structures. Neoliberalism is described as a 'social settlement', whereby society takes for granted a certain

way of being or doing; there is a general assumption that competitive, contributing individuals are both inevitable and correct, or '…a profound embedded resignation to the naturalness of the market forces.' (Massey, 2015 p. 85). Not only is the economy dominated by global neoliberal economic imperatives but cultural experiences have been infiltrated by neoliberal assumptions, normalised as the values and aspirations society should adhere to (Harvey, 2005; Somers, 2008; Hall and Massey, 2015; Rustin, 2015). Harvey (2005) explains:

> Neoliberalism has, in short, become hegemonic as a mode of discourse. It has pervasive effects on ways of thought to the point where it has become incorporated into the common-sense way many of us interpret, live in, and understand the world. (p. 3)

Rustin (2015) refers to such discussions of neoliberalism as a ''culturalist' approach to political analysis.' (p. 88). Prioritising corporations and profit over democracy and welfare (Tyler, 2013), if a person does not adhere to valued behaviours which include taking part in employment and contributing to society then they are framed as '… comparatively unworthy of respect.' (Fraser, 2003 p. 27). Fraser's link between misrecognition and 'unworthiness' is in line with market fundamentalist values which deny PWLD, along with others who are not seen to make valuable contributions to society, the right to participate in social life as peers. Neoliberalism as an ideology, as a set of beliefs about the expectations we should have of citizens, is therefore discussed throughout this research in relation to the citizenship of PWLD alongside the materialist realities of the theory.

Neoliberal ideology is identified in the thesis within government policy and rhetoric (Shakespeare, 2000; Oldman, 2003; Reindal, 2009; Fisher, 2011; Hale, 2011; Needham, 2011). In relation to this I refer to the Valuing People policies (DoH, 2001; 2009) amongst others (UN Enable, 1993; DoH, 1988; 2001; 2007; 2008; ODI, 2008; DoH, 2009; 2009b; 2010; 2011; 2012; 2014). I focus on the Valuing People policies (DoH, 2001; 2009) as the first of these, Valuing People (DoH, 2001), as the first white paper dedicated to PWLD in 30 years, set out a vision for improving their lives that has been subscribed to by consecutive governments, albeit with a reduction in funding in these areas. These documents are a representation of the current neoliberal social settlement in relation to PWLD, providing a framework based on the promotion of civil rights, independence, choice and inclusion through which service development was encouraged. Whilst the sentiment has been affirmed by consecutive governments there has been a significant reduction in funding in these areas with the Valuing People Now team being disbanded and the implementation now lying at a

local level. In relation to the reduced funding, James Churchill, chief executive of The Association for Real Change stated: "We are going to be in the worst of positions if we are not very careful, with a Rolls-Royce policy document without the means to get on and deliver it" (ARC, 2010).

2.6 Conclusion

This chapter, in providing an overview of the treatment and perceptions of learning disabilities in the past, has aimed to contextualise present understandings. In discussing the changing conceptions of learning disability over time, I have demonstrated that learning disability is socially constructed. Time and place have determined how learning disability is understood, resulting in PWLD being subject to various maltreatment and misrecognition. Against this past, more recent conceptions of learning disability in relation to the individual and the social model of disability were then discussed. The individual model, whereby a person with a learning disability is considered to be disabled by their impairment, does not look to society for answers in relation to their greater inclusion, framing learning disability as an individual pathology. The social model of disability looks to societal structures as the cause of an individual's disablement. The social model of disability, whilst conceptualised in relation to people with physical disabilities has been since used to contemplate the position of PWLD. When applied to PWLD, the social model is valuable to a point in that it can be employed to challenge assumptions regarding the societal barriers facing PWLD, however, as I have discussed it is problematic to place the cause of learning disability wholly on society. It eschews serious discussion of the realities of impairments for PWLD; potentially leading to the care and support needs of the individual being overlooked. In the following chapter, I discussed the need for impairment to be acknowledged when contemplating the inclusion of PWLD as citizens, and how they can be included in society in a meaningful way that recognises their differences and support requirements. Following from this, Chapter 4: Methodology and Methods discusses the centrality of acknowledging impairment when making methodological choices. Having discussed learning disability as both a social construct and a reality in need of acknowledgement, introduced theories of disability, and identified neoliberalism as a social settlement, the analysis chapters will go on from here to apply these understandings to the data.

Chapter 3: Citizenship and Social Justice

3.1 Introduction

In the previous chapter, following on from considerations of constructions of learning disability over time, with a focus on how this has led to different forms of exclusion, I discussed the individual and social models of disability in terms of their potential to exclude and include PWLD. This was discussed in relation to the current neoliberal social settlement whereby inclusion and participation are considered in terms of an individual's ability to adhere to normative conceptions of what it is to be a valuable member of society. The individual model's focus on impairment as the cause of disability being critiqued for pathologising disability, whilst the social model highlighting societal barriers is understood to potentially further exclude PWLD in focussing on society, not acknowledging the impairment, with PWLD possibly being seen to fail as citizens when the result of these societal barriers being addressed and opportunities provided, is not normative participation.

This third chapter moves on to contemplate the role of citizenship as a facilitator of inclusion. With discussions of universalist and particularist approaches to citizenship rights as a starting point, I develop points addressed in the previous chapter regarding the need to acknowledge impairment when contemplating ways in which PWLD can be included. Universal rights promise equal rights for all and their successful use in the fight for rights by marginalised minorities exemplifies the positive potential of such. The chapter moves on to discuss particularist or differentiated citizenship which looks to individual group needs in order to address inclusion. This is beneficial in that those who differ from the norm have their needs met by this approach, having rights provided directly in relation to these noted needs. In this section I discuss the respective limits of both approaches; universal rights being potentially exclusionary with its subscription to normative assumptions and by a lack address of difference, and particularist rights are seen to reduce the potential for citizenship rights to be used as a basis for activism.

Discussions of particularist or differentiated citizenship rights are followed by contemplating theories of recognition; theories recognising and valuing difference from the norm. Such approaches call for cultural understandings to alter in order that such inclusion can be facilitated, problematising normative values that centre on the previously discussed neoliberal values of productivity and self-sufficiency. Here I ask how, in such a climate, a person with a

learning disability can be afforded the rights which will lead to a fulfilling life when rights are largely determined by assumptions about what a citizen should contribute to society in order that they are afforded supposedly universal rights. Such discussions resonate with PWLD who are noted to experience implicit exclusion despite having the same citizenship rights as all others in society. PWLD illustrate the failings of citizenship as a strategy for inclusion. The personalisation agenda and recent government legislation is recognised here as reinforcing normative ideals which therefore serve to further marginalise PWLD when they fail to adhere to expectations.

A discussion of the critiques of recognition based theorising in relation to citizenship rights follow from this. These critiques centre on this approach to inclusion being understood as unable to succeed without the additional address of institutionalised disrespect, maldistribution, and the address of issues of representation. To elaborate, whilst positive representations of marginalised minorities and working towards the acceptance of different lifestyles are noted as contributors to greater acceptance and inclusion, this identity theorising is critiqued as focussing too much on the individual at the expense of overlooking the institutionalised patterns of disrespect which lead to marginalisation. A wider understanding of recognition, incorporating representations of marginalised people as well as address of institutionalised understandings, is termed the 'status model' (Fraser, 2003). This recognition is not understood to be able to contend with the resource related exclusion which is being exacerbated amidst an ever widening socio-economic gap. Identifying resource related issues as resulting in exclusion, the chapter concludes with a discussion of a need for representation – the understanding that some groups are not 'seen' in terms of citizenship rights, they are not included in considerations of justice, and do not appear to be represented politically on a par with other groups – as a necessary baseline from which recognition should be addressed alongside distributive issues, in order that citizenships inclusionary potential can be achieved. In relation to this, Fraser (2007) asks: 'Do all those who are included in a given political community really have equal voice?' (p. 75)

3.2 Citizenship

Citizenship is a contested, fluid concept, subject to change over time and between nations (Lewis, 1998; Glenn, 2000; Stevenson, 2001; Croucher, 2004; Gilbert et al., 2005). Citizenship originated as a political concept, granted to members of a society, with terms such as 'member' highlighting the fact that it was founded upon inclusionary – and therefore also exclusionary –

practices (Pakulski, 1997; Marks, 2001; Croucher, 2004; Isin, 2005). Historically, for example, in Ancient Greece, being classed as a citizen equated to being fully human, thus a member of society, and in Ancient Rome, being granted the status of citizen meant you were free by law (Turner, 2007). Being a citizen in these contexts was a political right and worked to exclude those not considered citizens including women, slaves and people with impairments.

Marshall (1950) discusses political, civil, and social rights as the three categories of citizenship rights that have evolved in the UK in modern times. For Marshall (1950), these rights corresponded with the 18th, 19th and 20th centuries. Civil rights involve the protection of rights such as freedom of speech and the right to justice (associated with the development of courts of justice); political rights are the right to political participation in the democratic process (associated with the development of Parliament and local elective bodies); and social rights involve a minimum level of social security, with the welfare state being viewed by Marshall as the final stage in the evolution of citizenship rights. Marshall explained that social rights were:

> …the whole range from the right to a modicum of economic welfare and security to the right to share the social heritage and to live the life of a civilized being according to the standards of the prevailing in the society. (Marshall, 1992 p. 8)

Marshall (1950) saw the three rights as mutually interdependent, stressing the need for social rights before all else in order that a person has the necessary resources in order to enact their rights. Marshall advanced that following the introduction of social welfare, the further evolution of social rights, as he predicted would occur in peace time society, would involve the reduction of the income gap, an extended area of common culture and experience, and the enlargement of citizenship with more rights granted to citizens. In this sense Turner (1993) identified citizenship as 'a set of practices (judicial, political, economic, and cultural) which define a person as a "competent" member of society...' (p. 2). Marshall (1963) was explicitly concerned with the relationship between citizenship and social class, understanding this to be the most pertinent issue at the time. Marshall saw the development of citizenship rights from the seventeenth century as coinciding with the development of capitalism, and describing citizenship and the capitalist social class system as 'at war' (p. 87) in the twentieth century. Social citizenship was essential for Marshall in ameliorating the status inequalities generated by capitalism, establishing citizenship as a reality for those previously excluded by poverty.

In the UK, citizenship rights are found in Acts of Parliament and are the state's duty to its citizens, as well as the citizen's responsibilities to the state. Alongside Common law and European law, they form part of the UK's unwritten constitution. Such rights are in principle '…universalistic but restricted to 'insiders' in society…' (Pakulski, 1997 p. 74). Since the end of World War Two, national citizenship has been supplemented by the UK's international obligations. For instance, the 1948 UN Universal Declaration of Human Rights (UN, 1948), set out the economic, social and cultural rights all individuals should expect as citizens, stating:

> Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality. (UN, 1948 Article 22)

This was followed with specific reference to socio-economic rights in The International Covenant of Economic, Social and Cultural Rights (1966) where it was explained that '…freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his economic, social and cultural rights, as well as his civil and political rights.' (UN, 1966 p. 1). Despite this recognition in international agreements, social, cultural and economic rights exist in the UK as part of the welfare state, and unlike civil and political rights they are not enforceable beyond the legislation in which it is incorporated (James, 2007). They exist currently in The Equality Act (2010), an umbrella act encompassing the anti-discrimination and equality legislation that came before it. James (2007) contends that such rights being unprotected definitively by law is not adequate. He argues that socio-economic rights should be on a par with civil and political, and that as a result of such there must be a 'shift from what is perceived to be bestowed on individuals by the virtue of the benevolence of a welfare state, to that of a right' (James, 2007 p. 10). Furthermore, Harvey (2005) discussing citizenship's universal promise, sees rights as affected by the state and by capital – how far an individual is granted these rights is dependent upon how far the state enforces them: 'If political power is not willing, then notions of rights remain empty. Rights are, therefore, derivative of and conditional upon citizenship' (p. 180).

With respect to the present day relationship between citizenship and exclusion, Croucher (2004) refers to the exclusionary practices of immigration policies; citizenship is not the right of those going to live in the USA, for example, but must be earned. Whilst practices differ, this

type of citizenship is echoed by other countries such as the UK, Canada and France. This type of citizenship is referred to as 'jus soli', meaning rooted in soil. In contrast, citizenship in countries such as Germany, Israel and Greece define a citizen as someone who is tied to the state by way of their ancestry; this is called 'jus sanguinis'. Croucher (2004) encourages us to question what citizenship means, who should be entitled to it, and what the responsibilities of citizen and state should be.

With reference to the three categories of citizenship, which form the rights of an individual with citizenship status in the UK, a person considered disabled has been referred to as a 'second class' citizen because although they have the right to the previously mentioned categories, they are often denied access to these rights in practice (Marks, 2001). The legal status of a disabled person is indeed that of citizen, however, addressing the legal position of a person seems insufficient if, despite this, they are subject to oppression. This is aligned with Marshall's (1950) stance that the social rights of an individual must be secured before all else. They must receive the social assistance necessary to live a life to the standards that prevail in society, as well as being equipped with the resources to be aware of their rights and to be able to act on them, such as having received an education to the same standard as all others in society and being secure in the knowledge that they are amongst peers socially, if not economically. Marshall did not seek to abolish the capitalist system but rather sought to give an equal footing to all members of a society from which they could prosper – a level playing field – amidst the inequalities created by markets.

In practice, Marshall's concept of social citizenship has been subject to the neoliberal critique that it leads to dependent and passive individuals, advising that rights should entail more extensive responsibilities to curtail this (Kymlicka and Norma, 1994). The retrenchment of social citizenship in line with neoliberal values has become increasingly apparent (Young, 1997; Fraser, 2003; Honneth, 2003; Harvey, 2005; Somers, 2008; Seymour, 2010; Hall et al., 2015; Hall, 2015; Rustin, 2015). Those who do not contribute in line with the neoliberal social settlement are framed as failing as citizens (Somers, 2008). In the following section I interrogate citizenship's universal promise in relation to this agenda.

3.3 Universalism and particularism

A discussion of universalist and particularist citizenship rights in relation to marginalised groups will follow here in line with discussions of how best to address the different

circumstances of all individuals in society. Universalism is a moral position whereby all human beings are afforded the same rights regardless of their particular circumstance or individual needs, whilst particularism looks to narrow group and individual experiences and requirements, attempting to provide rights appropriate to specific needs (Thompson and Hoggett, 1996).

In the recent past, the universal promise of citizenship rights for those within a political community has been used in the fight for inclusion by marginalised groups suffering exclusion and discrimination because of their perceived difference (Roche, 1992; Lister, 1997; 2007; Glenn, 2000; Lewicki, 2014). Roche (1992) and Glenn (2000) celebrate the use of universal citizenship rights by social movements to aid the cause of equality and inclusion, pointing out the relationship between rights being sought and rights being granted. Examples of such movements include the Civil Rights Movement in 1950s USA, Union of the Physically Impaired Against Segregation in 1970s UK (UPIAS, 1976), and the success of the civil rights campaign for same-sex marriage.

These examples illustrate the utility of citizenship as an emancipatory tool. However, there are also examples of where citizenship has failed members of a society in its lack of address of economic, social and cultural disparities (Glenn, 2000; Lister, 1997; 2007). Universal citizenship rights have been questioned in relation to implicit normative assumptions. For example, considerations of LGBT individual's citizenship rights have questioned the exclusionary, heterosexual language existing within current understandings that perpetuate exclusion and lead to inequality (Concannon, 2007).

Those theorising in relation to the citizenship rights of PWLD – and in relation to previous discussions of a neoliberal social settlement – have highlighted the contradictory position of a person with a learning disability in relation to expectations of a citizen in a neoliberal age, whereby the expectations of productivity and self-management leads to an individual being seen to fail if they do not meet these obligations (Gilbert et al., 2005).

Physical disability theorists have long since cited the 'ableist' discourses within government policy (Oliver, 1996), whilst 'liberal culturalists' such as Kymlicka (2001; 2004) discuss the rights of those from ethnic minorities, stating an individual's culture must be acknowledged and respected in order that they are able to exercise their rights as citizens. A liberal state allows its citizens the freedom to express their culture without interference and without the priority of one culture over another, however, this claim to neutrality is challenged by those who believe

positive intervention in some respect is necessary in order that equality of rights are secured for minorities. This approach would be defined as particularist or differentiated citizenship as one group is being treated differently to another in order to secure the same standing in terms of rights. A universal approach to citizenship rights results in everyone being treated equally; this may result in the implicit exclusion of people in marginalised positions who do not adhere to accepted knowledge, and are therefore discriminated against by the lack of address of this difference, potentially reinforcing dominant power structures (Turner, 1997). Universal rights, in their universality are also not connected to the individual's lived experience (Monro, 2005).

Particularist approaches to citizenship such as those above are offered as an alternative to universalism's failure to address difference. Particularist approaches observe the lived experience of individuals and offers differentiated citizenship based on the particular needs of the group. In contrast to universalism, the resultant narrow categories necessary to address such particular needs may however mean the lack of a large base for activism (Simon, 2001) and will potentially create fixed boundaries and hierarchies as differences are exacerbated (Bowes et al., 2000). Nevertheless, the limitations of large categories in addressing difference has further marginalised groups and individuals (Monro, 2005). In relation to this, Thompson and Hoggett (1996) highlight the influence of postmodernism on citizenship expectations. They point out that modernist attempts in social policy to balance universal rights and equality alongside individual diversity and choice gave precedence to univeralism. In contrast, a postmodernist focus on individual difference has shifted the focus to particularist understandings in theorising the rights of citizens, addressing difference in an attempt to facilitate inclusion.

Simon (2001) states that there is a need for minority groups seeking social justice to come together and create a unity based upon 'sameness' in order for their cause to be advanced, explaining that a 'homogeneous identity [is] a strategic essentialism' (p. 66). Simon understands that a label – the acknowledgement of a group identity – is understood as necessary for the practical purposes of addressing the problems a group of people with commonalities face. However, it must be remembered that this label focusses on only one aspect of an individual and does not encompass all there is to know about them (McClimens and Richardson, 2010). This therefore does not necessarily mean a movement means the same to all those involved – political necessity may have combined them but they are still individuals with individual concerns and plights (Simon, 2001; Kymlicka 2004; Monro, 2005; Bollard,

2009). Such challenges to normative, universal citizenship as discussed above interrogate the meaning of membership in a society, advocating that rights be addressed in a particularist way, acknowledging possible differences alongside avoiding comparison to a dominant norm.

3.4 Recognition

Expectations of assimilation to a normative ideal are not tolerated by difference centred approaches to citizenship (Pakulski, 1997; Stevenson, 2001; Kymlicka, 2004; Moosa-Mitha, 2005; Yuval-Davis, 2006; Lister, 2007). Grounded in new social movements, such models attempt to overcome the flaws of the civic republican and liberal models of citizenship as they challenge the dichotomous divide between those who are and are not accepted as a normal citizen. Freedom here would be the right of an individual to participate differently in society; freedom is interpreted as the recognition of agency – of the right to live life in a way that differs from the 'normal' way, yet still be valued equally. Moosa-Mitha (2005) explains a difference-centred model of citizenship would entail the concept of belonging being pivotal to the concept of equality, and belonging would equate to all experiences being regarded equally. It would be based within the experiences of those she refers to as 'citizens of difference' and would acknowledge the subjective nature of citizenship. Moosa-Mitha terms this 'differently equal'.

Stevenson (2001) emphasises the impact of cultural change upon the politically defined concept of citizenship; from this perspective the context and individual voices are essential considerations in the implementation of rights. Along with others (Pakulski, 1997; Kymlicka, 2004), Stevenson (2001) questions how we can continue to address citizenship in terms of civil, political and social rights without addressing the cultural with the same importance, if the goal of citizenship is truly to involve fair treatment for all. Stevenson (2001) seeks a 'cultural citizenship' that goes beyond rights and responsibilities in political terms, because exclusion may exist culturally but not politically. Such thinking is pertinent to the study of citizenship and PWLD as this group of people are entitled to the same civil, political and social rights as all citizens, but experience implicit exclusion in certain areas because they do not conform or contribute (Turner, 1997; Somers, 2008). Stevenson (2001) goes on to explain cultural citizenship concerns issues beyond the assumed rights of individuals, addressing conflicts which cannot be addressed by the implementation of universalist rights as these do not account for difference in context and between individuals.

Cultural rights would mean respect and acceptance without the need to 'normalise' or adhere to pre-determined social conventions (Pakulski, 1997; Marks, 2001). Pakulski uses the example of LGBT rights; advancing rights must go beyond that of a LGBT couple being able to legally to marry, towards how the union is depicted, such as recognition and portrayal of the marriage in the media as a legitimate act; the right for the cultures and lifestyles of marginalised groups to be valued and portrayed equally. Pakulski further explains:

> The claims for cultural citizenship involve not only tolerance of diverse identities but also – and increasingly – claims to dignifying representation, normative accommodation, and active cultivation of these identities and their symbolic correlates. (p. 77)

The above literature makes the case that, amidst recognition, some members of society are not receiving the social and cultural rights recognised by Marshall (1950) as essential for the other rights to be enacted; we then need to redefine both the obligation the state has to individual citizens and discuss its implementation of these rights. Marshall's (1950) understanding that social rights were necessary before the other rights are able to be contemplated finds resonance in relation to the present research – he said social assistance was necessary in order that all individuals could live to the prevailing standards in a society. Marshall was attempting to account for the inequalities created by markets. Accounting for economic exclusion in this way is in line with Fraser's (2003) understanding that distribution should be observed alongside theories of recognition and identity. Marshall saw social rights as the final essential right to be acquired – the welfare state being an embodiment of this. It was the final right to be acquired but the first right required in terms of citizenship. He saw it as granting a level playing field. Fraser, like Marshall, is interested in creating a level playing field. Her belief of 'participatory parity' whereby all citizens within a society are able to '…interact with one another as peers' (2003, p. 36) and understanding of justice in terms of negation highlight this.

Such a proposition has support from within learning disability research (Digby, 1996; Goodley, 2000; Marks, 2001). Digby (1996) states that in order that PWLD have fundamentally improved lives, culture and perceptions must be altered, and Goodley states learning disability must be: '...resocialized, culturalized and politicized; regained from individualistic, psychologising and medicalizing discourses which have maintained its essentialist difference and deficiency' (Goodley, 2000, p 36). Whilst learning disability is not apparent in cultural citizenship literature, the call for different ways of living being accepted and respected finds

resonance here, as does the need for equal representation of different lifestyles. With particular relevance to the social construction of learning disability, Stevenson (2001) explains: 'The market, under the guise of freedom and autonomy, can act as a mechanism regulating norms and instilling certain forms of behaviour.' (p. 33) He goes on to explain 'moralizers' and 'neo-liberal economics' will make the implementation of cultural citizenship a difficult task as they will separately attempt to create a common dialogue that advocates the independent, competitive individual, working in contradiction to a kind of citizenship which encourages the acceptance of different dialogues.

As such, the dialogue to which Stevenson (2001) refers can be evidenced in the personalisation agenda which focusses on normative independence and inclusion. Those who are unable to make use of the opportunities provided in such policies may be framed as deficient if they fail to achieve the valued outcomes (Chappell and Gifford, 2011). Alongside which, discourse re-labelling PWLD as capable with respect to independence and employment, if taken too far, has the potential to result in the support being removed, compounding the exclusion of PWLD (Vorhaus, 2005; Redley and Weinberg, 2007). It is difficult to balance the acknowledgement of impairment and the need for support alongside efforts in the name of inclusion; it seems cultural citizenship could play a positive role here as it will '…accord respect, recognition and opportunity for full inclusion, rather than offer cures and 'special provision' (Marks, 2001 p. 177).

In relation to cultural rights, Marks (2001) highlights the necessity for disabled people to experience 'endignifying representation' alongside other groups, such as LGBT people, who also struggle for the right to be different. Writing in relation to people with physical disabilities, Marks states that social movements whereby individuals come together to voice their demands for meaningful representation and to inclusion without assimilation, are important in the evolution of citizenship rights for disabled people, but structural inequalities, the material reality of exclusion, must also be addressed. The success of social movements of the past, as I have discussed earlier in this chapter, add weight to the importance of collective action.

However, Aspis, (1997) provides a cautionary note in relation to this, stating that we must question to what extent PWLD benefit from self-advocacy movements, asking how far PWLD are supported to challenge the lack of power that they have to change their lives as well as the wider structures of society. Aspis is wary of self-advocacy being encouraged and facilitated by service providers with the aim of consulting with PWLD on the quality of service provision.

Whilst this consultation is potentially useful for the lives of PWLD, this results in the individual being granted very limited choice and virtually no power to make changes to their lives. There is then also the theoretical position of the facilitator to consider as their position will determine the course the movement is able to take and the options people within the movement are granted. These considerations link to Fraser's (2003) warning of the dangers when people are marginalised in such a way that they are unaware of their subjugation. I will discuss this 'misrepresentation', as Fraser terms it, in detail later in this chapter.

3.5 Redistribution

3.5.1 Recognition critique

As discussed earlier in this chapter, being unable to achieve in normatively valued ways potentially results in individuals being seen to be failing as competent citizens (Pakulski, 1997; Gilbert et al., 2005; Chappell and Gifford, 2011). Some particularist inspired approaches to citizenship call for the dignifying representations of marginalised groups with respect and acceptance for different ways of living in order that inclusion and equality can be experienced (Digby, 1996; Pakulski, 1997; Goodley, 2000; Marks, 2001). Whilst structural impediments to inclusion, such as the institutionalisation of disabled people, are recognised as barriers to positive representation (Marks, 2001), recognition and positive representations in relation to identity dominate much of the literature as a way in which to begin to rectify marginalisation and exclusion.

This section relates to both (1) the above advanced need for positive representations and recognition of different lifestyles as equally worthy of respect and inclusion, contemplating not only the effects of a neoliberal social settlement – of common sense assumptions that affect these value judgements – but also (2) recognising the increasingly unequal economic reality that these judgements exist within (Fraser, 2003; Somers, 2008; Hall and Massey, 2015; Rustin, 2015). This will involve a turn here to considerations of materialist conceptions, understood by Fraser (2003; 2008) to be necessarily addressed in their own right, rather than as a consequence of recognition, problematizing a focus on identity politics in a neoliberal age whereby the equality gap is widening.

Fraser (2000), recognising how many contemporary social movements centre on claims for recognition notes a decline of calls for egalitarian redistribution alongside this, stating:

Once the hegemonic grammar of political contestation, the language of distribution is less salient today…thanks to the sustained neoliberal rhetorical assault on egalitarianism, to the absence of any credible model of 'feasible socialism'…their role has been greatly reduced. (Fraser, 2000 p. 107)

Fraser (2003) questions how far this is helpful as it does not seem feasible that the remedy for maldistribution and institutionalized patterns of cultural value can arise from such methods alone:

The effect is to view capitalism exclusively from the perspective of recognition – hence to assume…that all subordination derives from culturally rooted hierarchies of status; and that all can be remedied by cultural change. (p. 213)

Fraser contends that the equation of recognition with social justice does not serve the marginalised individual in the way its proponents (e.g. Honneth, 2003) believe; seeing this focus on recognition as resulting in both the reification of group identities, the creation of deep divides between groups, and the displacement of redistributive claims 'despite – or because of – an acceleration of economic globalization, at a time when aggressively expanding capitalism is radically exacerbating economic inequality.' (Fraser, 2000 p 108)

It is noted that the focus on recognition coincided ironically and problematically with a rise in neoliberal economics (Fraser 2003, 2010, 2011), or market fundamentalism, as Somers (2008) phrases it. This is an issue for Fraser as the very real socio-economic injustices that people face are no less pertinent despite the decrease in attention, as market fundamentalism continues to contribute to the widening of the economic gap (Somers, 2008; Piketty, 2014; Hall et al., 2015;).

In relation to calls for recognition amidst a neoliberal economic and social settlement, Somers (2008) aligns with Fraser's (2012) stance that we should be wary of structural issues being redefined as personal failings and mindful of any precedence given to individuality within a context where material restrictions limit the possibility of these valued goals being realised. Somers states that sociologists must consider the '"normative speculations" of philosophy' (Somers, 2008 p. xv) alongside conducting empirical research. Somers states that in seeking justice, '…empirical and the normative are mutually interdependent.' (p. xv). Somers explains that in the past sociological research has separated itself from philosophising on the meaning of the rights for which it fights, stating that this is not helpful – we should question the

assumptions we have about that which we are fighting, as well as considering and questioning the impact of these normative understandings of justice and rights. In the present research then, I am attempting to empirically discover how far the participants are included in terms of the current social settlements, at the same time as conducting a critique of the basis from which these settlements were born. I am attempting to both discover how individuals fare in relation to the current neoliberal, individualistic status quo, alongside questioning this settlements legitimacy to facilitate social justice. Such a discussion of normative assumptions, of social settlements, in combination with a critique of the macro, of institutional design, is 'a tricky kind of discussion to pursue rigorously. It is much easier to talk about concrete ways of tinkering with existing arrangements than it is to formulate plausible radical reconstructions.' (Wright, 2010b, p. ii) Wright states that we therefore need to focus therefore on the principles which underlie institutions; in thinking about the moral values by which understandings are rationalised and the practices of the institution, Wright sees hope for radical change.

3.5.2 Redistribution and recognition

Fraser's (2010) conception of social justice draws on both materialist and 'post-socialist' sociological critiques, being critical of both structures and institutions, and the linguistic/narrative turn in social research. She sees these as being separately in need of address, whilst also being conscious of their mutually reinforcing nature. Fraser is amongst others who have moved back to include discussions of both materialist sociological understandings and theories of recognition within a conception of justice (Philips, 2003; Somers, 2008). This Fraser sees as essential if social injustice is to be recognised and remedied, particularly in the present where economic disparities continue to increase (Fraser, 2003; Somers, 2008; Piketty, 2014).

It has traditionally been the case that redistribution and recognition were considered opposing models in the address of inequality, it being a choice between the two as to how inequality is addressed, the belief being that one would lead to the other (Young, 1990; Taylor, 1994; Honneth, 2003). In relation to such proponents of recognition, who view distribution as derivative of recognition, Fraser (2003) states: '…the goal [of recognition theorising], in its most plausible form, is a difference friendly world, where assimilation to dominant cultural norms is no longer the price of equal respect' (p. 7). This understanding of recognition resonates with the difference-centred theorists I have drawn on previously (Pakulsi, 1997; Marks, 2001; Moosa-Mitha 2005). In her goal to rejuvenate Critical Theory to include a return to materialist as well as these 'post-socialist' considerations, where 'group identity supplants

class interest' (Fraser, 1995 p. 68), she states: 'we must adapt it [Critical Theory] to a world in which struggles over status are proliferating amidst widening economic inequality.' (2003 p. 233) Fraser acknowledges the importance of recognition as an aspect of social justice, whilst arguing that this alone is not practically adequate if we want to address the widening economic gap. This widening gap has been acknowledged by various social and political theorists (Young 1990, 1997; Honneth 2003; Somers 2008; Hall et al., 2015).

Fraser's critics emanate predominantly from theorists working in the area of recognition (Butler, 1997; Young, 1997; Honneth, 2003; Robeyns, 2003; Hines, 2013). Honneth (2003) and Butler (1997), criticize her separation of redistribution and recognition, arguing that the two cannot be separated neatly as they feed into one another. Hines (2013) calls instead for 'material/cultural intersectional analysis' (p. 16) instead of a separation. However, this seems to also reflect Fraser's understanding of their relationship; her argument being however that separation is necessary in order to address different manifestations of injustice (Fraser, 2003; 2010).

Further to critiques of Fraser, it has been suggested that Amaryta Sen's Capabilities Approach is an understanding of justice that is better able to accommodate both recognition and redistribution (Robeyns, 2003). As identified by Pfister (2012), Sen's (1999) Capabilities Approach finds common ground with the more radical, contemporary perspectives on citizenship, as they strive to address social inequality whilst acknowledging diversity. The Capabilities Approach assesses social justice based on how far a person has real or effective opportunities to lead a life that they value. Sen noted that a fair distribution of resources must also take note of human diversity and wellbeing. Robeyns then understands Sen's Capability Approach to allow for the inclusion of 'non-normal' cases, such as PWLD, understanding Fraser's approach to fall down here, being of the opinion that Fraser's approach does not work for all individuals: 'Sen's capability approach has a wider scope and pays even more attention to human diversity than parity of participation.' (p. 17)

My understanding of Sen and Fraser notes similarities; redistribution and recognition are seen as inseparable, with both necessitating address to various degrees depending on the noted causes of injustice. There is not scope, nor do I feel that the differences between these two approaches to remedying injustice deserve further elaboration than this here – I reflect upon such critiques in relation to Sen to note that I am aware of them, but see their similarities as validation of both Sen and Fraser's understandings. As Fraser (1997) explains:

> Egalitarian theorists have long sought to conceptualize the nature of these socioeconomic injustices…For my purposes here, however, we need not commit ourselves to any one particular theoretical account. We need only subscribe to a rough and general understanding of socioeconomic injustice informed by a commitment to egalitarianism. (p. 13)

In relation to addressing resource related barriers, theories focussed on recognition – seeing redistribution as derivative of this – are seen to neglect the need for economic reform, relying heavily on goals such as changing the cultural representations of marginalised and repressed groups in order to facilitate their inclusion within society. In contrast, proponents of solely redistributive/materialist remedies for social injustice neglect the crucial area of negative cultural representations and understandings which feed into the institutionalised norms which then affect redistributive justice. Therefore Fraser calls for recognition and redistribution to be considered alongside one another. For Fraser, these justice claims have become unnecessarily polarized, explaining that '…we are effectively presented with an either/or choice: redistribution or recognition? Class politics or identity politics? Multiculturalism or social democracy?' (Fraser, 2003 p. 8).

For Fraser (2003; 2010) true inclusion within a society is understood to be based on an individual's ability to participate within it, referred to this as 'participatory parity'. As such, instead of incorporating an 'identity model' of recognition within her framework, she champions the 'status model'. The status model sees individuals denied their right to participate in society on a par with other members, with both misrecognition and maldistribution being explained through institutionalised practices based on an alignment with cultural norms. So assumptions made about PWLD, for example, feed into how they are then treated when it comes to both participation in society and resources. Fraser (2003) uses the example of social welfare policies stigmatizing single mothers by labelling them 'sexually irresponsible scroungers', and policy practices such as racial profiling whereby black people are associated with criminality, to illustrate her understanding of the basis of misrecognition. Therefore, as a matter of social status, misrecognition is understood as the more 'practical' social subordination, whereby a person is actually prevented from participating in different aspects of society, rather than it being based on feelings of marginalisation and subordination alone. For Fraser it is less about positive representations in, for example, the media, and more about changing institutionalised patterns of subordination. Fraser offers the status model as an effort

to both work towards removing institutional barriers – thus paving the way for participation – *and* recognise group and individual identity, rather than just the latter as the identity model is understood to do.

Fraser (2003; 2010) understands that at such a time as this, a method to achieve social justice for marginalised groups needs to focus on structural changes specifically, rather than seeing structural change as a natural by-product of the valorisation of group identity, stating: '…recognition should be treated as a matter of social justice, not one of self realization.' (2003, p. 47). It is the institutionalised disrespect within education, law, social welfare, and medicine that structure everyday life and impede parity of participation as much as distributive inequalities. This is what she means when she states that recognition is not about identity struggles alone – it is institutionalised, not individual.

The status model acknowledges the mutually reinforcing effects of institutionalised norms and the allocation of disposable resources, seeking 'institutional remedies for institutionalized harms' (Fraser, 2000 p 114). These remedies are understood to be found only in the consideration of both redistribution and recognition together whereby the experience of social injustice cannot be reduced to either maldistribution or misrecognition, but is a combination. Fraser acknowledges that different groups require attention in different ways with subordination considered a 'conceptual spectrum of different kinds of social collectivities.' (Fraser, 1995 p. 74). At one end of the spectrum there is redistribution and at the other recognition, with the effect of institutional norms and the allocation of disposable resources interacting causally, reinforcing one another to differing degrees dependent on the individual's circumstances. In every case therefore, the '…precise proportion of economic disadvantage and status subordination must be determined…' (Fraser, 2003 p. 25). Some groups will be at one or the other end. For example, the exploited working class will feature closer to the redistribution end of the spectrum, and LGBT individuals closer to the recognition end. Fraser goes on to give the example of 'race' as what she terms a 'bivalent collectivity' as this group features at both extremes. She further acknowledges that individuals are also part of different groups, however, like Simon (2001) is of the position that individuals grouping under a common cause is necessary in order that issues are able to be highlighted and addressed.

In line with the contested and varying justice claims in relation to redistribution and recognition, and as a development of her 'perspectival dualist framework' which incorporates these two justice claims (Fraser, 2003), Fraser developed her theory to incorporate a third

justice claim of representation (2010). This addition remedies the gap in her earlier framework (as noted by Honneth (2003); Lister (2003); and Robeyns (2003)), accounting for the inequality emanating from the political constitution of society, in addition to the inequalities that stem from economy and status. Misrepresentation occurs when political boundaries or decision rules function in a way that excludes certain citizens from participation. This misrepresentation is not confined to the political arena – i.e. they have little voice and usually, but not always, this is accompanied by economic inequality and overlooking of interests – and can occur independently of maldistribution or misrecognition, but is usually accompanied by them.

There are two levels of misrepresentation: (1) 'ordinary-political' and (2) 'misframing'. In the former we may ponder the representativeness of the electoral system – are minorities represented fairly and would a quota system be appropriate. In the latter '…injustices arise when the community's boundaries are drawn in such a way as to wrongly exclude some people from the chance to participate at all in its authorized contests over justice.' (Fraser, 2010 p. 19). The addition, Fraser explains, serves the purpose of '…remedying a lacuna in my previous theory, which failed to appreciate the relative autonomy of inequities rooted in the political constitution of society, as opposed to the economic structure or the status order (Fraser, 2010 p. 6). This is important as it will follow that those who are excluded are not considered in terms of distribution, recognition and ordinary-political representation. They are effectively excluded from considerations of justice; this is referred to as a 'special kind of meta-injustice' (Fraser, 2010 p 20) as it lays the basis from which individuals will then be considered in terms of the other elements of Fraser's justice. In terms of this exclusion, a person may be wholly excluded, or included in some political communities, whilst being excluded from others. Exclusion, either wholly or partially, may result in those suffering injustice becoming the object of charity as they are not then viewed on a par with other members of a society, institutionalising the notion that they are unworthy of such considerations – impeding participatory parity in the same vein as material exclusion.

Lister (2003; 2007) offers important insights into citizenship in relation to people with disabilities in her understanding of citizenship as both the outcome of rights, and as a process through which agency is exercised, such as within social movements' demands for civil rights. This notion of citizenship as a process is useful as a person may be granted rights on a par with others, but it is the opportunity to exercise these rights, to 'parity of participation', that is important. It seems that Fraser's (2010) addition of representation, whereby a person may be

excluded from participation structurally, or may be 'misframed' resulting in their not being considered in equal terms to other citizens, is a significant addition. By way of explanation, it may be the case that a person is not accorded this agency to begin with, therefore even if they have rights, and even if society was structured in a way that they are able to exercise them, they are misframed; they are overlooked in terms of agency, deemed outside the legitimate political community. Fraser's premise that, as a matter of justice, all individuals should be held to the same conception of justice, is aided by this addition as it allows us to interrogate which groups may be being misframed resulting in their not being considered in terms social justice (Fraser, 2010). It is not possible to imagine the three tenets (redistribution, recognition and representation) of Fraser's (2010) conception of social justice being met within a social system whereby how much a person is worth is based on their ability to contribute to society along very limited neoliberal terms.

3.6 Citizenship of PWLD

In relation to the citizenship debates discussed throughout this chapter, disability is an important area in which to contemplate the promise of universal rights. Alternative citizenship theories have highlighted various ways where marginalised groups are further excluded by the lack of address of difference – by a lack of recognition or respect for their lifestyle which differs from normative expectations. Whilst there is much research in relation to marginalised minorities, citizenship research is minimal in relation to disability politics whereby disability theorists have incorporated citizenship within their theorising and empirical research, but it is rare that citizenship theorists incorporate disability (Lister, 2007).

The current discourse in relation to the citizenship of PWLD produces contradictory notions to those of the past; individuals now being framed as capable workers, consumers and members of the community, when until recently they were constructed as dependent and in need of care:

> From the fieldwork it is clear that while many individuals with learning disabilities might be considered incomplete products in terms of self-management, the role of services and professionals is to encourage and support people towards this goal. (Gilbert et al., 2005 p. 294)

Gilbert et al.'s (2005) study highlighted the lack of a clear idea of citizenship within the services provided for PWLD. They identified strategies used in order to make individuals able to self-manage by way of training and being confined to certain areas within communities where they

could be under surveillance. Altering the environment in this way may prove to have positive outcomes, however, it is unlikely to result in significant cultural change and greater inclusion (Digby, 1996). Current policy goals that aim to improve the inclusion of PWLD frame them in terms of the market and related ideals of independence and competitiveness. The claim that we must change the perceptions society holds of PWLD for actual inclusion to be realised (Bollard, 2009) rings true here as PWLD will be seen to fail if not.

In relation to the understandings of what it is to be a successful citizen, Gilbert et al. (2005) conclude that the very way in which PWLD have been positioned in the past; from defective, to subnormal, to citizens, has resulted in fragmented service provision. In the UK, a person with learning disabilities is a citizen, with the same rights as all other citizens, however, in practise Gilbert et al. (2005) see this status as unachieved. They cite the existence of 'functional integration' of PWLD in the community, but 'large scale exclusions' in the workplace setting' (p. 293), whilst remaining dependent on support organisations. The ideal 'self-managing' individual is found to be at odds with feelings of self-reliance as they do not feel that they are self-reliant, with obligatory attitudes to the community being mediated by institutions such as support providers; inclusion is orchestrated. This 'tokenism' was also identified by Redley & Weinberg (2007).

Redley and Weinberg (2007) question whether the repositioning of PWLD as independent, capable citizens in policy actually results in them being regarded as deviant and deficient if they fail to achieve economically. The 'rights and responsibilities' agenda of the UK government (UN Enable, 1993; DoH, 2001; DoH, 2009; DWP, 2010) imply this to be so. How can an individual be regarded positively when the government continues to frame a successful person as one who is able to carry out performative competencies, such as being employed (Somers, 2008; Dwyer, 2004; 2016)? Such expectations are at odds with a person with learning disabilities leading a life in which they are vulnerable and dependent upon others for support to some degree (Redley and Weinberg, 2007; Redley, 2009).

Somers (2008) explains that democracy and the free market are conflated but you should not have to earn rights. Somers discusses the holocaust whereby Jews were made stateless, making it possible to remove any rights they previously held, dehumanising them. They were no longer a part of society. Somer's explains that presently, people are not excluded from society in this civic sense but they are excluded in relatively subtler ways which result in their being seen as less deserving of rights. Citizens are excluded from society unofficially when they fail to

contribute to it in valued ways. The rights and responsibilities agenda is an example of this in play. Responsibilities are economic contributions. Rights are earned through the fulfilling of responsibilities.

As discussed earlier in the chapter, Redley and Weinberg (2007) claim to have conducted the first detailed study of the dynamics of a self-advocacy organisation in practice. They are critical of the extent to which we are able to draw on liberal models of citizenship which involve the valuing of an individual's right to make choices, prioritising their 'voice over care, security, and wellbeing' (p. 767). They highlight the improved legal protection of the human and civil rights of PWLD which were a direct result of *VP* (2001). Independence and choice are highlighted in the *VP* (DoH, 2001), and thereafter in the *VPN* (DoH, 2009) agendas; however, in line with Gilbert et al (2005) the extent to which an individual with a learning disability can exercise the rights afforded to them is questioned, and the policies criticised on the grounds that they result in further exclusion when an individual is unable to participate by making such choices.

Furthermore, Redley and Weinberg (2007) are critical of Goodley (2000) and his belief that we should focus on what people are able to do rather than what they are not. For Redley and Weinberg (2007) this is akin to the pitfalls of VP in that the individual's needs will not be met if they are framed as capable and independent. In reference to the social model and PWLD they explain:

> The political danger in presuming the only source of interactional trouble with learning disabled people stems from the incapacities of others to recognise their competence is that, taken to the extreme, it undermines any basis for the claim that citizens with learning disabilities are entitled to special assistance. (Redley and Weinberg, 2007, p. 782)

As Redley and Weinberg (2007) point out, the issue of support vs. independence must be addressed because it is unlikely that a person with a learning disability will be able to achieve this independent status. Although government literature is clear that PWLD are not expected to live without support, this is somewhat beside the point as independence is still espoused as the ideal or 'normal' situation.

In relation to this, support for the social constructionist and identity based theorising turn in literature and the addressing of labels, should be wary to not overlook the reality of what

intellectual impairment entails (Shakespeare and Watson, 2001; Redley and Weinberg, 2007), as well as the economic realities faced by marginalised groups generally (Fraser, 2008). Government policy continues to move towards goals of inclusion in relation to PWLD, however, such inclusion appears to come at the cost of assimilation to the dominant order which involves, as the quote below illustrates, taking part in employment and education:

> … the evidence is that people with learning disabilities have very few relationships and limited opportunities to form or sustain them. People are often lonely. One of the reasons for this is their exclusion from the kinds of places where other people form and maintain relationships, *such as work*, college, clubs, places of worship, leisure centres, etc., but there are other reasons for this, mostly based on assumptions about people with learning disabilities. (DoH, 2009 p. 93)

Such aspirations of inclusion in society, however, are contradicted by a dominant neoliberal social settlement which results in PWLD being seen to fail when they do not achieve the desired outcomes. A change in culture, whereby individuals are included in society in a way that does not require alignment with dominant neoliberal values seems a more appropriate model of inclusion, changing perceptions instead of aspiring for assimilation (Simon, 2001; Bollard, 2009).

Shakespeare writes with reference to people with physical impairments, however, his work in the area of citizenship and his questioning of the value placed upon independence is applicable to PWLD in many respects. Instead of seeking ways in which disadvantage can be addressed and disabled people integrated he calls for the removal of both physical and cultural barriers in society. He calls for a move beyond the type of care which is '...individualizing and excluding...', going on to explain; '...the key to this is recognizing the civil rights of service users and radically revising the way we understand need and independence.' (Shakespeare, 2000, p. 63). We must recognise difference, and that society is based on interdependence. Shakespeare challenges the potential of personal assistants and direct payments to have any real consequence for disabled people. Importantly for the present research, Shakespeare argues that without structural and cultural change strategies of inclusion such as these only reinforce the idea that disability is an individual problem, helping disabled people to potentially lead more fulfilling lives whilst continuing to adhere to an individualist, normalising ideology in line with a neoliberal conception of citizenship.

3.7 Conclusion

This chapter has discussed citizenships potential as an inclusionary and exclusionary tool, focussing on the particular position of PWLD who are often left out of discussions of citizenship. Following an overview of the development of political, civil and social rights in the UK, I have discussed current citizenship rights held by UK citizens. Whilst these rights are universal in that all UK citizens hold them, I develop a discussion of how far these rights and understandings of the responsibilities of a citizen, facilitate an inclusive society. The inclusion of PWLD specifically highlights the flaws of current citizenship conceptions. These current understandings are shaped by hegemonic discourses of normative independence and participation, which leads to those who cannot adhere to expected roles seen to fail.

In line with discussions in Chapter 2, this chapter proceeded to discuss the acknowledgement of difference amongst individuals in society, developing the argument that impairment requires acknowledgement in order that disabled people are able to experience inclusion. Chapter 2 saw impairment as overlooked by theories of disability which seek to address exclusion, this being understood to potentially exclude PWLD further by a lack of address of difference. In the present chapter, conceptions of citizenship are discussed in relation to their alignment with a neoliberal social settlement which leads to those unable to fulfil criteria dominated by normative notions such as independence and economic contributions

In discussing materialist and post-socialist understandings of citizenship rights, this chapter has developed a position that considerations beyond identity based theorising, and beyond recognition in terms of institutionalised disrespect and marginalisation of minorities, are necessary in order that inclusion can be realised. To address exclusion and theorise on a form of citizenship that can facilitate the inclusion of all individuals in society, the chapter posits that we must address resource related issues alongside these other considerations as recognition alone will not remedy the widening economic gap.

The present chapter, alongside Chapter 2, has provided a theoretical framework from which to conduct the research and carry out the analysis. The previous research and theorising discussed here has illustrated the potential of citizenship as an inclusionary tool, pointing to the need for further research in the area to contemplate the citizenship of PWLD in particular, as this group is rarely included within citizenship theorising.

Chapter 4: Methodology and Methods

4.1 Introduction

4.1.1 Chapter overview

This chapter details the methodological approach, the research design, data collection, and analysis employed. I explain my theoretical position, relating this to the research goals and the narrative methodology and thematic analysis employed. My theoretical position and understandings, the reasons for conducting qualitative research using a narrative approach, alongside the theoretical, practical and ethical issues involved when including this vulnerable group in research, were key issues and are discussed throughout this chapter as well as in their specific sections.

In the first section of this chapter, the following deliberations related to my position in the research and what I understood as the potential achievements of the research: Did I believe objectivity to be achievable? Did I think the participants should hold more centralised roles in the research about their lives? Did I see myself as an expert? Would I ideally have liked to carry out participatory or even emancipatory research, whereby I would have handed over greater control to the participants? These questions were not easily answered. My position evolved over time; I moved from believing emancipatory research to be the ideal (although there was not enough scope to discuss this here), to a less definitive conclusion which saw a greater inclusion of my own understandings of social justice and knowledge, recognising that I was analysing the data I had jointly created with the participants, incorporating their (and my own) understandings in a reflective and honest way. I use the word 'honest' here, as opposed to objective, because my theoretical position negates the possibility of achieving objectivity or finding the 'truth' in positivist terms. The narrative approach (see below for a description of this methodology) therefore fits well with my theoretical position as well as understandings regarding how best to gain insight into the lives and understandings of the PWLD involved in the research.

The second section of this chapter covers the more practical side of the research process and the ethical considerations in relation to this. This includes a discussion in relation to accessing the organisation and participants, the recruitment process, and sampling method employed;

issues surrounding informed consent; the data collection process; the necessity to create narratives; the process and justification of thematic analysis; and a reflective piece.

The issue of informed consent is discussed at length in this section. In research generally, informed consent is sought prior to interviews taking place (Taylor et al., 2016). Whilst I followed this general approach, because the individuals partaking were identified as a vulnerable group, further measures (including consulting with family members and carers pre and post-interview to check the welfare of the participant) were taken to ensure true informed consent had been gained, and every effort made to confirm the individuals were happy to continue as participants (Burawoy, 1991; Hill Collins, 2000; Kellett and Nind, 2001).

My decision to carry out interviews with PWLD within the context of the narrative approach, analysing the data thematically, is discussed in relation to the acknowledgement that the suitability of this approach when involving people who may not be able to express themselves well in the traditional sense has been questioned indirectly by narrative theorists who call for 'inarticulate' participants to be excluded from this research (Plummer, 2001). Alongside others (Booth and Booth, 1996; Owens, 2007; Baldwin, 2008), I challenge this assumption. I will detail the ways in which researchers have illustrated techniques by which narrative research can successfully include those described as 'inarticulate'.

I initially planned to conduct semi-structured interviews involving a loose interview guide, however, the need for greater pragmatism became apparent as the participants steered the interview topics more than I had anticipated. I discuss here how I adapted to this development, referring to the work of those working with PWLD who have advocated the need for the researcher to create a method which best serves the participants, rather than attempting to follow a prescribed method (Booth and Booth, 1996; Owens, 2007).

The reflective account looks back at the research process and my role within in, focussing on my feelings throughout, detailing the ways in which I felt I impacted on the research and the research impacted on me.

4.1.2 Research aims

The three research aims were to: (1) Explore service users' understandings of enablement, independence and inclusion; (2) Develop understandings of citizenship in relation to people with learning disabilities, focussing on the idealisation of independence and the concept of

inclusion; and (3) I will explore the necessary changes indicated by the empirical and theoretical research to support the inclusion of PWLD in society both culturally and structurally.

The first two aims illustrate my desire to investigate perceptions, with the third aim of indicating ways in which the findings may be used to suggest necessary changes. Such a goal involves the interpretations of the researcher being made into practical suggestions; this is noted as a difficult task as the researcher is acknowledged to both affect the data in terms of their interactions with the participants, as well as then interpreting the findings from their own particular position (Silverman, 2013). However, the dilemma of researcher affect is inherent in any data gathering procedure, regardless of the method used; the acknowledgement of this means the research is represented honestly and the reader is then able to assess the information from an informed position (Harding, 1987; Polkinghorne, 2007; Smith and Sparkes, 2008).

4.2 Methodology

In qualitative research we need to recognise:

> [1] …the (contested) theoretical underpinnings of methodologies; [2] the (often) contingent nature of the data chosen; [3] the (likely) non-random character of cases studied. (Silverman, 2010 p. 331)

Silverman goes on to explain in order to cover these areas when writing about our research we should: (1) make clear our theoretical assumptions; (2) explain why the particular area and people are involved in the research; and (3) explain why the particular findings would be relevant outside of the particular setting. I have attempted to cover all of these points within this section.

4.2.1 Ontology

In a discussion of ontology, the study of being, we are asking what is there to find out about the world; does a reality exist separate to social actors imposing meaning upon it. This question '…stalks through the history of sociological theory' (Archer, 2010 p. 225), the magnitude of which – and the affect this has upon how the data is then seen – means it is essential to make clear my own ontological assumptions and discuss the impact of these (Walmsley, 2001).

Traditionally, there are two dominant positions in relation to this question. Firstly, there is objectivism, which understands there to exist an objective, testable reality, separate to our individual perceptions and understandings (Durkheim, 1895). Emile Durkheim, one of the key thinkers of early sociological study, explained:

> …our main objective is to extend the scope of scientific rationalism to cover human behaviour by demonstrating that…it is capable of being reduced to relationships of cause and effect, which…can then be transformed into rules of action for the future. (1895 p. 33)

This school of thought generally employs positivist/quantitative methods in an attempt to acquire an understanding of society. These methods include, for example, gathering empirical data that can be compared and analysed in search of answers to research goals. They seek to uncover the singular truth.

Secondly, and in contrast to this, interpretivism does not believe there to be an objective reality; reality does not exist separate to the meaning social actors make. This position sees society and individuals actively constructing and reconstructing reality, making meaning from their interpretations (Weber, 1949). Max Weber, also a key thinker in early sociological theory (Karl Marx being understood as the third), explained: 'All knowledge of cultural reality, as may be seen, is always knowledge from particular points of view.' (Weber, 1949 p. 81)

The interpretivist school of thought employs interpretative/qualitative research methods, such as interviews and observations. The researcher aims to understand the position of the participant from the participant's perspective, whilst acknowledging that they are working within a specific socio-cultural frame of reference. They do not seek a singular truth but aim to vigorously analyse the data and represent the subjects' lived experience.

My theorising in this area has been a journey, with my position evolving throughout the research process as I questioned and critiqued my understanding of what can be said to exist and how it came to be so. I began by thinking in far more definite terms than how I proceeded. I began with the understanding that my assumptions as to what social reality is meant I could refer to my ontological stance as that of an interpretivist, whereby 'realities' are socially constructed and reconstructed (Denzin and Lincoln, 2011). I saw reality as an idea that can be challenged and altered; current norms and representations can be confronted and altered, replaced with ones that better serve marginalised groups (Bertens, 1995), such as PWLD. It

seemed a hopeful vision. This position appealed because it seemed that normative world views and expectations are skewed in the favour of those whose voices are heard; it gave me hope to think that this was only the way of things as a result of dominant voices, and could be challenged and changed.

However, deeper reading and considerations highlighted the dangers with this theoretical position; rendering all 'truths' as valid in their own right may result in the inability to deem certain acts and positions as inhumane (Burawoy, 1991). Whilst I acknowledge that my interpretations and understandings are subjective, I do not see ethical and moral positions as relative. I believe in the existence of moral positions that cannot be understood as, or reduced to, one of many truths.

These ontological considerations are exemplified by a discussion between Foucault and Chomsky in 1971 (Elders, 2011), in which Foucault stated his belief that we do not have fundamental human characteristics which can be separated from culture and socially conditioned practices. The human condition does not have an underlying morality that exists separate to culturally conditioned understandings. Chomsky disagreed, stating the human condition does have intrinsic qualities – that there is such a thing as human nature. Elders (2011), discussing the continued relevance of the debate, wrote: 'Chomsky and Foucault bring to light the existing clash in the heart of Western culture and politics itself' (p. 2).

In relation to such a debate, I have moved from greater alignment with the social constructionist position of Foucault, to now feeling more ontologically akin to the critical realist position to which Chomsky indicates. There is danger in taking social constructionism to the extreme that Foucault does here (Joseph, 2004). When we believe only the transitive world is accessible, the intransitive world becomes '…a lost cause…then knowledge becomes knowledge of knowledge, not the real world' (Joseph, 2004 p. 146). Critical realism, however, a relatively contemporary ontological position, understands that society is constituted by both transitive and intransitive realities (Bhaskar, 2011). That is, there is the 'real' reality and the 'actual' reality; the 'real' is intransitive, it is not accessible because an individual interprets via their cultural lens, thus imposing a constructed meaning – an interpretation – upon it. It encompasses concepts that we may understand to exist, such as human nature, but that we debate the meaning and measurement of. The 'actual' reality we can observe; for example, we can observe the way one individual treats another, and attempt to debate from this observation whether or not the action is moral. The basic premise of this position is that some things do exist separate of the

mind imposing meaning upon them, whilst others do not. Critical realism is useful as it offers a position which both claims an objective reality, as well as acknowledging that the social agent will impose their own subjective meaning whilst attempting to understand it (Bhaskar, 2011).

The conceptual changes I have experienced throughout the research process have highlighted the dangers of stating a philosophical stance too ardently (Lopez and Potter, 2001); I have instead attempted to make clear where I have resided in the ontological debate throughout the research process.

4.2.2 Epistemology

It is commonly understood across sociological theory that social structures are a product of social actors, and social actors are in turn then shaped and influenced by social structures, with different theoretical positions leaning towards each in differing degrees (Archer, 2010): '…both structure and action were indispensable in sociological explanation.' (p. 225). I have already discussed my ontological position – my understanding of whether there is an objective reality separate to understandings and interpretations of it – the traditional spectrum between objectivism and interpretivism is a difficult place to locate oneself. I draw on critical realism as a useful alternative, as it allows for an objective reality which we are not able to observe empirically because of the socially constructed subjective meaning that we will impose upon it (Archer, 2010).

My epistemological position requires a discussion of how best we can acquire knowledge based on these understandings. I had to decide how to carry out the research in relation to the research goals, as well as in a manner that would cater for the needs of the research participants. As such, a positivist methodology was not appropriate in relation to the research aims, needs of the participants, nor my ontological position. I wanted to understand individual realities; I wanted to empathise and gain insight into the meaning that they were creating about their worlds, and then relate this to the structural and identity related injustices I observed in their situation and more broadly. It would not have been useful for the aims to have adopted positivist methods, such as questionnaires, that I would then analyse statistically, as this would not have provided the insight I sought. It would also not have been appropriate for the research participants as most of the individuals were not able to write and, importantly, needed the one to one interaction with the researcher in order to express themselves.

As previously discussed, these goals are in line with a critical realist ontology whereby the perceptions of the individual are not understood to represent an objective reality, but rather that individuals understandings are subjective and have been constructed in relation to the structures in which they exist (Bhaskar, 2011). I have analysed the data with the aim of understanding individual perceptions in relation to normative citizenship goals, going on to explore how the lives of the people I interviewed could be improved by greater address of these desires. In line with my critical realist leanings, I have then continued on to a discussion of how these understandings are shaped by the structures (e.g. institutionalisation) in which the individuals live, critiquing the macro. I was therefore wary of overemphasising individual experience whilst neglecting a discussion of structural forces – a common critique of narrative research (Riessman, 2005) – as my aims and theoretical understanding lead to a discussion of both.

4.2.3 Justifying a narrative approach

This section develops the discussion of my theoretical understandings in relation to the narrative methodology and methods I elected to use to gather and understand the data. The narrative approach is an umbrella term for approaches which seek to understand and represent individual experiences over time and within a specific context (Clandinin and Connelly, 2000). Because narrative analysis is concerned with what the stories told mean for the individual, as opposed to seeking an objective truth, narrative analysis is within the interpretivist, rather than positivist, paradigm. As discussed earlier in relation to ontology and epistemology, interpretative research goals, theoretical position and research methods are intrinsically linked (Clandinin, 2007).

Unlike research carried out under positivist aspirations of objectivity, within the narrative approach it is not possible to separate the researcher from the research process, the data and the participant. Objectivity, validity and representativeness are not gained by attempts to remove the researcher, rather, objectivity is an impossible goal, and the usefulness of the findings in terms of their validity and potential to be said to represent the participants, are reduced as a vital factor is overlooked (Burawoy, 1991; Kramp, 2004; Mantzoukas, 2005). The research is a product of the researcher and the researched; it is this acknowledgement that will determine the validity of the findings, not whether they are able to represent 'reality'.

Narrative research assumes that we live storied lives; that we understand our lives through the stories we and others tell of them (Clandinin, 2007). Stories are a way in which to understand

a person's internalised world; society and culture are said to 'speak for themselves' through the individual's account (Riessman, 1993). As previously discussed, I do not consider myself a staunch narrativist/interpretivist, whereby all is relative. In line with critical realism, I want to understand perceptions and interpretations, and go on to discuss these in relation to structural inequalities as I understand them (Archer, 2010).

As such, narrative approaches have the potential to use personal insights to challenge dominant assumptions (Biggs, 2001; Goodley, 2001; Plummer, 2013). An example of such work is carried out by Biggs (2001) who used the narrative approach to challenge contemporary assumptions of ageing within social policy, and to observe the construction of older age. Biggs points out the power that stories have to expose injustices – a narrative researcher must then not focus on the text alone but also ask where the story comes from and what surrounds it – they must look to structures. In relation to my research with PWLD, this is a useful premise; the interviews, as well as the literature review, led me to question the structural conditions affecting the participants. Narrative encourages this focus on the micro in combination with the macro (Riessman, 2005).

Narratives are produced in specific social, cultural and historical contexts and should be a concern of all sociologists due to much empirical material taking a storied form (Franzosi, 1998). They have been affected by factors including the socio-historical context, the researcher, and the specific context in which the research is carried out, and they must therefore be acknowledged as a product of personal biography and social structure (Riessman, 2005). Riessman explains that 'Narratives are useful in research precisely because storytellers interpret the past rather than reproduce it as it was' (p. 6). The insight received from narrative accounts provides information about current perceptions, interpretations of the past, and projections for the future (Gilbert, 2004). They therefore do not exist in a vacuum, but are co-constructed by all, including the researcher (Plummer, 1996; Gubrium and Holstein, 2009).

Due to the co-constructed nature of narratives, it is understandable that different interviewers may elicit different accounts from the participants; it is also likely that there will be more than one meaning attached to an experience, as well as different ways in which to interpret it (Silverman, 2010). As such, it is essential to make clear my ontological and epistemological understandings, include a detailed reflective account, and offer the reader as much insight as possible into my relationships with the participants and the organisation (Kincheloe and McLaren, 2008). The aim of this is to provide the reader with an honest account from which

they can interpret the research (Harding, 1987; Clough and Goodley, 2004; Smith and Sparkes, 2008).

4.2.4 Narrative research with people with learning disabilities

Carrying out narrative research is a process by which agency and opportunity are afforded to the participants; they are able to make claim and construct stories about their lives, and in doing so are able to articulate that which they deem important. It is potentially an emancipatory exercise as it is a way in which the voices of the marginalised can be heard and empowerment facilitated (Baldwin, 2008; Lesseliers et al., 2009). Narrative research, characterised by its practicality of approach, attempts to gain a full understanding of the subject matter from the perspective of the narrator; it respects the story teller, using sensitive and appropriate methods which best suit them (Clandinin, 2007). It was therefore an appropriate choice for the present research not only because of its theoretical assumptions, but because a major aim of the research was to represent and acknowledge the importance of the perceptions of the participants. Such a goal has been called for numerous times by researchers across a broad spectrum (Booth and Booth, 1996; Oliver, 1996; Goodley, 2001; Walmsley, 2003; Gilbert, 2004; Walmsley, 2006; Goodley and Roets, 2008). Goodley (2001), for example, conducted research with PWLD, employing narrative analysis to challenge taken for granted impairment dominated discourses about PWLD.

In terms of the practical aspects of carrying out research with PWLD, it has unfortunately been claimed that narrative research requires that the research participant be articulate and have the ability to tell a good story (Plummer, 1996; 2001). Such criteria has been noted as exclusionary and unnecessary by researchers who have demonstrated the potential for even those with profound communication difficulties to be involved in narrative research, without compromising the storied outcome of the approach (Booth and Booth, 1996; Owens, 2007; Baldwin, 2008). This research has demonstrated the need to, and feasibility of, working pragmatically and creatively with the narrative approach. In relation to this, Booth and Booth (1996) point to four issues which may arise when conducting narrative research with PWLD: (1) inarticulateness; (2) unresponsiveness; (3) lack of a concrete frame of reference; (4) problems with time. Narrative analysis has traditionally called for participants who are able to overcome these issues (Plummer, 2001). My data confirmed Booth and Booth's claim that PWLD who are able to fulfil such limited criteria will be an exception, rather than the rule.

Booth and Booth (1996) echo my own thoughts about the involvement of PWLD in research. In line with advocates of the social model of disability (Barnes and Mercer, 1997), they see disability being framed as an individual pathology, resulting in PWLD being excluded because limitations are seen to be a result of the individual's impairment, rather than the lack of accommodation by society. In relation to the research process, this is likened to the ability of the researcher to accommodate for difference. In line with the individual model of disability, the exclusion of PWLD from narrative research reproduces inequality; working to make narrative accessible for all challenges this model (Owens, 2007). Narrative methods have the potential to be used to liberate the voices and empower those who are usually overlooked in research (Holland and Kilpatrick, 1993; Booth and Booth, 1996; Kellett and Nind, 2001; Gilbert, 2004; Elliott, 2005; Owens, 2007; Smith and Sparkes, 2008; Bhopal, 2010). When conducting narrative based research with PWLD, the researcher needs to be prepared to find ways to communicate and draw out responses (Booth and Booth, 1996).

Owens (2007) suggests the researcher moves away from rigid research structures in order to allow the research to be inclusionary, stating: 'I propose that using narrative methods entails each researcher acting as their own methodologist' (Owens, 2007, p 300). Methods, when interviewing PWLD, are seen to be reliant on the skills of the researcher. I followed such an approach when conducting my research. There were times when the interview became more akin to a conversation, for example, but this was an appropriate action given that without doing so I may have silenced participants.

As I discuss in greater detail later in this chapter, from my experience of being a support worker, and having worked with the participants previously, I had some understanding of how each individual communicated. Although the interview situation brought about some new ways of interacting, this previous experience undoubtedly assisted both the participants and myself. That it changed the data I received is also undoubted, but my understanding of interactions – my interpretivist leanings – are based on all those involved in an interaction creating shared knowledge. I would have affected the data no matter what my previous relationship with the participants (Mantzoukas, 2005). The benefits of my having known them in my capacity as a support worker was on the whole beneficial to the data I was able to gain.

With regards my role as a researcher in an environment which I was also a support worker, the roles merged as the participants treated me as the support worker that I was, and I treated them as I had prior to conducting the research. Any goals of separating myself from my support

worker role in order to adopt that of 'researcher' would have been futile, in line with a positivist position I do not hold, and ultimately damaging to the research, and possibly the participants and myself as I tried to interact in unnatural ways. This previous relationship and knowledge did not always feel wholly beneficial, particularly in relation to my own wellbeing. As I discuss later in this chapter, at times, I felt that the service users may have expected our discussions to lead to positive changes where they told me about things they would like to be different. There were also times when participants did not understand that our time conducting interviews would be limited; there were instances where it was difficult to draw the process to a close as I did not want to cause distress.

4.3.2 Inclusive research?

> ...it is worth noting that significant gaps remain in the way that research has so far been able to include people with learning disabilities. (Gilbert, 2004 p. 299)

When considering the inclusion of PWLD in research, however far we strive to include, or give control of the process to PWLD, we must initially ask: is the research worth doing and whose interests does it serve? The answer to this will determine whether the research should be conducted (Kellett and Nind, 2001; Walmsley, 2004). My review of the literature, previous experience working with PWLD, as well as the research I conducted for my Masters project, has resulted in an understanding of the need for the current research to be carried out in order to contribute to a field of inquiry in which the inclusion of PWLD in society is brought into question, and ways to aid true inclusion are sought. In terms of whose interests does the research serve, the research aims to positively affect the lives of PWLD, as well as questioning normative, arguably damaging, assumptions about all individuals in society.

Debates within the social sciences have led to questions of how power relations can be managed, and how marginalised groups can best be included within research about their lives (French and Swain, 2004; Nind, 2008). As such, when coming to the research process: 'One of the first methodological decisions to be made, for example, might be whether the research is on or with people with learning/communication difficulties' (Nind, 2008 p. 5). Traditionally, where research has sought to involve PWLD it is research 'on', rather than 'with' them (French and Swain, 1997; Kiernan, 1999; French and Swain, 2004). How far this is an ethical way to proceed with research involving PWLD is questioned by advocates of more inclusive research approaches, such as participatory and emancipatory research, whereby greater control is held

by those whom the research concerns (Cornwall and Jewkes, 1995; Kiernan, 1999; Chappell, 2000). These approaches will be discussed in further detail below.

For participatory research advocates, a situation in which the researcher is placed as the expert – as is traditionally the case in the social sciences – is not conducive to tackling inequalities in neither the research process nor society (Park, 2006). This approach advocates the sharing of control by all involved in the research (Walmsley, 2001). Park (2006) explains that this approach believes people whom the research concerns the lives of should not only be consulted as part of the research process, but should play an active part in directing and generating the research. By way of definition, in participatory research: (1) the research issue can be identified by either the disabled people or the non-disabled researchers; (2) the research issue is analysed collectively; and (3) these alliances between researchers and the group whom the research concerns must serve the interests of the disabled people (Cocks and Cockram, 1995).

Alliances between researcher and participant illustrate participatory research acknowledging impairment when including PWLD in research, the issues which are likely to arise when research involves PWLD, and the intellectual demands of conducting research which means the involvement of researchers without learning disabilities is essential for the outcome of the research (Chappell et al., 2001; Kitchin, 2000). The research quality and relevance is understood to be strengthened by the greater inclusion of those whom the research is about in this way (Kitchin, 20000). The researcher, drawing on either theories of normalisation (social role valorisation), phenomenology (understanding experiences from the perspective of the individual), or the social model of disability (societal barriers are the root cause of exclusion), uses qualitative methods to interpret the experiences of the participants (Gilbert, 2004).

Participatory research has been viewed as an intermediary to emancipatory research (Zarb, 1992). Morris (1992), Oliver (1992) and Zarb (1992), when discussing the definition of emancipatory research, concluded that this type of research should: (1) be used to facilitate improvements in the lives of disabled people; (2) disabled people should have an increased opportunity to be researchers; (3) researchers must strive for reflexivity, whereby they reflect on the way their actions affect the process, understanding their influence on the research; (4) the research should be sought and commissioned by disabled people's organisations who have identified the need for the research; (5) and the researchers are answerable to the organisation. The emancipatory model of research arose from discussions regarding the increasing general demand of disabled people to be in greater control of that which affects their lives (Morris,

1992; Oliver, 1992; Zarb, 1992). This approach draws on the social model of disability (Walmsley, 2001), with the goal of societal change, rather than reducing stigma, as participatory research is understood to aim for (Chappell et al., 2001). However, in relation to learning disability it is often considered an approach in its own right due to its feasibility, achievable goals and ethicality, whereby the researcher is committed to the improvement of people's lives (Chappell, 2000). Chappell explains: 'I would argue that participatory research can be understood better as a pragmatic compromise between the conflicting pressures on researchers.' (p 40).

In relation to previous discussions of the pitfalls of the social model of disability (Redley and Weinberg, 2007), emancipatory research has been criticised for its failure to acknowledge the existence of impairment – as is particularly necessary if the social model/emancipatory research is to be used to work towards improving the lives of PWLD (Gilbert, 2004).

Walmsley (2001) coined the term 'inclusive research' to refer to all branches of research whereby 'people with learning difficulties…are involved as more than just subjects or respondents' (p. 188). Walmsley critiques inclusive research in relation to theories of normalisation (Wolfensberger, 1980) and the social model of disability (Oliver, 1992; Barnes, 1996), understanding this type of research to be used to promote valued social roles and positive images of PWLD (participatory research), and/or standing with the social model in understanding that societal barriers have thus far prevented PWLD from having control in research about their lives (emancipatory research).

In relation to the societal barriers emancipatory research attempts to overcome, Strnadova et al., (2016) explain:

> Challenges to inclusive research…remain – academia is rife with inherent barriers…such as difficult timelines, funding requirements, ethics committee misunderstandings in regard to inclusive research and publication policies. (p. 62)

If these structural barriers can be overcome, inclusive research has been reported to provide benefits to all involved in the research process, being described as ''the right thing to do'' (Strnadova et al., 2016 p. 62), often driven by values which push for social justice where once it is seen to be lacking (Walmsley, 2004). Considerations of inclusive research have impacted on both those who aim to carry it out as well as those who carry out more traditional research with PWLD taking part as participants; it has affected research culture and encouraged

researchers generally to seek ways to both attempt to include PWLD in the research process ('with'), and to carry out research about their lives by asking them about them ('on'), rather than looking to families and carers as was the case in the past (Walmsley, 2004).

However, even if the structural barriers discussed by Strnadova et al. (2016) were overcome, methodological issues would remain (Kiernan, 1999). Cornwall and Jewkes (1995) note that 'Control over the research is rarely devolved completely onto the 'community'; nor do 'communities' always want it…participatory research is certainly not a simple alternative.' (p. 1672). Conducting inclusive research is potentially more practically problematic than traditional research because of the expectations that are placed on the individual in terms of both understanding and communication (Kiernan, 1999; Atkinson, 2004). In line with critiques of the social model of disability, research which aims to place greater control and responsibility in the hands of PWLD without due acknowledgement/accommodation of their impairment is not useful in relation to the participant experience nor research outcomes (Booth and Booth, 1996; Kellett and Nind, 2001; Murphy and Dingwall, 2001; Tuffrey-Winje et al., 2009).

Elements of participatory research are present in my research, but I do not aspire to conduct a piece of research that wholly draws on this and the research cannot be said to be 'with' or 'on' PWLD, but rather 'for' (Nind, 2008). My adherence to an interpretative stance means I wish to discover the participants' constructions but also regard my own interpretations as an important aspect of the research. Murphy and Dingwall (2001) discuss researcher attempts to share control of the interpretive process, stating that an issue is not necessarily understood based on our experience of it, and participants '...may not be in a position fully to grasp all the relevant aspects of context' (p 345). In relation to participatory, and particularly emancipatory research, this is a controversial position as it opposes the goals of the participants having greater control in the research process, and that of removing the researcher as the 'expert'.

The method must be adaptable when research involves PWLD (Booth and Booth, 1996; Gilbert, 2004; Owens, 2007), with a focus on the empowerment which can be gained from taking part in research. In relation to including PWLD in research, Gilbert (2004) explains:

> At the same time, as a commitment to an ethic of participation, researchers will need flexibility and patience, as well as imagination, ingenuity and reflexivity. A good measure of persistence would not go amiss either. (p. 307)

As is the case in the present research, individuals with severe and profound learning disabilities are likely to be left out of research generally due to constraints in terms of time, resources, and the inability of the researcher to accommodate for difference, and are particularly unlikely to participate in research, no matter how inclusive it aspires to be (Kiernan, 1999; Kellett and Nind, 2001; Gilbert 2004; Tuffrey-Wijne et al., 2009). Excluding people from my research on such grounds is clearly an ethical dilemma. A possible solution for future research would be '…through the triangulation of multiple sources of evidence. However, caution must remain around the levels of interpretation involved' (Gilbert, 2004 p. 304).

A detailed discussion of inclusive research was essential here to illustrate my awareness of the current push towards this kind of research, and in order to justify my own methodological approach. Whilst I do draw on aspects of inclusive research in that I aspire to conduct research that improves the lives of PWLD; work reflexively; and try to work in relation to the concerns of those PWLD who were part of my research, I did not aspire to carry out inclusive research in a prescriptive way, but rather worked pragmatically in ways that I felt were appropriate to the research aims and the individuals involved. This meant at times I was compelled to move away from that which I had identified as a necessary subject to discuss, and focus on the topic important to the participant. Kellett and Nind (2001) discussed the question of research 'on' or 'with' PWLD, explaining that they too did not carry out either of these kinds of research, but were conducting research with the goal of positively affecting the lives of PWLD. They warned of the danger in striving to carry out inclusive research at the cost of excluding those from the research with the greatest disabilities, going on to state that not all individuals would desire to be involved in the research even where capable of doing so.

The present research, having identified a research area that the interests of PWLD would be served by the study of, aims to conduct research that positively impacts upon the lives of PWLD. Researcher reflexivity is a key component of inclusive research approaches, this facilitates the PWLD playing a key role in directing the research (Walmsley, 2004). Considerations of reflexivity dominated the present research in this way.

4.3 Methods and Ethics

According to the Economic and Social Research Council (2015), in order that research is ethically conducted, the following criteria must be met: the participants must take part voluntarily; the rights and dignity of the participants must be respected; the research should be

worthwhile, providing value that outweighs any risk or harm; the participants should be informed of the purpose, methods, and intended uses of the research; the rights of the participant to anonymity should be upheld; the integrity of the research must be upheld; and any conflicts of interest made clear to the participants. I will detail here how I fulfilled these ethical obligations in relation to the particular needs of the participants. There is a substantial focus here on ethics because of the acknowledged vulnerability of PWLD (Hill Collins, 2000; McCarthy, 2003; Lewis and Porter, 2004; Tuffrey-Winje et al., 2009). The method and ethics are woven together before and during the research process so it seemed appropriate to discuss them together here.

Here I detail my decisions in relation to the practical and ethical issues related to my research. Access to the organisation and the recruitment of participants are discussed in relation to sampling, 'gatekeepers', and my relationship with the organisation and service users before and during the research. Informed consent is then addressed in relation to the particular challenges of striving for true informed consent from individuals with learning disabilities/intellectual impairments. Moving on, I discuss the process of data collection and the particular challenges I faced when carrying out research with people who had learning disabilities. In relation to this, it was essential that I worked pragmatically and reflexively. Leading from this, the following section, ''Creating' Narratives', details my attempt to provide an alternative way for the participants voices to be heard where interview data alone did not do justice to their stories. The data analysis section discusses this further, whilst also including details of the transcription process, coding, presentation of findings, continued anonymity and confidentiality.

4.3.1 Access and recruitment

As discussed in greater detail in Chapter 1: Introduction, my previous involvement with the organisation as both a researcher for my Masters project and support worker led to my conducting the research within this context. Access to the context was the first point in gaining access to the participants. Because of the experience I had there, I was both familiar with how the organisation operated and with most of the staff and service users. This I experienced as wholly beneficial to the research process; I had previously experienced being new to the organisation, service users and staff, and it had taken a substantial amount of time to build relationships whereby many of the service users wished to engage with me.

The organisation were the 'gatekeepers'; able to facilitate or block my research attempts (Tuffrey-Wijne et al., 2009). However, the organisation had been aware and supportive of my wish to conduct further research within the setting for some time as I was currently employed there and they knew of my PhD plans. Following submission of a detailed plan in relation to ethical considerations to the University of Huddersfield, I had a meeting with the Chief Executive of the organisation where I would recruit participants. At this meeting I discussed the aims of the study and the ethical considerations I had made. The research was approved by the Social Research Ethics Panel at the University, and I was granted formal permission to recruit willing participants by the Chief Executive of the organisation. As noted by Stalker (1998), gaining access to the organisation does not necessarily mean you will be welcomed in by staff '…on the ground [who] wield considerable power in terms of facilitating or impeding access…' (p. 8) In the case of the present research, however, I was not impeded by support staff. I believe my previous experience and current relationships with the staff helped with this as I was not viewed as an 'outsider'.

Access to the organisation assured, I then needed to recruit participants. As I discuss in detail below, PWLD have been found to be compliant (Kellett and Nind, 2001; McCarthy, 2003; Tuffrey-Winje et al., 2009). There are numerous theories put forward by the aforementioned researchers and others as to why this is the case, however, for the present research that this may be the case was my primary concern. Therefore, when approaching potential participants I kept this at the forefront of my thinking in order to be particularly aware of indications that an individual did not want to take part despite possibly agreeing. As acknowledged as useful by others researching with PWLD (Stalker, 1998; Goodley, 1998; Burke et al., 2003), the substantial amount of time I had spent with many of the participants meant that I was particularly attuned to such cues, and the participants were far more at ease talking to me than they had when I had started working there two years prior.

I recruited participants using theoretical and then opportunity sampling. Theoretical sampling methods seek populations that illustrate a feature which the researcher is interested in (Bryman, 2016). In the present research, this feature was that all participants be defined as having a learning disability. Silverman (2013) goes on to state that the sample must be chosen carefully and critically, with the research questions and the researcher's theoretical position in mind, and the group of participants chosen must fulfil criteria that will help the researcher achieve their research goals. I wanted to explore understandings of independence and inclusion amongst

PWLD; I therefore chose the organisation based on the presumption that having known the participants and the organisation for a substantial length of time would aid the research process and findings. It is essential to reiterate here that PWLD are not a homogenous group, therefore the researcher cannot make assumptions about the similarity of the participants needs, abilities or generalizability of findings because of this label (Lewis and Porter, 2004; Goodley, 2008).

4.3.2 The Consent Process

The gaining of informed consent, whereby the potential participant understands key information about the research, is a '…core principle of social research…' (Ritchie and Lewis, 2014). This information should include the aims of the research, why it is being conducted, and how the information will be gained and recorded, as well as assuring the potential participant of their right to withdraw from the research, that their data will be kept confidential, and when quoted they will be referred to by a pseudonym (this varies across research settings, here pseudonyms were used as a rule in order that the organisation and participants remain anonymous). Once this discussion has taken place and the participant both understands and agrees to take part in the research, they will traditionally sign a consent form as evidence (see Appendix 1).

How far signing a consent form is useful to the participant has been questioned by Ritchie and Lewis (2013), who point out that this technique emanates from biomedical ethical standards. They argue that the consent form is useless to the participant and may cause them to feel uneasy about withdrawing from the research process if they wished. However, they go on to note that the form provides some protection for the researcher or research organisation as evidence that the individual wished to participate in the research.

Whilst I did ask those who agreed to take part in the research to sign a consent form, I did so under the wider understanding that my moral responsibilities to the participant did not end there; particularly where PWLD are research participants, assumptions of understanding cannot be made and constant vigilance to the needs and desires of the participants is necessary (Booth and Booth, 1996; Kellett and Nind, 2001; McCarthy, 2003; Tuffrey-Winje et al., 2009). I therefore explained the research agenda and process as well as I could, varying the approach to the individual's needs, however, in some instances I could not be sure that this resulted in understanding despite agreement to take part.

From my experience of working with the participants, I did foresee being able to gain true informed consent from some of the potential participants, however, as found by Kellett and Nind (2001), there will also be those individuals from whom it is not possible to gain consent in the traditional way, as although they may agree to take part, it is unlikely that they will be informed of the process following this because of general issues with understanding that learning disabilities entail, and a lack of exposure to research as a concept. PWLD tend to be very compliant and therefore likely to take part in research that they may not understand due to a number of factors, including little exposure to the concept of research and perceived power relations (McCarthy, 2003; Tuffrey-Winje et al., 2009).

Below is an example of where I believe I gained true informed consent from one participant, illustrated by her repeating information I had previously given her, asking questions, and finishing my sentences:

> R: So that's what we're doing. And here, this is a consent form -
>
> P: Hmm.
>
> R: - and it's just to say that I've explained -
>
> P: To me and to the manager.
>
> R: - what I'm doing, and it's totally up to you -
>
> P: It is.
>
> R: - if you want to take part or not.
>
> P: I do.
>
> R: So these boxes here are just for you to tick. This first one says that you've been told about what I'm doing -
>
> P: I've been told by you, yeah.
>
> R: That you've agreed to take part.
>
> P: I have, yeah.
>
> R: And that you don't have to take part and you can stop anytime you want.
>
> P: Cos we can carry on another week.
>
> R: Yeah.
>
> P: When you come in.
>
> R: And if you don't want to carry on another time that's fine as well, it's all up to you. But you said you were happy to didn't you?
>
> P: Yes.

R: Erm, and that when I write my essay -

P: Yeah.

R: - at uni. If I write about what you've said -

P: Please.

R: - I won't use your name and then no one will, it'll be confidential.

P: Confidential. Oh yes.

R: It will be anonymous, so they won't know it's you that's said it.

P: Because, because I can say everything, both good and bad.

R: That's exactly it, yes – so you don't feel that you can't say some things-

P: Oh thank you.

R: - cos it will be a different name.

P: Because it is my life whatever I've done.

R: Yeah, exactly.

P: And, you know, if my life's going to be in the book then...be published...I've got to say everything.

R: Yeah, well it's not exactly a book, it's more like a really big essay.

P: Essay, good.

R: Like an -

P: Exam?

R: Not an exam, it'll look a bit like a book when I'm finished -

P: Good.

R: - because it'll be quite big, but it won't be like a book you can buy in the shops, it's a book that will be at university.

P: University?

R: Yeah.

P: For others...are going to see it.

R: Yeah, others will read it as well. Other people – probably more people like at university, rather than...not in a book shop, just at the university.

P: Yes...And I can do what I've been through?

R: Yes.

P: Yes! I understand.

R: Erm, and the recording that I make and anything that I write will be kept safe so no one else can see it apart from my supervisors at uni -

P: Good.

R: - the people who are helping me to write it.

P: Good, yes, erm, somebody who is yours at...there.

R: Yeah, that's the only other people that will be able to see it.

P: Oh good, yeah.

R: Erm...or see the things that we record and write about but everybody will be able to see it at the end but that's when your name's taken out.

P: Oh good, lovely.

R: It'll be anonymous...Erm, yes so I'll get you a pen…

[I find something for Sarah to rest on and explain where she needs to sign and tick. We leave the room we are carrying out the interview in so Sarah can sit at the desk in the office as she want to 'do it right'.]

P: How does it look? Is it alright?

R: That's great, thank you.

P: Great, thank you. Great, isn't it my dear? I just signed all that. I can start on it.

This was in the minority, it was more frequent that I did not feel that I had gained true informed consent as the below excerpt illustrates:

R: I'll just sit next to you and show you this first. Right, this one here – do you want me to read it to you or do you want to read it?

P: You read it.

R: It's a consent form and it's just to say that I've told you – like I told you before – what I'm doing and why. I'm going to give this to, er, erm, like my teachers at uni, just to show that I've asked you if it's OK to talk to you and you've said yeah. And everything else that I've told you is on there, like the, the recording that I take of us now, it'll be kept safe and no one else will be able to listen to it, just me and my supervisors. And you know when I write about you? I'll use a different name -

P: Its stopping recording?

R: What's that?

P: Not recording.

R: Yeah, it's recording.

…

R: Erm, so if you're happy -

P: Yeah.

R: - if you can tick each box and then put your name there.

P: Where?

R: Write out your name there and tick each of these boxes if you're aright with everything.

P: Where you going?

R: Just closing the door.

P: Done it. Done it, Vicky.

In relation to the validity of the informed consent process, non-participation in the research has been cited as an indicator of this (Cameron and Murphy, 2006). Cameron and Murphy explain that this is particularly important when including vulnerable groups in research as it '…is one way of checking whether compliance is occurring through the power relationship which inevitably exists in a research project.' (p. 116). In relation to the present research, it is therefore encouraging that several people declined to take part in the study.

Rather than thinking of informed consent as something that had been 'gained' it is understood as an ongoing process. I followed an approach which involved consideration of 'ethics of responsibility' and 'ethics of care', whereby the participant's wellbeing is under constant consideration because they are regarded as vulnerable (Hill Collins, 2000). This meant that there could have been a point when I was obliged to cease carrying out research with a participant; for example, if they were showing signs that they were stressed, or the process was having too much of a negative impact on them. There were two occasions where this was almost the case – I detail these further in the following Data Collection section – but instead I supported the individuals through the telling of the stories as they seemed to want to explain them to me. The topics concerned previous abuse by support staff and the death of the participant's mother.

Both my having worked as a support worker at the organisation and my position as a researcher, meant that I could have been viewed as a figure of power by the service users (Burawoy, 1991; Freedman, 2001; McCarthy, 2003; Nind, 2008; Tuffrey-Winje et al., 2009). I think this was potentially detrimental in two main ways; firstly, my position may have silenced or dominated interactions; and secondly, the individuals involved in the study may have believed that I was

able to make changes in relation to the issues we discussed. I believed this to be a potential dilemma because I had experienced this situation on a number of occasions whilst working at the organisation as a support worker. For example, I once discussed sleeping arrangements with a woman who was unhappy about having a bedroom on the first floor of a residential home, preferring a ground floor bedroom because she had back problems and did not like taking the stairs. It was apparently not possible for her to have a bedroom on the ground floor, but after our discussion, where I was empathetic to her dilemma, she believed I would speak to the staff at the care home and arrange a bedroom move. She was annoyed when she found out I had no power in the matter. I did agree to speak to the care home as at this time I was not aware that it was not possible for her to move, but she believed that telling me meant a move would be possible.

Following others (Freedman, 2001; Kellett and Nind, 2001; Cameron and Murphy, 2006), I involved a network of people who knew and were trusted by the individual, such as family members and carers, in order to continually assess if they are comfortable with taking part in the process. I included myself in this group of people as I knew and was trusted by many of the participants; that I had this relationship with certain individuals prior to taking on the role of researcher cannot be overlooked, and I believe it would be unethical to do so.

These considerations of informed consent were an ongoing process, whereby the autonomy of the individual was balanced against protecting potentially vulnerable people (Freedman, 2001). Informed consent has to be functional and '...make real the notion of the participants' right to withdraw at any point' (Kellett and Nind, 2001, p. 53), which can mean becoming more involved in the lives of participants than would traditionally be the case. The many ethical dilemma one may face in the research process means that to adhere ardently to a prescriptive approach to ethics may result in participants not being protected due to a lack of reflective practice (Murphy and Dingwall, 2001).

The question of consent was therefore something I kept at the forefront of my mind whilst conducting the interviews, as well as during all interactions with the participants – a 'yes' was not enough. A 'yes' is arguably mainly for the benefit of the researcher; this highlighted the need for measures that truly address consent. Aided by previous interactions, I watched for signs that the participant was distressed or did not want to continue the interview. This observation of participant's willingness to participate was continued by family members and support staff. In this way considerations of consent reflect wider discussions of autonomy

versus protection of PWLD, and the acknowledgement of impairment and vulnerability. The consent process was a difficult line to walk as I was perpetually debating the ethicality of my actions.

4.3.3 Data Collection

I conducted 18 semi-structured, in-depth interviews with PWLD. I had aimed to carry out 20, however, I faced two barriers to achieving this. Firstly, some of the service users had communication difficulties which meant I did not have the capacity to include them in the research. This exclusion of individuals from the research, as previously discussed, is a serious ethical issue but one which I could not avoid. Secondly, after accounting for those who declined to take part in the research, and those whom I excluded based on an understanding that whilst they said they would take part in the research, I felt that they were doing so from a position of compliance, rather than truly consenting to take part, there were few potential participants left.

I had planned to conduct a minimum of two interviews with each participant, each interview being between ten and fifteen minutes in length. I made this plan based on my understandings of the way the participants interacted with me in my capacity as a support worker. As predicted, in some cases it was difficult to engage with participants, however, there was also the other extreme whereby the participant wanted to talk at length. Few interviews were the ten to fifteen minutes I had predicted, the majority being between 30 and 60 minutes. I conducted one interview rather than the planned minimum of two with eleven of the eighteen participants. I assessed this as the appropriate action, taking cues from the participants in terms of their desire to take part in further interviews, as well as in relation to the data and whether I felt that I had covered enough within them. That the interviews were lasting longer than predicted also often negated the necessity to carry out a further interview. In some instances I found difficulty in ending the interview as I did not want to upset the participant nor end the flow of interesting information about their lives. For example, I carried out three interviews with one participant, each lasting almost an hour, because she was so excited to have the opportunity to tell me the story of her life.

In order to facilitate participation I had to play an active role in the construction and telling of narratives; I prompted participants and engaged in discussion, disclosing my own thoughts and feelings at times. Such researcher influence is acknowledged in narrative research (Burawoy, 1991; Lesseliers et al., 2009; Silverman, 2010). As such, it was imperative that the research

was conducted with reflectivity on my part and that my own understandings, feelings about the subject area, and theoretical position are illuminated. Frank (2010) explains, when conducting narrative research – or 'storytelling' (p 665) as he prefers to call it – we need to understand the principles by which the researcher is guided, as well as '…recognising how storytellers are *holding their own* in the stories they tell…' (p 666).

Observing connections between the past, present and future proved to be a useful way in which to hold conversations with my participants where they often reflected on the past in order to discuss their current thoughts and feelings. For example, at the start of the interview I would say something along the lines of:

> *R: When doing interviews with other people, I've found that it's easier to just start talking about the earliest thing they can remember…so, can you remember when you were younger? … Do you remember when you were really small? … What do you remember?*

Goodley (1996) utilises life story techniques in order to help the participants to tell their own story, and by reflecting on the past, make claim to the future. The life story approach, from my experience of working at the organisation, was a potentially useful strategy for engaging with the participants. My time working with PWLD evidenced that it is often difficult to sustain conversations, therefore I thought a focus on discussing the past or plans for the near future may be helpful in keeping the conversation flowing. I used this technique pragmatically, where it seemed appropriate.

I attempted to steer the interviews towards a discussion of topics such as independence, inclusion and autonomy, and in many cases the discussion progressed in this manner anyway. In all instances I moved the conversation on in the way that appeared to best ensure the participant remained comfortable and responsive. This meant veering away, in some cases, from my research topics. This often resulted in participants disclosing interesting, unexpected insights. Many of the participants clearly really enjoyed telling me about their lives, many of whom do not often have such an opportunity to do so due to living in institutions where a lack of resources and time mean support workers are limited in the amount of time they are able to dedicate to an individual.

It became apparent that my initial plan to carry out two interviews with each participant had to be judged on a case by case basis, not least because the subject matter was at times potentially

distressing. There were times where the participant became distressed either during or after the discussions we had. Examples of this include one participant disclosing information regarding abuse she had suffered when carers had tied her hands to a chair to stop her from biting her nails, whilst another participant talked to me about her mother who had died recently. These were clearly distressing subjects for the two individuals to disclose to me. I attempted to give them time and support within the interview in order to address what they had told me. Following the interview I was contacted by a support worker who worked at the institution where the participant who had told me about her mother's death. She told me that the participant had been very distressed that evening as a result of talking to me and no longer wished to take part in the second interview we had planned.

An important aspect of the data collection process was keeping a journal where I noted down thoughts and experiences in and out of the research setting. In this I reflected on previous interactions and understandings I had of the participants, my experiences and interpretations within the interview process, and made notes of comments made by family members and support staff outside of the interview setting. This was useful in many respects, including in relation to the data analysis process, however, as an alternative way of illustrating some of the participants stories proved a necessity if their data was to be included in the research, the journal was invaluable. A discussion of this alternative method of illustrating individual stories and understanding follows.

4.3.4 'Creating' Narratives

Narrative seeks to elicit these storied accounts from participants, and can be understood as both a method and a story (Clandinin and Connelly, 2000). This approach to research collates storied accounts, compares them in search of common themes, and relates these commonalties to the structures within which the experiences are occurring (Clandinin, 2007). I am aligned with the interpretivist epistemology of the approach, and it fits with my desire to understand individual perceptions in relation to the cultural, historical and political structures in which they live (Plummer, 1996; 2001). However, traditional research methods have dominated the interpretivist approach, excluding some people from a methodology, which considers that all human beings live storied lives.

During data collection it became apparent that not all participants were able to convey how they felt or what they thought in ways that would translate well to transcripts. Therefore,

following the advice of Owens (2007) that the researcher deviate from traditional methods in order to accommodate PWLD in research, and drawing on Booth and Booth's (1996), I constructed narratives from data where responses were limited, but where information was gained from other areas. This came mainly from previously supporting the participants when I worked at the organisation. I did not set out to draw on these techniques; my initial plan was to carry out interviews only. However, it became apparent that transcription of interview data alone would have resulted in the exclusion of some of the participants from the research because when transcribed it would not be clear what they were trying to say. It was often apparent to me what the individual was intending to say, as I had previous experience communicating with them and was better placed than I might have been understand. This was also aided substantially by the previous knowledge I held about their lives in which I was able to relate the information they were giving me. These 'created' narratives within the analysis chapters are italicized in the same way as the quoted material and prefixed with the abbreviation 'CN' (created narrative).

The researcher in narrative research is '…an active participant within the field, who can grasp, understand, interpret and reflexively represent the perspectives and experiences of people' (Owens, 2007). Owens critiques the methods generally employed in narrative inquiry, explaining that whilst narrative has moved on from an understanding of the researcher as objective, to understanding the researcher as playing an active part in the construction of the findings, the methods employed to elicit data from participants with communication and comprehension difficulties have not.

Owens refers specifically to PWLD in relation to the need to develop narrative methods of inquiry, arguing that in order to represent individuals who are not able to articulate themselves in normative ways, the researcher must:

> …empathically [capture] situations, feelings and experiences, transforming them into text…The use of the reflexive stance becomes important…because it examines what our motivations are and why and how we are using a particular tool…Employing alternative methods is not without its problems, but in using narrative methods I propose that in moving away from more traditional qualitative methods…we are attempting to include people with profound learning difficulties… (Owens, 2007 p. 311)

Goodley (1996) suggests building a biography from other informants to assist with the interview process. In a way, I followed this advice. I had inadvertently conducted over two years of participant observation whilst working at the organisation. Participant observation is noted as a useful when carrying out research with PWLD as it gives both the participant and the researcher the opportunity to get to know how each other communicates and build a relationship of trust (Fish, 2016). I found this to be true. I both knew much about many of the participant's lives before conducting the research, and had spent a lot of time building relationships where I was trusted and able to understand those with speech or communication difficulties. I therefore made the decision to use this information to create narratives based on that which I gained in the interview setting and the information I already held. Whilst receiving information from families and carers, as Goodley suggests, would undoubtedly have provided me with a rich amount of information, this would have also complicated my findings as not only would I then have had to consider the joint creation of data by myself and the participant, but also these wider networks.

Owens (2007) highlights the problem of trying to create a research method that caters for all the individuals involved in a research project, pointing out the difficulties in relation to time and resources, as well as the individual needs of the participants. I experienced the dilemma that Owens describes. I could envisage ways that inclusion in the research could be facilitated but time and resources meant it was not possible to put these into practise. However, I do feel that my prior relationships with the participants, as well as my experience of interacting with PWLD, meant I went into the research well prepared. This experience allowed me to alter the way I interacted with each participant, moulding the process to fit their needs in a way which would have taken a substantial amount of time and planning had I not already been familiar with them.

Atkinson and Walmsley (1999) and Goodley (1996) raise questions about story contamination and ownership when the researcher creates a story in this way. I would argue such issues are evident in research regardless of the way in which the data is gathered, presented and analysed; had I only transcribed the interviews, my 'contamination' of them would still be assured (Burawoy, 1991; Kramp, 2004; Mantzoukas, 2005). Also, to not use this technique to facilitate the inclusion of valuable data would be to unnecessary exclude people from the research. It is this awareness of this influence, alongside transparency and reflectivity on the part of the

researcher, that will produce an honest account of the data gathered (Harding, 1987; Kincheloe & McLaren, 2008; Smith and Sparkes, 2008; Lesseliers et al., 2009).

Narrative seeks to elicit these storied accounts from participants, and can be understood as both a method and a story (Clandinin and Connelly, 2000). This approach to research collates storied accounts, compares them in search of common themes, and relates these commonalties to the structures within which the experiences are occurring (Clandinin, 2007). I am both aligned with the interpretivist epistemology of the approach, and it fits with my desire to understand individual perceptions in relation to the cultural, historical and political structures in which they live (Plummer, 1996; 2001). However, traditional research methods have for too long dominated the approach, excluding some people from a methodology that is of the position that all human beings live lives that they understand through stories.

I followed the advice of Booth and Booth (1996) who advocate the researcher creating a storied account from responses gained when they are short and not articulated in a narrative form. This was not a planned approach to the research, but rather an adaptation of my methods in line with the needs of the participants during the data gathering process, when I realised the semi-structured interview technique, followed by transcription, would not alone suffice to include some of the participants' data in a meaningful way.

As a result of this 'participant observation', when I was in the interview context, the participants did not always repeat information they knew I was aware of, and would reference people, places and information they had discussed with me in the past without explanation or elaboration, for example. I often did not ask them to elaborate as I felt this would stifle the interaction because they would have known I was asking them to repeat that which I was already aware. A combination of this occurring, the rich data I had from the 'participant observation', and the inarticulateness and unresponsiveness of some participants in the interview setting, meant that I not only felt it would be useful to find a way to better illustrate the perceptions of the participants, but it also felt unethical to leave this information out.

In order to give people the ability to voice their understandings and have these understandings included in the research I created narratives from the data gained in a similar way to Booth and Booth (1996). I differed in that within these accounts I often included transcribed data from the interviews, setting this within the broader understanding I had gained from the individual

outside of the interview setting. Katherine's storied account is an example of the usefulness of setting the interview excerpts within the storied account:

Katherine's current home is the fourth place she has lived since leaving home. By chance, she now lives close to her boyfriend who lives independently with support worker visits; however, they do not visit each other's homes but see one another at the day centre. They have been going out for a long time, but Katherine cannot remember exactly how long that is. She would like them to see each other at home, but has not told this to her support workers. She has never seen where her boyfriend lives. On the day of the interview she was going to be taken home in the same bus as him so could potentially see it then. Her boyfriend has lived in his house for only a couple of months. Her boyfriend was eager to live independently – Katherine has never lived independently but would like to do so:

R: Has he lived on his own before?

P: Not before he hasn't, no.

R: Has he not?

P: No.

R: Oh. Big step then.

P: It is, yeah.

R: Have you lived on your own before?

P: No.

R: Do you think you would want to live on your own?

P: Yes.

R: Do you?

P: I'd like it so much, yes.

R: What do you think would be good about it? About living on your own.

P: Er, I can do everything, I can do much more than I did before.

This example illustrates the necessity for the creation of storied accounts as I had information regarding the context and Katherine's relationship that she had discussed with me at length previously. I made the decision not to ask Katherine to elaborate too often on areas that she had discussed with me before. I made this decision predominantly because I did not want her to think I had not been listening to her when she had opened up to me in the past. I could not

be sure that Katherine would understand that I was only asking her to repeat herself because I wanted to record the information and I did not want to cause her any undue distress. This was the case with most of the participants; it was an aspect of conducting the research that I had not anticipated, and it furthered the need to create narrative accounts.

4.3.5 Analysis

I drew on a thematic approach to analyse the data. This approach involves searching for commonalities across data, drawing these observations together to create themes which are then used in theorising on the cases as a whole; it is a method of analysis that can be used across a broad spectrum of research paradigms (Braun and Clarke, 2006). Proponents of thematic analysis foreground the interpretations and involvement of the researcher (Guest et al., 2012). Guest et al explain that this type of analysis involves attempts to understand the text empathically, identifying commonalities where they exist across the data. This method of analysis was therefore appropriate for my research aims and theoretical understandings.

Within different paradigms, thematic analysis, Braun and Clarke (2006) explain, must be treated differently in order to be in line with the ontological perspective of the researcher. It is essential then to view the findings here noting that the research was directed by my interpretivist and critical realist ontological leanings. I therefore analysed the data understanding that it was the creation of the participant and I, both of whom were influenced by the structures to which they were a part (Riessman, 2005).

The use of thematic analysis alongside narrative inquiry is questioned by some narrativists; searching for common themes is understood to be an inductive approach that seeks to generalise across cases, and therefore is not in line with narrative inquiry and its focus on the individual experience (Riessman and Speedy, 2007). Riessman and Speedy criticise 'inductive thematic coding…[whereby]…Snippets of talk (mostly non-narrative, stripped of sequence and consequence) were presented to illustrate common thematic elements across the interviews.' (p. 434). However, I am of the position that thematic analysis can work with the research I have conducted, as well as in relation to my goals and theoretical perspective. Thematic analysis is not a prescriptive approach to data analysis, beyond the need for the researcher to be rigorous in their approach to the data and a verbatim account of the verbal being provided, this method is flexible and open to researcher interpretation (Braun and Clarke, 2006). Verbatim accounts were provided where possible, with the addition of narratives created by myself from the data

gathered and past experiences with the participants. This, as discussed in detail elsewhere, was both a necessary and useful addition. In terms of narrative, Riessman and Quinney (2005) stipulate that research should: include attention to language; interrogate transcriptions; attend to research relationships and sociocultural contexts; take epistemological and methodical issues seriously and critically; and involve researcher reflexivity. I have observed these points, alongside justifying the necessary variants in my approach to thematic analysis.

Polkinghorne (2007) explains that the process of validating narrative research is done via persuasion and argumentation; the researcher attempts to convince the reader of the assertions about the data through providing evidence to support their claims. I would assert that the interpretations I made about the data received are valid based on my previous understandings and relationships with the participants; my efforts in terms of reflexivity and reflectivity; and my understanding that I influenced the findings in such a way that I cannot be removed from them. The evidence I provided for these assertions were sought thematically across the different data sets but also by looking for themes within individual accounts.

In relation to the practicalities of carrying out thematic analysis, the analysis began during the interview process and whilst transcribing the data, when I started to notice areas of interest and patterns. After transcribing/creating narratives from the data and 'participant observations' I carried out 'careful reading and re-reading of the data' (Rice & Ezzy, 1999 p. 258). Guest et al. (2012) advise the researcher to look to the objectives of the research before doing this in order to remember what they are looking for in the data. They explain that refreshing your memory as to the analytical objectives will '…frame how the text is viewed and ultimately determine which themes are worth the effort of tagging, defining, and coding' (p. 65). However, whilst I did enter the research wishing to cover specific areas of the participants' lives, I also wanted to explore areas that were important to the individual that I had not foreseen.

The themes found were therefore the result of that which can be understood as both inductive (data driven) and deductive (theory driven) thematic analysis – I allowed for themes to emerge from the data, as well as being driven by the research aims and literature review. Fereday and Muir-Cochrane (2006) referred to the search for both as a 'hybrid approach'. In order to demonstrate rigour when working within an interpretivist framework (social phenomenology) where individual perceptions are sought, but also incorporating a desire to seek out certain subjects that were theoretically driven.

Following Braun and Clarke (2006) I scrutinised the text, highlighting and making notes where I noticed something useful, or saw commonalities. I made lists of ideas, wrote in my research journal and commented on the transcripts/storied accounts. Initial codes were then produced. Codes were plentiful and were part of the process of moving towards the creation of themes. Codes were eventually grouped together under broader themes. Braun and Clarke explain that the coding process will differ dependent on whether you are conducting data-driven or theory-driven research. Similarly to Fereday and Muir-Cochrane (2006), I was attempting to do both.

From the initial codes, themes began to develop. I noted my influence on the themes that were 'emerging'. They did seem to emerge, to manifest as I read and reread the data, however, I was conscious that the themes were based on my own perceptions and another researcher may have found different links and understandings in the data (Braun and Clarke, 2006). Like Braun and Clarke, I sought themes with the understanding that there is not:

> …one ideal theoretical framework for conducting qualitative research, or indeed one ideal method. What is important is that the theoretical framework and methods match what the researcher wants to know, and that they acknowledge these decisions, and recognise them as decisions. (p. 7)

I noticed that many of the codes and overarching themes that were developing did not come as a surprise. I believe this was the result of (1) being entrenched in the research environment with the participants prior to conducting the research; (2) the time I had spent in the data gathering process, including transcribing and creating narratives; and (3) the familiarity with previous research in the area, understandings of policy and, importantly, that I had set out research aims that I sought to achieve.

I named the themes in relation to the codes from which they were born, influenced also by the aims of the research, which the findings illustrated had been areas in which the participants often wished to talk. From my experiences with the participants prior to and during the interviews, I do not feel that they would have engaged in discussing the topics I had suggested were they not wishing to as illustrated in silences that occurred when this was the case.

From this point I looked at the themes in relation to the codes from which they came, and the data from which these were derived to '…ensure that the clustered themes were representative of the initial data analysis and assigned codes.' (Fereday and Muir-Cochrane, 2006 p. 90). Braun and Clarke (2006) explain that at this point the researcher should be in a position to write

a detailed analysis, be able to justify the themes, explain the story and history of each theme, and tell an overall 'story' about the data.

The analytical chapters were then produced with the aim of convincing the reader of the validity of my findings, providing quotes from the data to back up my interpretations and argument (Braun and Clarke, 2006). Here, I was wary to demonstrate that the findings were a product of my interpretations in relation to specific structural understandings, and that I considered the imposition of these structural and theoretical understandings as both useful and unavoidable.

4.3.6 Reflection

Whilst conducting the research for my Masters I gained an insight into the organisation, leading me to believe I would enjoy working there. I started working for the organisation when my Masters' data had been collected, ten months into the research process; I then worked as a support worker from July 2010 until November 2014. Unbeknown to me at the time of taking up the post, my working there would shape future research. From my time there, I gained an understanding of how the organisation worked, built relationships with support workers and service users, as well as management staff and members of the board. My time there gave me the opportunity to really immerse myself within the future research environment. I observed practice, worked to support PWLD, and witnessed reactions to changes made from within and outside of the organisation. I believe this was of great benefit to the research which I came to conduct. In the reflective piece for my Masters I wrote:

> The emotions I have witnessed and personally experienced have been varied. The professionals I have observed have confirmed the conclusions I came to in my research; the role, for many, is defined by a great deal of passion and commitment that transcends work/home life boundaries. There is a general desire to see standards improved for the people who use the service; at times I have seen members of staff become very emotional with regards to this. The passion exhibited by the professionals seems to be related to the service; there does not seem to be evidence of attachment to particular service users. There is a constant drive to promote independence and enable the service users as much as possible. This came through in the interviews I conducted, and has been since confirmed by my observations of the majority of people I have come into contact with whilst working there.

I have personally experienced feelings of stress and frustration in relation to my role there. Roles I have had in the past do not compare to the one I have at the organisation in relation to emotional investment. If I believed a colleague was not fulfilling their role adequately in previous positions it did not affect me further than feeling a little frustrated or annoyed, however, in this type of work, a person not carrying out their role to the best of their ability has real and immediate consequences for people's lives. I refer to a particular member of staff whom I observed as being neglectful in her duty. This has caused me a considerable amount of distress because I could witness the effect for the service users. I can understand how feeling like this over a long period can affect a person's life outside the work environment as I have found myself thinking about it outside of work, even though I had taken the appropriate course of action and informed the management about what I have witnessed and how I felt about it…

On a personal level, not agreeing with the treatment services users were experiencing from the support worker I speak of affected me more than I could have anticipated before going to work there.

In relation to my own wellbeing when in the field, having experienced the feelings I describe above meant I felt somewhat prepared for any distress the research may have caused me – far more, at least, than were I to have been entering the research environment for the first time.

Reflecting on my experiences over the first month of working at the organisation made the idea of conducting an ethnographic study appealing as I could see the benefits of becoming immersed in a setting in order to understand it. During this first month I went through a process of feeling out of my depth and rather awkward much of the time, to feeling more at ease and seeing the beginnings of relationships form between myself and some of the service users. As such, the idea of conducting an ethnographic study, whereby I spent a substantial amount of time with the research participants, was appealing because I felt that this could really help me to investigate and understand my research questions as I would enter the research setting with these in mind.

However, such thoughts meant I somewhat overlooked the aims of my research; I am not trying to gain an understanding of the organisational environment, rather, I am primarily interested in understanding the perceptions of a group of PWLD. The organisation was the place in which I was able to access PWLD, rather than a context I wished to gauge understanding of the

concepts of independence and inclusion. A closer look at my research goals and discussions with academics at the end of my first year resulted in changes to this plan. It is important to detail this as it shows how I reached my chosen path (Alasuutari, 1995).

Changing to a narrative approach seemed appropriate because I wanted to know what the participants desired in terms of citizenship, and how they defined and understood terms such as independence. I was using this research as a platform from which to question the status quo, the common sense assumptions, or the 'social settlements' as Massey (2015) terms it. The research therefore stemmed not only from a desire to discover understandings but also from questioning the assumptions made about what PWLD understand and desire.

Before carrying out the research I spent a lot of time considering my position in terms of my effect on the participants, the data and findings. I thought less about the effect of the research on myself. The consideration I did give to this was in relation to my previous involvement with the participants and the research setting; leading me to conclude that this was only going to be beneficial to the research process as a whole. I thought the involvement I had already had meant I would suffer less emotionally, however, it was not that straightforward. I did feel buffered by my previous experience to a certain degree, but also more fragile as my prior knowledge was built on in the interviews as I questioned aspects of the participants lives on a far deeper level than I had before carrying out the research – and I think further than I would have had the capacity to were I not to have had this prior experience.

I think that whilst working as a support worker, to a large degree, I only really had the time and capacity to focus on the immediate and necessary needs of the service users I worked with, whereas as a researcher I had more freedom and opportunities to reflect on the research process. This came as a surprise to me; I had considered in depth the roles of 'support worker' and 'researcher' in terms of how I would approach discussions with the participants, how the different roles affected our interactions, how I would or would not attempt to separate the two roles, and how I would explain this to the participants. I did not foresee being affected emotionally more than I would have been as a support worker alone.

In the interview situation I had the opportunity to give the participants as much time as they wished to talk about whatever they chose. Whilst working as a support worker, this opportunity to interact in such a one to one way was a scarcity and when it did occur it was usually with a purpose, such as escorting someone to an appointment or going shopping, for example. I did

not expect to gain such insights into the participant's lives during the interview process when I was already so familiar and had spent a lot of time with many of them previously.

I think this is testament to the difficult position a support worker finds themselves in whilst supporting PWLD; it led me to think about how well support workers actually know the people they spend such large amounts of time with. The different interactions I had as the researcher led me to reflect on my work as a support worker and I felt quite sad because I much preferred being the researcher. From my experiences here, further research in relation to this would be an interesting and useful addition because I believe that I was in in quite a unique position being support worker turned researcher.

Chapter 5: Independence and Autonomy

5.1 Introduction

This first analysis chapter will discuss my interpretations of the data in relation to the concepts of (1) independence and (2) autonomy. Although often used interchangeably, here I will use the terms to refer to far less synonymous situations and feelings. I shall first explain my definitions and use of these two terms with reference to related literature, before moving on to make observations of the data relative to such. This analysis illustrates that for the PWLD involved in this research, it is essential that a distinction between autonomy and independence is highlighted as the data indicates autonomy – understood here as the right to make choices in relation to your own life – is clearly sought over and above independence which is understood here in the normative sense of doing things on your own, without the assistance of others, such as living alone.

'Independence' in relation to normative assumptions which centre on this self-managing individual who takes part in activities that will lead to them being better able to self-sustain, such as working and taking part in education, has been identified as part of a continuing government agenda (Shakespeare, 2000; Reindal, 1999, 2009 Fisher, 2011). This conception of independence is therefore understood here as exemplified in current policy literature in relation to PWLD which refers to independence alongside the goal for individuals to experience autonomy through making choices and being in greater control of their own lives (DoH, 1988; DoH, 2001; DoH, 2009). Empowerment is equated with economic independence (Chappell and Gifford, 2011; Fisher, 2011). This understanding of independence is evidenced in *VPN* (DoH 2009) which refers to social inclusion in terms of living independently and contributing economically:

> …the NHS and DH have recognised the link between good health and social inclusion. This will mean meeting people's health needs in order to support them into work and to be able to live independently (DoH, 2009 p. 129)

I have experienced a culture of enabling independence within services provided for PWLD. It seems that it is one of providing choice and support for the individual, whilst at the same time encouraging normative notions of independence in line with a neoliberal social settlement. Policy in relation to PWLD emphasises this with the goals of 'rights, choice, inclusion and

independence' (DoH, 2009). Whilst framed in terms of both liberal ideals, with emphasis on equality and choice, and contractual communitarian ideals of 'rights and responsibilities', there is an apparent underlying goal of economic efficiency (Shakespeare, 2000; Oldman, 2003; Reindal, 1999, 2009; Fisher, 2011; Hale, 2011). This is potentially problematic in terms of the unrealistic expectations that may be placed on PWLD.

I pose a question that has been posed many times before by those thinking in terms of able-ist notions of what constitutes a 'normal' individual, to those who question the neoliberal policies where economically independent individuals are the ideal (Barnes, 1989; Oldman, 2003; Redley and Weinberg, 2007; Reindal, 1999; 2009; Shakespeare, 2007; Fisher, 2011): I ask why independence, as it is understood within the political and social context in the UK, is something that should be aspired towards and revered. For example, Fisher (2011) and Oldman (2003), in discussions of physically disabled people and older people respectively, are aligned in their stance that independence is encouraged because of economic rather than moral imperatives. Over two decades ago – and still a valid point today – Barnes (1989) argued physically disabled people and professionals were not speaking the same language in relation to independence, with independence defined by professionals in terms of the daily tasks a person is capable of doing, such as dressing themselves and making their own meals. Oliver (1990, 2013) has long argued that we must include 'sociopsychological decision making' in the definition of independence in order to acknowledge the importance of autonomy. This is in line with others (Shakespeare, 2000; Reindal, 1999; 2009) who have more recently challenged our conception of independence in relation to PWLD specifically, asking that independence be redefined in order to acknowledge interdependence as an '…indispensable feature of the human condition' (Reindall, 1999 p. 354) in order to acknowledge that all individuals are dependent on others in different ways, some are seen as 'normal' and some are not. Independence, arguably, should be understood as embedded within relationships of interdependence (Fisher, 2011).

This expectation is at odds with the 'economic marginalisation' – a form of Fraser's (2008) maldistribution – suffered by PWLD, whereby individuals either have no access to work or only to poorly paid jobs with few hours. This situation echoes the position of Pateman (1989) who argued that living conditions should be untied from economic contributions.

Data congruent with the above literature is evidenced within this chapter. Using the data, I evidence how many of the participants involved in my research found what seems to be a sense of empowerment and autonomy through being supported, having choices, and being

autonomous, rather than in the performative competencies and independent status – the 'normative citizenship' (Fisher, 2011) – emphasised within policy and government rhetoric.

Whilst collecting the data, there were often occasions when I would initiate a topic for discussion and it was clear that a participant was not interested in talking about it, or did not understand. Independence and autonomy (although often not termed as such by the participants) were not such topics; these were both understood and elicited interest in all cases. Often discussed as independence and being able to make choices about their own lives, autonomy is understood as distinct here in line with the above definition. Independence was not viewed by the participants in exclusive or normative terms. There was a spectrum of desires and understandings in relation to this concept, from participants referring to it in terms of doing things on their own and living on their own, to making decisions about their own lives, to the need for assistance from a support worker or family member so they could do more things. This meant making the decision to live in a residential setting, for example, for one participant, Ellan, who saw a move from her family home into a residential setting as both a positive and independent move; she was exercising her right to make a decision and following it through. Here, this is understood as an exercise in autonomy as Ellan's ability to self-govern is the underpinning contributor to her situation and wellbeing. Were Ellan not to have been provided with the opportunity to make this decision – that is if it had been made for her – I do not believe she would have felt positively about it in the way that she did. The sense of autonomy appeared to be the predominant positive factor. When speaking to her it seemed clear that her sense of wellbeing came from having the ability to choose how she lived her life. She referred often to 'my life' when referring to decisions she has made.

In relation to this distinction between the concepts of autonomy and independence, the majority of participants referred to the opportunity to make decisions as an ideal. I found that for the PWLD involved in this research, one does not equate to the other as it often seems to in policies which appear to subscribe to a liberal approach to citizenship. As discussed previously, within such a liberal approach, equality of opportunity equates to justice; independence and choice are viewed as ideals, with wellbeing considered to be accounted for by provision of these freedoms (Sen, 1999; Redley and Weinberg, 2007). The emphasis within the data was in relation to autonomy; participants, in most cases, seemed to have concluded that they need support and do not strive to live independently, but do wish to have greater control over their lives – to be more autonomous. Therefore, based on the data, as well as research goals and

literature, it seems essential that a clearer distinction is made between the concepts of independence and autonomy when discussing PWLD. Normative independence is an ideological endeavour that is not an aspiration in the way that autonomy is; autonomy is understood as a just endeavour because it seeks to provide real choice (Bollard, 2009; Reindal, 2009; Pfister, 2012).

Although the Valuing People policies (DoH, 2001; 2009) make clear that opportunities for independence must run alongside adequate personalised support and be directed by the individual, PWLD are still considered to be framed as deficient and unable to take part in 'normal' society, as unspoken assumptions about what constitutes a 'normal' person continue to be recognised in policies related to disabled people (Hahn, 1986; Chappell and Gifford, 2011). In relation to this, and because my own experience working with PWLD led me to believe this would be a pertinent issue, I encouraged the participants to reflect on their understandings and experiences of independence. I believed this would allow me to reflect on the form of citizenship for PWLD. I seek to illustrate how the people involved in this research wish to live their lives, interrogating citizenship's universal promise, advocating a particularist stance in line with difference centred theorists.

Rights are inextricably linked to notions of citizenship (Pfister, 2012). Pfister points out how claims to 'new' rights challenge understandings of citizenship as people identify where current conceptions are lacking or serve to exclude certain groups of people. The evolving nature of citizenship (Stevenson, 2001; Croucher, 2004) and its use as a tool in the campaign for social justice (Lister, 2007) have been demonstrated by difference-centred theorists who call for citizenship rights beyond the traditional civil, political and social rights in order that marginalised individuals – individuals that differ from the norm – are able to be included in a meaningful way. The participants voicing desires for greater control of their lives illustrates the need for citizenship to continue to develop towards a more inclusive approach (Pakulski, 1997; Lister, 2007; Moosa-Mitha, 2005).

Pfister (2012) discusses Amartya Sen's Capabilities Approach from a citizenship perspective. Here, agency is discussed in relation to well-being; Sen acknowledges the diverse interpretations people hold regarding agency, asking what does the individual desire, rather than what are they able to achieve in terms of well-being. This approach asks not if we can achieve a particular goal, but if we want to achieve it. This relates to the present narrative analysis of how PWLD understand and desire independence and autonomy. I question

government literature and rhetoric which assumes an individual to be successful and happy when certain normative achievements are made, rather than when that person feels happy with their situation. Pfister and Sen's arguments are aligned with the narrative methodology I draw on, looking to the interpretations of the individual to guide theorising.

Citizenship does not necessarily equate to justice and equality (Isin, 2005; Lister, 2007), however, struggles for rights and inclusion throughout history can be seen as struggles for citizenship (Pfister, 2012). Here, I would point to the citizenship demands of those who argue for citizenship to further acknowledge the right to *feel* that you are included, and your voice is heard (Lister, 2007; Moosa-Mitha, 2005):

> Overall, we are facing a space of citizenship studies constituted by a rich variety of practices, concepts and claims. Thereby, the problems and questions raised by radical challenges have to be taken very seriously as they are voiced by people suffering real disadvantage. (Pfister, 2012 p. 245)

In both the holistic and reductionist understandings of independence, the data demonstrates that issues relate to resources, as well as the need to recognise PWLD may want something other than the goals set out in government policy and those which are generally accepted to be desirable in a culture where norms are dominated by a neoliberal ideology. The potential solution to this resource related issue would be radical in relation to current circumstances; I discuss this in greater detail in Chapter 7: Redistribution, Recognition, Representation.

5.2 Independence

Discussions of independence were frequent throughout the interviews; although I initiated many such discussions, that dialogue continued to the extent which I saw indicated participants willingness to talk about this. As noted above, often, when the participants spoke of independence they were referring to autonomy – to the right to make their own choices, rather than the ability to be self-sufficient and do things on their own, and other normative assumptions of independence.

Tia is discussed an example of this. In the past Tia wished to live less independently than those involved in her care thought she should, and was assessed as capable of. She was scared to live on her own at the time and had to really push to be returned to a residential setting, rather than

live alone in the flat where she was initially placed. She was not happy in her flat and did not feel safe:

CN: At one point in her life, Tia moved from Huddersfield to a group residential home in Wales with eleven other people and two members of staff. She moved to the residential home because she did not feel like she could cope living independently. She decided to live there until she felt that she could manage in her own place:

P: I used to…I moved from Huddersfield down to Wales I did.
R: Oh right?
P: I went to live in a home 'cos I didn't feel like I could cope trying to live on my own and that so I lived with a group of people and then when I felt like I was ready to actually handle a place on, my own…

…
P: They had to fight to get me into that home, yeah.
R: So were there a lot of people in there a lot less able?
P: Yeah they were meant to be there 'cos they got more disability than me. There was one girl named Jade like erm and I think I'll be able to talk about her now, now I don't live there. Er Jade, er Jade come from what you call 'em they got locks on the door?
R: Oh erm… like a secure unit?
P: Yeah she come from one of them and she was drugged up so much her eyes used to disappear all the time. She used to stand there rocking backwards and forwards, her eyes used to disappear into her head so Julie ended up weaning her down on them but they couldn't take them off of her 'cos it probably could kill her or summat.
R: Right

…
P: But she was like a little kid 'cos they kept treating her like that in this place and she never really got chance to you know…think, grow and develop in her brain what is a bit mean and cruel but she was wonderful.
R: Yeah, was she?
P: [Laughs] She was good at making you laugh.
R: Well that's a good thing as well isn't it? How many people lived there?
P: There was fourteen people in that house.
R: Yeah that's quite a lot then it must have been a big place.

P: I think er two of them were members of staff so twelve of them 'cos they gotta have two members of staff there. Sometimes er at Christmas though might just be just one member of staff there and supposed to be two. So they took a chance on asking me to help out, see I was more able and they knew I'd lived on my own with my brother so they used to ask me. I used to help out with some of them I used to take them to the pub so I was trusted to take them to the pub

R: - Oh yeah

P: and allow them to have three halves of lager 'cos some of them were on tablets so you gotta…I had to be careful.

R: Yeah

P: So they knew I understood that.

R: Yeah.

P: And they used to love going the pub with me.

For Tia navigating her life seems to be a balance between having the autonomy she has seemingly always demanded and the independence that she now appears to desire, whilst seeking support where necessary. She acknowledges her need for support, explaining that others see her as more capable than she sometimes feels. This was especially true in the past as Tia now does live alone; this is something she developed a desire for and she knows that before this time it would not have been right for her.

Tia thinks that having this independence would never be right for some people. For example, she has a relative, Jason, whom she refers to as her nephew. Tia spent a lot of time discussing Jason throughout the interviews; she has played an important role in his life – his mum once told her that she is a better mother to him than herself. Tia does not believe that Jason should or could live as independently as she does:

Jason is doing well at the moment and attends college. However, although he is doing well, Tia does not believe that he will ever be able to live on his own the way that she does. Tia does not think Jason would cope well were he to live on his own as he gets very stressed with his college work and she does not think he could cope with anything more than this. He also spends money on silly things and does not recognise the importance of understanding money yet.

In relation to living alone, Ellan, like Tia, also wished to move out of her family home. Ellan was 26 when she made this decision, deciding that she wished to be more 'independent', as she termed it. However, the independence that Ellan desired differed from that which may be assumed; it was a move away from her parents, but, more importantly than adhering to normative assumptions of independence, it was the feeling that she gained from this that was important to her:

> *Ellan lived with her parents until the age of 26, at which point she decided that she would like to leave home and live in a supported living situation. She wanted to be more independent and was also aware that one day her parents would not be there to support her, and so was also looking to the future and thinking about her own wellbeing:*
>
> *P: I sat her down and said mum, I love you two very much but I want my own life. I like it here, and I like you and James and my dad but I just want my own life.*
> *R: Yeah.*
> *P: I mean, I know, I know I've got my parents now, but I know deep down that one day I might not have.*
> *R: Yeah.*
> *P: And that's what worries me. I hope to god it's a long time! But I know damn well that I won't have them one day.*
> *R: Yeah. Cos -*
> *P: Everybody get older, but I just hope it's a long time.*

Ellan and Tia are similar in their desire for autonomy; they are explicit in their wish to make their own life choices. These desires differ from notions of independence referred to in the Valuing People policies, echoing a question posed by a number of scholars with regards the value placed on the independent individual, as well as the definition of independence and the ideological overlooking of inter-dependence (Reindal, 1999; 2009; Shakespeare, 2000; Fisher, 2011).

In line with Shakespeare's (2000) call for the value and understandings we have of independence to be questioned, Ellan's understanding of independence can be seen as a cautionary note for narrow definitions of this concept, and assumptions that such independence equates with happiness. This is in addition to providing justification for an argument that autonomous individuals should be sought over independent ones; allowing people to make their

own informed life choices, rather than seeking an idealised way of life that may be neither achievable nor desirable. As such, all individuals can be seen to be interdependent to some degree, however, this is only seen as acceptable in some forms and is rarely acknowledged as such (Reindal, 1999; Shakespeare, 2000); Ellan's position on how she would like to live evidences the need for such understandings to alter (Digby, 1996).

Whilst Ellan spoke of having her own 'independence', this was alongside understanding that she does need support. By moving into a residential setting, she wanted to ensure she would be supported throughout her whole life, acknowledging that the support from her parents will end when they pass away. This is an interesting insight into Ellan's life; such reasoning involved in the decision to move out of her family home was specific to Ellan, however, the majority (13) of the participants had also moved from family homes into supported living or residential settings.

Simon also recently moved from his family home. He has lived with his family for the majority of his life and has lived independently in the past, but moved back in with his family when living this way did not work out for him. The main reason for this was that Simon is diabetic and struggled to plan his diet appropriately when living alone. Very recently Simon has moved out of his family home again into his own flat. He has support workers who visit him twice daily and he sees his family regularly:

> *Simon has a lot of choice and control over his life; control he shares with his dad. He feels more independent now that he is living on his own. He is happy to share this control with his dad but does not appreciate his sister also having some control over him, even though he acknowledges that she says things to him because she does not want him to get ill because of his blood sugars changing.*

> *The support he has had from his dad and his brother has meant he now lives independently in his own flat. He is very grateful to them for supporting him to be able to do that, and will always remember it.*

> *Before and since this first attempt at living on his own, Simon has lived with his dad and his dad's partner. When Simon decided that he would like to move out his dad had the intuition to know that this was something that Simon wanted:*
> *R: You decided that you wanted to live on your own?*
> *P: Yeah.*

R: Yeah.

P: Yeah, but my dad knew that, my dad knew that straight away.

R: Yeah. Did you tell him that you wanted to live on your own?

P: Yeah.

R: How did he take it?

P: He just knew.

R: So he was happy for you to do what you wanted to do.

P: Because me and dad are so close.

R: Yeah. ... Do you feel more independent now?

P: My heart is.

It seems that the correct levels of support equate to independence for Simon as without this support he would still be living with his family. Simon sees his living more independently as an achievement; however, the important point to note here is his sense of autonomy. Simon has chosen to live this way and is happy, as has been evidenced with other participants; within the data, autonomy has been shown to result in many different and less 'independent' ways of being. Simon also said he would experience a greater sense of wellbeing were he to receive additional support in order that he is able to get out and about and do more of the things he wishes to do.

Diane further exemplifies how understandings of independence can take different forms. She lives in a residential home and likes it there, although she was unhappy when she first moved out of her family home. She does wish to have what she understands as more independence, but this equates to having her own bedroom, and being able to catch the bus on her own from the residential home where she lives to the day centre she attends several days per week:

> *Diane is forty years old and lives in a supported living residential setting with eight other service users. She thinks her living situation is nice because she has her own bedroom; she likes this because she enjoys having her own space.*

> *Next week Diane is due to have a service review where they will talk about how she is doing at the moment and anything she would like to change. She is going to tell them that she would like to bake more. She enjoys the reviews as she will talk with her key workers and others who help to support her about lots of different things.*

Recently, Diane caught the bus on her own. This was important to Diane and something she really wanted to do. She thought it went alright, however, when her dad found out about this he was not happy about her crossing a lot of main roads. Diane has not caught the bus on her own since; however, she hopes to do it again sometime:

P: And then staff took me last time on the bus on my, meet me on the bus and then we, last time, erm, come on the bus, someone took me on the bus last time, a girl took me on the bus
R: Yeah.
P: - And help me, help me on the bus and I do it myself now, I do it myself. I did it myself and then a woman, a woman took me. Come to my house, come and see me and – you know, on the bus – and then every time – not everyday – last time I did it on my own.
R: Yeah.
P: I don't go on the bus on my own now.
R: Yeah. You don't?
P: No.
R: No.
P: I want, I want to. I'm waiting for my review on Wednesday, next Wednesday. We're going to talk about it again.
R: Yeah.
P: So my dad wasn't happy, my dad wasn't happy going, my dad wasn't happy. You know why? I go to town on my own, I go to the bus, to the bus station.

Simon, living in his own flat, is seemingly more independent than Diane. However, Diane wishes to go places on her own, whereas Simon has asked to have more support in order that he is able to do more things, such as go to town, as he needs and wants support whenever he leaves the flat:

Simon has recently become a lot more independent when he moved into his own flat. In addition he would like to have more support in order to travel independently. He would like to be able to use public transport in order to travel into town and to the day centre. He would like to have someone there to support him with this.

Whilst many of the participants acknowledged a desire to have some form of support, even if they wished to live more independently, Gerald was alone in the stance that he did not want or need the support workers that visit him on a morning and an evening:

> *Gerald is happy to live on his own and would not like to live in a home with other people because he likes peace and quiet. Since living with his mum he has always lived on his own.*

> *Gerald has carers that come in twice a day – in the morning and in the evening – to give him medication…The carers have a set amount of time that they spend at Gerald's and he can't understand why they need to spend so long with him. He does not think it is necessary.*

> *R: So you know your carers, how many times a day do they come round?*
> *P: They come in a morning, teatime, that's it. They go when they want. I don't tell them to go – you can't, you can't tell them when to go. They go when they want, when their time's up. They stop 'til about quarter to five. I don't know why!*
> *R: You don't know why? Do you not need them?*
> *P: No, I don't need 'em, no I don't need 'em.*
> *R: What sort of stuff do they do when they come round?*
> *P: Nowt, it's not their job, (name) says.*
> *R: What do they come round for then?*
> *P: To give me tablets and fags.*
> *R: Oh, to give you tablets.*
> *P: And fags, yeah, yeah, cigarettes and that. 'Cos me mam can't do it.*
> *R: Right.*
> *P: So they've took over it, haven't they. If they don't turn up I go to Number Five.* (Number Five is a nearby residential home that is run by the same organisation as the day centre. Gerald knows the staff and service users there.)

Like Gerald, Hannah feels that she is able to live without support also; however, she still currently lives at home with her mum because of financial reasons:

> *Hannah thinks she will be living with her mum for quite a long time as she cannot afford to move out. She would like to but this is not a possibility for her financially. If she were able to move out she would like to see how she would cope on her own; organising bills*

and things like that. She would like to be independent; to be able to come and go as she chooses, and have time on her own:

P: But I'd also want to have my own independence and be able to, like, just like, be on my own, like, 24/7.
R: Yeah.
P: To have that peace and quiet, I mean I know its peace and quiet here, but to just have that bit more peace and quiet on my own.
If and when Hannah does move out she would still like to live near to her mum:
P: It's like me, when, when I eventually move out, if I can afford, I want somewhere round here so I'm closer to my mum.

Hannah is definite in her desire to live alone and seems to feel somewhat helpless in this goal because she lacks the finances to fulfil it. She cannot see a time when this situation will be different. Hannah has sought ways to equip herself with the necessary skills to find paid employment; she has been on a course in order to boost her confidence, takes cooking classes, goes to a book club, volunteers at an RSPCA shop, and is planning to start a childcare course. She is waiting for the college to get back to her as it may be the case that she needs to retake some exams before she can be considered for enrolment on the course. This highlights the warnings of Redley and Weinberg (2007) who question whether the repositioning of PWLD as independent, capable citizens in policy actually results in them being regarded as deviant and deficient if they fail to achieve economically, as Hannah fears she may do if she is unable to secure a place on the childcare course. Hannah seems to desire living independently above all else but worries that she will not be able to find paid employment fuel concerns that she may not be able to achieve this goal.

Hannah is experiencing maldistribution (Fraser, 2008) as a primary social injustice here; she experiences economic marginalisation in relation to the difficulties she faces in securing work and moving out. Compounded by being part of a marginalised group subject to misrecognition, whereby she is judged and judges herself on normative cultural expectations of independence; and misrepresentation, whereby she is misframed, not being acknowledged as part of a legitimate political community and therefore having her social rights overlooked (Fraser, 2008).

It does seem possible that Hannah will be able to gain some form of paid employment based on the structures that are in place to support her to do so, however, for those PWLD unable to achieve economically, expectations of assimilation to dominant norms is at odds with a person leading a life in which they are vulnerable and dependent upon others for support to some degree (Redley and Weinberg, 2007). As such, in relation to employment, warnings that we should be wary to not overlook the reality of what intellectual impairment entails ring true here (Shakespeare and Watson, 2001; Shakespeare, 2007). In line with this, the noted emphasis that governments places on independence and self-sufficiency (Barnes, 1989; Shakespeare 2000; Oldman, 2003; Reindal, 1999; 2009; Fisher, 2007; 2011) was not found to be valued, or in some cases possible, by many of the participants in this research, with Hannah being in the minority of those who aspired towards this.

Like Hannah, Sarah, who is now nearing the age of retirement, also places importance on the idea of working. She worked on a farm for 18 years from the age of 18. This was something she had always wanted to do as a child and so was happy when she had the opportunity to do so. However, Sarah was not paid for the work that she did because the village in which she lived was set up to accommodate PWLD and give them roles within a community. Sarah values working hard, as she illustrates when talking about her time spent working on farms:

> P: ...I was the hardest worker in [place name]. On the land. I was the hardest worker there, on the farm.

Later in the interview she reflected further upon this work in relation to her current health:

> Sarah is concerned about her health at the moment and feels the work she has done in the past has contributed to her suffering with a bad back now. She feels that she has worked hard whilst others have not. She appears to be quite bitter about this as she sees the work she has done in the past as the reason for having a bad back and arthritis now:

> P: I feel as though...why should I work and others don't. That I've worked, I've got to keep moving so I won't go in a wheelchair at this age. I've saw physios that I see, and they've shown me some things I could chose to help me.

Alongside valuing and being proud of hard work, Sarah seems to place value on earning money, which she does through selling items that she knits:

R: What sort of things do you like doing most? Out of your whole week?...Or things that you'd like to do that you don't do?

P: I like only to have a good knit.

R: Yeah.

P: Yeah. And to make money. Every day, because this week I asked Joyce when making lunch on a Friday, if they're OK to ask [name of organisation], the manager there, if I could help by making things and selling them.

R: Instead of making lunch?

P: Yes.

R: Instead of helping out to do that.

P: I could make some money by doing craft work in the other room.

R: Hmm. And are you going to ask them to ask -

P: Yes.

R: Or have they already done so?

P: Joyce can't do it; it's up to Sian who works on the reviews. And I can't change until Jane comes in summer. If I can change my job round in Craft.

R: Right. So you've got to wait until Jane.

P: Yes. Then I can see what I could make to make some money in Craft.

R: You like to sell things and make money don't you?

P: Yes.

R: What would you do with the money?

P: It goes towards charity and for – you know – for, because I'm making a stall at Craft now and money's now made for charity now.

Sarah loves to knit, and she loves to sell the items that she knits. It is clear that she values working hard and making money, even though she does not keep the money she makes – it either goes towards more wool or to charity. She also seems to feel angry that she spent such a large part of her life working without being paid for it – or without being valued for it, when she saw that those around here were. That she now gives the money she makes away to charity brings me to the conclusion that she is not trying to make money to broaden her scope for independence, but rather it is the value she places upon being recognised for her efforts that she has made. She does not seem to feel that she was recognised for her efforts when she worked on the farm. As I will discuss in the following section where I look at the data in relation

to participation and inclusion within society, Sarah seemed to value being valued; being recognised (Fraser, 2008).

In relation to independence, Sarah serves as an example of a participant who valued what might appear to be independence, however, she did not mention a desire for independence in the normative sense. She did not wish to live alone, she did not wish to do things on her own, and she did not – despite valuing the act of working – aspire to have more money in order that should could partake in activities on her own. This final point differs from the majority of the other participants who did wish to engage in more activities than they currently do – be this with or without support. However, Sarah was aligned with other participants in favouring the ability to make choices about her life. Self-determination, as discussed in detail in the following section, is identified within the data as a key desire, leading me to the understanding that, in line with inclusive and difference centred citizenship theorists, citizenship must be seen as a 'momentum concept' (Hoffman, 2004), to be used in the fight for social justice, not as a static concept. In discussing inclusive citizenship, Lister (2007) discussed self-determination as a key area – alongside 'justice', 'recognition', and 'solidarity' – that needs to be addressed if citizenships inclusionary potential is to be a reality.

Recognition by alternative citizenship theorists (Moosa-Mitha, 2005; Pakulski, 1997; Lister, 2007) that there is a gap between rights being granted and rights being felt, particularly in relation to marginalised groups, points to the need for citizenship theory to be developed in order to challenge dominant conceptions of social justice and fulfil its inclusionary potential (Lister, 2007)

5.3 Autonomy

The data illustrates that whether a person desires greater independence or not, this does not correlate with their desire for autonomy, which was desired across all participants.

Mark, for example, seems to be happy with his life and has made his own choices to the degree he wishes. When I spoke about how he would like to live he did not seem very sure about what situation he would see as ideal:

> *Mark is twenty-four years old and lives with his parents. He has two older sisters who have now left home and have children. He says he is going to wait and see what happens with regards to moving out himself.*

Mark seems to be very open and talkative so I do not think he was holding back his thoughts. He is also articulate, does lots of things on his own, and does not seem to hold back his opinion but on this point he just did not seem to have much to say. It seems that he just has not decided or is happy with his present situation. The above extract from the narrative I created gives some context to Mark's words. The exact quote was:

> *R: And, erm, last time you were saying that you lived with your parents and your brother?*
> *P: My mum and my dad.*
> *R: Your mum and you dad, right, I see. Erm, can you imagine, er, how do you see the future? Do you imagine yourself living with your parents or would you like to move out on your own?*
> *P: Erm -*
> *R: Do you have any thoughts about that?*
> *P: I'll just wait and see.*
> *R: Yeah.*
> *P: Yeah.*
> *R: Just see what happens?*
> *P:Yeah.*

As illustrated in the quote, if Mark had acquiesced here, as PWLD are noted to have greater potential to do (Kellett and Nind, 2001; McCarthy, 2003; Tuffrey-Winje et al., 2009), he would have said that he wished to move out of his parents' home. He did not do this. The interview situation, as well as my past involvement with him when I worked as a support worker, illustrated that he would state his true opinion and thoughts quite definitely. I believe Mark would be capable of living independently if he so wished, however, he did not seem to have any burning desires for this, but did talk animatedly about other subjects, such as training in the café at the day centre, going out with friends, and animals – his favourite subject. Throughout the interview with Mark, as well as throughout interactions in the past, he also placed a lot of value on the time he spends with his friends, where they will go to town or the cinema. When taking part in these activities, Mark was demonstrating independence as he was not being supported or accompanied by a family member or carer. Mark has mild learning disabilities and it is easy to envisage how it would have been possible for him to do these activities independently. Mark did not seem to aspire to carry out normative independence,

such as living independently and taking part in paid employment (he was taking part in unpaid training schemes at the time).

According to policy, personalised support means allowing the individual, once informed, to make decisions about how they live their lives (DoH 2001, 2009); as an individual with autism, Mark may feel anxious about making such a decision because the thought of such a change is distressing. If, like Ellan, Jade, Rebecca, Pam, Chloe, Jane and Diane, Mark decides that he does not want to live on his own, it is the assumption here that all ways of living should be valued equally and that the opportunity to make such a decision be the key goal. Although current government policy – as detailed in Chapter 2: Background and Policy – appears aligned with this in many respects, stating aspirations of personalised support, there appears to be an underlying ideology whereby the independent, self-sufficient, active citizen is the ideal (Driver and Martell, 1996; Clarke 2005; Gilbert and Powell, 2008; Hale, 2011).

Analyses of government ideology since 1979 to the present day indicates a turn towards neoliberal values (Shakespeare and Watson, 2001; Redley and Weinberg, 2007; Massey, 2015; Donaldson and Harris, 2015). Many of the individuals involved in the research did not generally have aspirations aligned with such values, nor indeed, the opportunities to fulfil such ideals. Redley and Weinberg (2007) question how individuals are viewed when at once they are not achieving in normative ways, at the same time as being subject to neoliberal ideology where they are seen to fail if they do not achieve valued outcomes. They ask how an individual is to be understood as a successful and valued citizen when they are seen to be at odds with valued ways of being.

Like Mark, Hannah, Jade, Rebecca and Pam also live at home with their families, and have always done so. Apart from Hannah, they are all happy to live with their families and wish to remain there. Many of the other participants do not live at home but wish they did. If they wanted to do so, based on my experience of working with these individuals and understanding their needs, I believe the majority of them would be able to live more independently than they currently do.

It is here that the independence/autonomy divide is very clear as the individuals have made the decision to remain living with their families. They have exercised autonomy and it is not in line with the valuing of independence.

Pam is 65 years old and lives with her mum and brother:

Pam has always lived with her family. Pam has never wanted to live anywhere other than with her family and does not want this to change. She also does not think she would be able to live on her own. Pam and her mum have been to visit a respite centre to see if Pam would be able to spend some time there and allow her mum to have some time on her own. They were told that Pam was not ''bad enough'' to have a place. They have since arranged for a support worker to spend time with Pam and support her sometimes instead of her mum:

R: You've always wanted to live, to stay at -

P: Home.

R: - home.

P: I couldn't live on my own anyway.

R: Right.

P: Like my mum says, in case something happens to you.

R: Yeah.

P: With your legs.

R: Yeah...This person I was talking to yesterday said they live on their own but they have a support worker that lives there all the time, just different people.

P: Yeah.

R: I suppose that's a bit like you living with your mum, isn't it? You always have someone there to support you. Don't you?

P: Yeah.

R: Yeah.

P: My brother he always supports me.

Pam told me that resources meant she was unable to secure a place at the respite centre because she has mild learning disabilities. It seems that this is a funding issue; were there not limited places at respite centres then it would not be a problem for Pam to go there, allowing her mum and brother time to themselves in order to continue to be able to support Pam effectively. Pam and her family came to the decision that a respite place was needed for Pam in order that she then be able to receive effective support from her family the rest of the time. That she was unable to secure a place meant Pam was not able to exercise self-determination and was clearly a cause of some distress to her. The compromise of having a support worker spend time with

her was of some comfort but this would be within the family home whilst Pam and her family had wanted her to leave the home for short periods.

Whilst Pam lives at home wishing only for the opportunity for respite care, in thirteen instances the participants had permanently moved out of their family homes. In three of these thirteen cases this move was explicitly undesired, with participants wishing to remain with their families. At times, this continues to be an issue for Chloe, James and Diane who spoke of the distress moving caused and the continued effects:

> *Diane moved out of her family home when she was a grown up after she had been to college. Diane was not happy about this at the time:*
>
> *P: Yeah. I wasn't happy.*
> *R: Yeah.*
> *P: I wasn't happy moving, I wasn't happy. I'm all the time, erm, move out, I wasn't happy. Erm, I like my own house, like my own house. My dad, I had to move anyway.*
> *R: Right.*
> *P: Cartwright and Cry House. I wasn't happy.*
> *R: But when you moved, when you left your family home, erm, how did you feel about leaving your parents?*
> *P: Not happy. You know how I feel like? Tight. Yeah.*
> *R: Yeah, erm, whose decision was it -*
> *P: My dad and my mum, my dad and my mum.*
> *R: Yeah.*
> *P: Yeah, yeah.*
> *R: Did they tell you why they'd made the decision?*
> *P: No, No. It, erm, when I live at home, they took me out, took, me out of the house. Someone come see me about it.*
> *R: Yeah, yeah. To talk to you about it.*
> *P: Yeah, yeah.*
> *R: And how did that go?*
> *P: I wasn't happy about it; I wanna stay in my own house.*
> *R: How do you feel about it now?*
> *P: I'm alright.*

From the interview as well as the time I have spent with Diane previously, she makes it clear that she wishes she still lived at home in many respects. When I conducted the interview, her mum had died a few months before and I was told by support staff that it may seem that she is coping well but she struggles when at the residential home or when she goes to visit her family. I therefore did not mention her mum, leaving the subject for her to bring up if she wished. She did mention her mum early on in the interview when she mentioned living in her family home:

> *P: Yeah. When I was at home with my mum and my dad.*
> *R: Yeah.*
> *P: And that's why, and I haven't got a mum. So I miss my mum and I'm alright now about it, I'm not getting upset much. Sometimes I get upset, sometimes I get upset that's why. I'm alright about it, so and that's why I come here, I come here, I be, I'm happy here.*
> *R: Yeah.*
> *P: I like everybody else's, I like every centre's people.*
> *R: Yeah.*
> *P: I do something and then every time I do something, keep me, keep me happy.*

Diane likes to keep busy and be distracted at the moment. She is most happy when she is at the centre or out and about. Going to her family home makes her upset because her dad will look at photos of her mum and things in the house will remind Diane of her. The topic of her mum's recent death and Diane moving into a residential home many years ago both led to discussions of what can be termed autonomy. Diane was angry that when her mum was poorly no one told her – she did not have the time to understand that her mum was so ill, only finding out when her mum took the wig off that she had been wearing following treatment for cancer:

> *P: Yeah, my mum had cancer. I'm only telling, I've got some good, I've got good news: when I was at home I were in bed, I got myself up out my bed and my mum had got one of those things on her head. One of those things, a net, a net, what's it called? Those nets?*
> *R: Erm.*
> *P: A wig, a wig on her head, yeah a wig, and my mum's got one of those wigs on her head and then she took it off, and nobody told me she was dying in bed, nobody told me, and I was crying all the time at home.*
> *R: Right.*

P: So, I wasn't happy, I wasn't happy, nobody told me at home.

R: So you didn't realise she was so ill?

P: Nobody told me.

Diane's frustration at her lack of power within both these situations is clear. When considering autonomy and independence, as these discussions led me to do, this was evidence of an individual craving greater control over their lives not independence in the normative sense. Diane became aware that others knew what she did not about her mum's illness, and did not think this was fair, and she indicated that she felt left out of her family's decision for her to move out and into residential care. I get the impression that Diane's main issue is that she would like to have greater control over her life, she accepts that she had to move out of the family home, but emphasizes the desire that she is consulted.

James, who moved from his family home when he was in his late teens, still seems to struggle with his supported living situation. His move as a young man was also decided by his parents, who thought this was the best thing for him; at times he asks his dad if he can move back home, telling him he does not know what to do. An excerpt from the interview with James where he tells me about this move follows alongside material from the storied account I created with the data and information I already held about him:

P: Oh, school, yeah, I used to like school.

R: Yeah.

P: But I can't remember [?]. When I left school when I was, then I stopped at home with my family, I had a roof by my dad and my mother, but [?]. then I was about 17, 15, 16, 18, 19, 20, when I was brought up as a man.

R: Yeah.

P: And I was [?]

R: What, sorry?

P: I've seen hard places.

R: You've seen hard places?

P: Yeah. And that's what I did.

R: Yeah. Where did you go when you were being brought up as a man?

P: I went in a home.

R: Yeah.

P: Cos my family couldn't do nothing about me. That's what they done to me. And

then they come back and fetched me home. That's what they done to me.

R: So, did you live in a home for a little while and then you moved back in with your family?

P: Yeah. That's what [?].

R: Yeah.

P: Yeah.

James's independence was decided by his family. He was not happy about it at first. He was not able to determine any of the terms by which this came to be. He is happy sometimes but misses his parents.

James's dad encourages him to be independent; when James is unsure what he should do regarding his house his dad says he knows what to do because he is a man now and not a boy anymore. His dad will tell him that because he is a man now if he does not know what to do he should find out himself. This is because his dad wants him to do what is right for himself.

James, Chloe and Diane now appear to experience greater independence in the sense that they do not live with their families. The way in which they live is referred to as 'supported living'. This is particularly true in relation to James, who lives alone but there are support workers in his house at all times. Chloe and Diane live with other PWLD in group homes. However, this move to what may be regarded as greater independence was not a choice; they did not exercise autonomy in order that they live in this way, and there are examples within the data, as detailed above, illustrating that they are not content with this situation. This illustrates the greater importance placed upon autonomy rather than independence by these individuals.

In contrast to these feelings, Sarah, who now lives in a group home, was happy to leave her family initially because she was training to work on a farm, something she had always wanted to do:

Although working on the farm resulted in ill effects on Sarah's body – she blames her work there for ailments she has since suffered from – at the time at least she saw this as a positive move because she had always wanted to work on a farm.

R: What did you enjoy most about living at Botton Hall?

P: Botton Village. Er...I liked, I liked how to farm because I wanted to work on a farm when I was a little girl and it happened when I got older, from when I was 18 years old, and it happened then. And my wish came true. And in Botton Village I also worked in the woodwork shop – at the weaver. And I used to knit in the weaver.

Sarah has not had any friends since leaving the farm twenty-seven years ago because the people she has lived with have either had more severe learning disabilities than her or were a lot younger, so she did not have anything in common with them. She looks forward to seeing her family, particularly when she goes to visit them, rather than when they go to her:

Sarah goes to the day centre for three days per week, to another centre for one day, and on Tuesdays she cleans out her own bedroom. At the weekend Sarah usually stays at the residential home and they will go shopping and out for lunch. Sometimes she spends the day at one of her sister's or father's home, but this does not happen very often at the moment because her dad is getting older now and her sister is looking after her partner who is ill:

P: Yeah. And, er, I've been told that, that I can't go home now so much anymore.
R: With James being poorly.
P: Yes. Hmm. Yeah.
R: It must be a hard time for Sandra.
P: Yeah. Hard time. And now he's had some treatment now that I can go – I might get my hair permed soon for Easter.
R: Oh right.

As detailed above, Sarah refers to her dad and sisters' homes as her own home. This is the same for many of the participants. Within the interview context, as well as during the many other times I have spent with her in the past, she often talks about wanting to see her family. Although Sarah did not feel that she was sent away in the same way that James, Chloe and Diane did, she does seem to feel that she cannot access her family when she chooses. This is something that seems to frustrate her. There is a common theme of powerlessness amongst many of the participants in terms of accessing their families again, with decisions about when they can see them being largely out of their hands – seen as a decision made by either their families or support workers.

When Chloe moved out from her family home she too felt sad. Chloe then lived in several residential settings. Prior to this she lived with her mum, sister and her nephew. She sees her nephew often still, however, her mum has moved to a different house and she does not see her as often anymore. She was bullied in one of the residential settings she lived and requested to move out. This was arranged for her and she seems content where she now lives.

> R: You know when you stopped living with your mum and your sister?
>
> P: Hmm
>
> R: Who decided you were gonna go and live with other people? And live with your friends? Who decided that was the best thing to do?
>
> P: I don't know
>
> R: Was it something that you wanted to do?
>
> P: Yeah
>
> R: How did it feel moving from living with your mum to living with other people?
>
> P: Alright
>
> R: Yeah. Can you remember how you felt? .... Were you happy or sad or nervous –
>
> P: Sad
>
> R: Sad
>
> P: Sad
>
> R: And then how did you feel once you got used to it
>
> P: Alright

Donald is also happy in the residential home he currently lives in at the moment and does not seem to have any issues with self-determination. He lived with his parents for a long time but seems to have adapted well to his current living situation. He was not very happy where he lived in the past but has since moved and likes where he now lives. Donald seems happy with his situation:

> Donald is happy in the house he currently lives in; he likes it very much, however, he did not like where he lived before this as his bedroom was really small. When his social worker saw how small his room was she immediately found him somewhere else to live.
>
> He is able to do what he wants in his flat without interference from anyone else, and can lock his door if he chooses. It is important to Donald to be able to do what he wants to do. For Donald, having his own space is important. However, in terms of autonomy,

Donald has only acquired his own space as a result of the interventions of others. Interventions he did not call for; although he is happy that they happened.

Katherine has lived in the same residential home as Donald in the past. Donald and Katherine are good friends but have very different feelings about their living arrangements. Donald is happy with where he now lives, as illustrated above, however, Katherine would like to live on her own:

R: Has he [her boyfriend who has recently started living on his own] lived on his own before?

P: Not before he hasn't, no.

R: Has he not?

P: No.

R: Oh. Big step then.

P: It is, yeah.

R: Have you lived on your own before?

P: No.

R: Do you think you would want to live on your own?

P: Yes.

R: Do you?

P: I'd like it so much, yes.

R: What do you think would be good about it? About living on your own.

P: Er, I can do everything, I can do much more than I did before.

Katherine has support staff at her home at all times and does not go out without a member of staff being with her. She feels 'alright' about this, although she would like to live on her own in the same way her boyfriend does.

Similarly, there have also been times for Tia when she was unhappy with her living arrangements, however, in contrast to Katherine, Tia has been unhappy because she did not wish to live alone. Again, the issue here is autonomy – Tia felt that she should have had greater control over her situation so had to tactically work to make her wishes a reality:

Tia has had to manipulate situations in order that she receives greater support because she has been regarded as able to be more independent than she has felt she could be. In terms of autonomy Tia is succeeding it seems. She finds ways to be in charge of her

life; she has had to be cunning in order to achieve her goals. Having the choice of where she would like to live, for example. In order to live in the area of her choice she had to persuade the doctor to change his medical report so that she could move into the flat of her choice, for example.

When she lived in a residential home she also employed manipulative tactics, knowing how to manipulate a situation to her advantage, and had a lot of fun times there. However, she much prefers living on her own now because she does not like being told what to do.

In relation to feelings of autonomy Tia told me about why she decided it was time to leave the residential home:

P: ….they didn't want to let me go, the money what they were getting.

R: oh right ok – so was it the people that worked there that didn't want you to go?

P: Yeah they were getting loads of money. And once I saw the book and that, the money what they get for me, and we used to only get ten pounds to spend. And if we wanted to go on holiday we had to give them five pounds of that money.

R: Right

P: So we had to get soap, shampoo and everything else out of that. And I do not live in a home again 'cos its rules. Can't do this, can't do that. You're only allowed to have three drinks of lager you are.

R: [laughs] Oh well that won't do any good will it?

P: [laughs] Three drinks of lager? That's not me, I though yep. And you've got to be in by a certain time, you've gotta go to bed by a certain time and everything. It was like "Hmmm…that's not gonna work out".

This highlights again this desire for control; Tia had chosen to live in a residential home, she had moved over one hundred miles away from family whom she was close to in order to realise this goal, and was unhappy not with the limited independence but rather with the degree of autonomy that she felt lacking.

'Active citizenship', whereby an individual has greater choice and control, plays an active role in their community, contributes to society, and plays an active role in determining their future,

appears to be encouraged in policy (Clarke, 2005). Alongside 'Rights', 'Independent Living' and 'Inclusion', 'Control' is one of the four guiding principles of VPN:

> This is about being involved in and in control of decisions made about your life. This is not usually doing exactly what you want, but is about having information and support to understand the different options and their implications and consequences, so people can make informed decisions about their own lives. (DoH, 2009 p 31)

The principle of control was found to be desired amongst the participants. Where individuals did not have control over their lives, they sought to be recognised and informed on issues that would affect them. Be this, Chloe wanting to be kept informed about her mum's illness like the other people in her family were, or Gerald wanting the right to tell the support workers when he would like them to leave, Simon wanting to tell his sister that he only wants to share control of his life with his dad.

5.4 Conclusion

When analysing the data, it became apparent that the majority of participants did not value normative understandings of independence, which centre on notions of self-managing individuals, whereby, for example, individuals aim to live independently and enter paid employment. These normative understandings, which have been identified as the outcome of a society influenced by neoliberal values (Driver and Martell, 1996; Shakespeare and Watson, 2001; Redley and Weinberg, 2007; Hale, 2011; Owen, 2012; Hall, 2015) were apparent to a degree, however, I found the dominant desire was not to be independent and self-sufficient, but rather to have greater control over the course their life takes as well as day to day decisions.

These findings led me to contemplate what the participants' desires would be if they had a greater sense of autonomy; would they seek these normative ideals. In relation to this I found that the individuals had to desire independence or autonomy in order that they were able to value 'achieving' it. James provides an example of this; as discussed above, he was forced to live a more independent life by his father, moving into his own flat. James became more independent in the normative sense – he had moved out of his family home. However, James felt that this had been forced upon him and continues to be unhappy about the arrangement. As a further example, Tia, explained that she had to move over a hundred miles away to live in a residential home because she had been assessed as capable of living alone but did not feel capable of doing so. Tia was clearly very proud that she had managed to achieve her residential

home goal; despite the odds against her she had achieved her desired living situation. Such desires for autonomy evidence the need for a continued interrogation of citizenship rights in order that PWLD are included in a way that is meaningful to them.

The high regard for independence in terms of performative and economic capabilities within policy and government rhetoric was not reflected as a desire throughout the data to the degree that autonomy was. I found choice and self-determination to be key desires within the data. As Tia illustrated above, autonomy can be the determining factor to happiness, not whether, for example, someone assessed as capable of living on their own is actually doing so.

The data therefore poses a challenge to the assumption that independence in the normative sense is an ideal. The analysis indicates that autonomy is more important for the participants, with some of the participants wishing to be more independent in the normative sense, and others seeking what may be observed as more dependent circumstances. For the individuals concerned however, the important point is that they are able to direct their own lives and have a sense of control. Although this is a noted goal of government policy, market driven goals appear to dominate the definition of valued ways of living. This further illustrates the need to distinguish between independence and autonomy as the examples given above illustrate the varied desires of the participants in relation to these two concepts.

Chapter 6: Participation and Inclusion

6.1 Introduction

This second analysis chapter will discuss my interpretations of the data in relation to the themes of participation and inclusion. I shall first explain my definitions and use of these two terms with reference to government policy and related literature, before moving on to observe the data. In the same way that independence does not equal a sense of autonomy for the participants, and a sense of autonomy is rarely equated with independence in the normative sense, the data indicate that participation does not equal a sense of inclusion. Participation is understood here as the taking part in different aspects of life (family, school, work, community) – in a similar understanding to my use of the word independence, participation is viewed here in relation to behaviour, whilst inclusion is understood to mean how far a person feels that they are included in those parts of society which they value, I am interested to discover what the participants value, rather than how far they are 'succeeding' in terms of the prescribed goals.

The themes of participation and inclusion follow and overlap with the previous major themes of independence and autonomy. Within this chapter I will discuss how individuals participate in society and their feelings about this – they may be 'doing' participation, but do they feel included? Participation was revealed as a theme when the participants spoke of engaging in the world outside of their homes. An example of such is the commonly held view amongst the participants that doing things away from the home is determined by others and is out of their control. It was this reliance on others to determine where they were able to go, and when, that contributed to my somewhat juxtaposing of 'participation' and 'inclusion' as I wanted to differentiate between the action and the feeling. Like the theme of independence in relation to the theme of autonomy, participation in society was valued when accompanied by a sense of inclusion; it was not the 'doing' alone – this must be preceded by the desire, and often also by a sense of autonomy. Do they desire to participate in that way? Did they choose it?

This chapter illustrates the desires of participants to participate/feel included to a greater degree in several areas, including greater participation in family life, and opportunities to spend time away from institutional confines. Government policy has noted that barriers to participation in public and social life have led to disempowered and marginalised individuals where such barriers are felt (DoH, 2009).

The desire to lead a more active life was discussed or implied in several cases; this goal was often seen by the participants as constrained by a lack of support. Examples of this include participants acknowledging barriers in relation to working and training, seeing their families, and making decisions about their own independence – such as being able to catch the bus on their own.

The data here indicates the participants' options are limited and that they are often lacking the opportunities to take part in activities that they desire. Furthermore, the act of participating, and a sense of inclusion for the majority of the people involved in this study was often determined by those who support and care for them. In many cases, opportunities to participate are limited by the amount of choice received – or by how informed an individual was of the choices they have. For example, a person having a choice about what to do with their day may be seen positively, but on closer inspection how positive is this when the individual has a very limited amount of options? This issue was relevant to many participants.

Participation seems to be a valued goal of both government and PWLD, however, akin to the previous chapter, how this is defined and understood by the participants warrants attention. In policy, PWLD are framed as capable workers, consumers of services, and members of the community (Gilbert et al., 2005; Gilbert and Powell, 2008). The VPN (DoH, 2009) policy document has a section entitled 'Work, education and getting a life'. Within this document it states:

> People with learning disabilities want to lead ordinary lives and do the things that most people take for granted. They want to study at college, get a job, have relationships and friendships and enjoy leisure and social activities. (p. 16)

The document goes on to detail the expansion of employment and education opportunities for PWLD. The eighth point of the 'Key Policy Objectives for 2009–12' in VPN states:

> All people with learning disabilities and their families will be treated as equal citizens in society and supported to enact their rights and fulfil their responsibilities. (DoH, 2009 p. 22)

The opportunities and support referred to in the document do not seem to be felt by the participants here, with feelings of frustration disclosed in relation to work, community and family inclusion – for example, participants wishing to work, and being encouraged to seek

employment by those who support them, but feeling disenfranchised in relation to paid employment as charity work is often the only available option. It was also often the case that the individuals involved in the research did not aspire for the goals stated here. Statements such as this may further the exclusion of PWLD if they fail to 'achieve' when an apparent opportunity to engage in 'normative citizenship' has been provided (Redley and Weinberg, 2007; Fisher, 2011), potentially creating 'contractual transgressors' (Somers, 2008); and paving the way for PWLD to be regarded as deviant when they fail to achieve the targets which the government has stated they both desire and have the opportunities for (Lewis, 1998; Turner, 1997; Vorhaus, 2005; Redley and Weinberg, 2007).

6.2 Family

In the previous chapter, my observations and interpretations in relation to the family were focussed on how autonomous the individuals felt they were – how far they felt they could determine their living arrangements and make decisions about living with their families, for example – and how much they valued this. Alongside this, I observed their understandings and experiences of independence and how far this was valued. Here, I focus on participant's understandings of participation and inclusion in relation to their families. For example, do they feel that they are included in family life to the degree that they wish to be and – drawing on the theme from the previous section – how much control do they feel that they have in relation to the act of participation?

The previous chapter and the present somewhat overlap particularly when observing reflections in terms of the family and the home as emotions and experiences are linked to how autonomous an individual feels they are. As observed in the previous chapter, discussions of the family arose often and elicited much discussion during the interviews, with the majority (14) of participants not currently living at home.

Chloe, as part of this majority, lives in a supported living residential home and is an example of the above as she shows apparent frustration at being – what she seems to experience as – constrained in relation to her family. There are often occasions when Chloe gets very upset. Those who support Chloe have concluded that this is related to her missing her family and I would agree; it appears that Chloe no longer feels included in her family, which makes her feel unhappy:

Before living in her current home, Chloe lived in one other residential setting, and before that with her mum, two sisters and her nephew. She sees her nephew, who is now grown up, often. She also likes to see her aunty, however, does not see her as much as she would like to. Her mum has moved to a different house and she does not see her as often. When Chloe moved out from her family home she felt sad.

Chloe is always eager to speak to members of her family and mentions her aunty often. Chloe made it clear that she would like to have a mobile phone in order to make contacting her family easier:

Chloe does not have a mobile phone, although she would like one; they are not allowed because they are too expensive.
P: We're not allowed phones, we're not allowed phones. Too expensive.

Chloe stated this in a way that was both very matter of fact and dejected. Chloe has no means of acquiring a mobile phone – and potentially this could be the situation for the rest of her life. It seems that she is constrained by both a lack of resources and by being institutionalised to a degree that she will not actively address her desire for a mobile phone – her telling me that she would like to have one in the interview setting is not reflective of her often voicing this desire; this was the first time she had said this to me and I had spent a substantial amount of time working with her over the past two years. This illustrates a form of social exclusion as access to her family is mediated by support staff, her family, and institutional confines. Fraser's (2008) concepts of redistribution and recognition are appropriately applied here. Chloe, would like to work but has no access to the workplace, thus experiencing 'economic marginalisation'. There is nothing that Chloe can do to change this situation, she has often said that she would like to work, and has volunteered at various places, but I see no possibility that she will be able to take part in paid employment. I discuss this further in the following section where I ask the question, how, when there is no apparent scope for this to change, can Chloe be legitimately denied something as essential to most in UK society as a mobile phone? Secondly, she experiences 'non-recognition' as her plight is rendered invisible.

Somers' (2008) notion of the 'contractualization of citizenship' finds resonance here. By this she is referring to the value judgements based on whether a person is able to fulfil their duties as citizens in relation to the market. This, she explains, 'distorts the meaning of citizenship from that of shared fate among equals to that of conditional privilege' (p. 3). She explains that

social inclusion and moral rights are now conditional; instead of being a right afforded to all members of a society, they are based upon an individual's ability to exchange something of equal value. The dominant ideology as far as Somers understands it is 'market fundamentalism' or, in the terms of this thesis, a neoliberal social settlement. Somers explains how 'conversion narratives' are being used in order to induce fear regarding the current status quo and therefore produce a rationale to switch from a social approach to market principles. A conversion narrative is a process by which individuals are taught to see the world differently, unlike narratives generally, a conversion narrative has a single goal and employs persuasive strategies in order to achieve this. The success of such conversion narratives are evidenced in that participants have desires which were seemingly denied based on the individual's inability to contribute to society in a way that is valued. The conversion narrative posits that if the individual had been able to contribute they would have been worthy of their desires coming to fruition, but as it was, they did not deserve them.

In relation to seemingly unattainable desires that are taken for granted by others, and in a similar vein to Chloe's desire for a mobile phone, Sarah has had her participation at church mediated by others her whole life. She seems to accept this, at the same time as making it clear that she does wish to attend church, explaining that she has in the past been able to go but only because her circumstances allowed it in that there were support workers available to take her. Sarah is often vocal about what she wants, I have many experiences of this from working with Sarah as a support worker. However, her interviews illustrated how she also accepts circumstances that I do not think it would be unreasonable for her to challenge.

It seems appropriate to discuss Somer's (2008) understandings of the changes to citizenship here as the lack of access faced by many of the people involved in this study is in relation to artefacts and experiences which could be said to be taken for granted by people who do not have a learning disability. Chloe's inability to acquire a mobile phone, and therefore inability to make contact with her family at the time of her choosing, and Sarah's limited opportunities to attend church, because there are not enough support workers to spare in order to take her, is reflective of similar barriers to participation in family life and society expressed by others and seems to possibly illustrates a dominant status quo /social settlement which feeds into resource allocation and therefore the rights of PWLD. Fraser's (2008) misrecognition category of 'cultural domination' is appropriately applied here. This she defines as where a group or culture

is interpreted based on another culture. The neoliberal social settlement can be said to have rendered all who are not contributing economically as deserving of their position.

The desire felt by Chloe in relation to accessing her family is echoed amongst other participants. Sarah, like Chloe, no longer has the opportunity to participate in family life to the degree that she would like. She misses the time when she lived with her family and seems to be always looking forward to a time when she will be able to see her sister or father. This appears to cause her frustration. She will often mention her family and will look forward to seeing them for weeks beforehand:

> *P: And I might go home again.*
>
> *R: Yeah.*
>
> *P: Another day. And my dad wants me to see him on Sunday.*
>
> *R: Oh, does he? This Sunday?*
>
> *P: One Sunday.*
>
> *R: One Sunday.*
>
> *P: One Sunday again – And I haven't heard which one yet.*
>
> *R: Yeah.*
>
> *P: When I go home to him. But when I do I get pizza. Pizza for lunch.*

When I asked what she did on a weekend Sarah explained:

> *P: I knit and go out in the bus. On some weekends our Sandra and Alison, and my dad and Julia have me home for a day. But not often, so I'm at South Lees every weekend.*

Katherine also would like to participate in family life more. Katherine used to live with her mum and dad but she does not feel included anymore as she no longer sees either of her parents very often:

> *Katherine is twenty-five. She currently lives in supported living accommodation, but lived with her mum, step-dad and younger brother and sister as a child. She can remember living in one particular area when she was twelve years old, but cannot remember before this and did not live in this area for very long. After this she moved from her parents into a supported living situation, but cannot remember when this was; she does remember that it was when she was still quite young.*

If she could change anything about her life it would be to see her mum again. She last saw her a few weeks ago but does not know her address and would like to see her more often.

James also evidenced frustration in relation to his participation in family life as his dad and his brother will go to visit him, however, they have the control over when this happens and James rarely goes to visit them. This was evidenced throughout the interviews, with participants explaining that their families were able to access them but often they could not access their families at the time of their choosing. Over half of the participants (Chloe, Sarah, James, Katherine, Diane) living in supported residential settings explicitly stated that they felt this way.

Ellan provides an example in contrast to this. She sees her family when she chooses and goes to visit her boyfriend's family as well. Unlike the other participants, Ellan referred to these visits as something that she was in control of, rather than as a passive participant. Whilst she explained one of her reasons for leaving her parent's home was the need to address her own support needs, acknowledging that her parents would not always be there to support her, she also explained that she wanted 'my own life'. This was discussed in the previous chapter, I mention it her in relation to Ellan's positive framing of her relationship with her family as a result of having moved out. She stated:

> *R: Yeah. And you've got better relationships now you said than ever?*
> *P: Yeah.*
> *R: People say that a lot.*
> *P: Don't argue as much. We might disagree but we don't fall out as much as we used to.*

Diane echoes this, explaining the improved relationship she now has with her sister as a result of moving out of the family home:

> *P: Yes. And my grandma, and my grandma. I was alright when I was there. I was arguing, I was arguing with my sister. Arguing.*
> *R: Yeah.*
> *P: I'm alright with her now.*
> *R: Now that you don't live together?*
> *P: Yeah, I'm alright with my sister, I'm alright with my sister – I don't get on with my*

sister last time, and then I move out.

R: And how do you get on now?

P: Alright, alright. I see my family, I see more of my family now.

R: How often do you see them?

P: On a weekend.

6.3 School

In 1970 an act was passed detailing the right of PWLD to attend school (DoH, 1970), since which the UK has many times reaffirmed its commitment to inclusive education (DES, 1978; DES, 1981; DfES, 1988; DfE, 1993; DfE, 1994; DfEE, 1997; Hansard, 1999; DfEE, 1999; DfES, 2001; DoH, 2009). According to The Foundation for People with Learning Disabilities (2010), presently 89% of children with moderate learning disabilities, 24% of children with severe learning disabilities and 18% of children with profound multiple learning disabilities are educated in mainstream schools, with current government policy (DfE, 2012) stating disabled and non-disabled pupils must have the same rights in terms of access to education opportunities. The majority of the participants, with an average age of 45 years (ranging from approximately 17 – 65 years old), attended a 'special school' as it was often termed throughout the interviews. In this section, I observe how the participants felt about school, discussing their understandings of having attended 'special' or mainstream schools and what this meant to them in terms of participation and inclusion.

Eight participants (Donald, Chloe, Katherine, Hannah, Jade, Pam, Rebecca, Tricia) disliked school for various reasons, for example, not liking certain lessons and teachers. Of these participants, Hannah and Donald attended mainstream school. Donald did not detail reasons for disliking school and Hannah disliked it because she was bullied, but began to like school once she moved to a special school and was no longer bullied. Another four participants (Mary, Jane, James, Mark) stated that they liked school. Of these participants, Mark attended mainstream school.

In terms of schooling and wider societal inclusion, Sarah, for example, refers to having attended a 'normal' school as a child. Does this mean that Sarah feels an element of inclusion from wider society? I am not sure based on my discussions with her, but it does seem clear that Sarah sees herself as less than what she considers normal, being very aware that she has a learning disability and seeing this in exclusively negative terms:

Sarah is very much aware of this saying how her sister is 'normal' and she is not:

> *R: Erm, they're the things I've written down anyway but like I said if we could just talk about your life -*
> *P: My life, yes.*
> *R: - starting I suppose with your earliest memories?*
> *P: Yeah. That I was born in [place name]. And our Sheila came first – my twin.*
> *R: Yeah.*
> *P: And she didn't know she was having me, my mum, and she was having twins.*
> *R: Oh, she didn't know she was having twins.*
> *P: No. And I came second, and she didn't know she was having me. I came but I never had an incubator...when I was a baby and I came and the nurses got me and I was handicapped – how I am today. It's their fault for not giving me one because if I had one incubator I'd be normal, how my sister is now today, but I never had an incubator so I'm like I am now.*
> *R: I see.*
> *P: And I had the worst of things when I was – all my life, but being a baby I can't remember when I was one and three years old but my mum and dad they told me later on in my childhood, I was told that I couldn't walk 'til I was three years old.*

Only three participants (Hannah, Donald, Mark) attended schools that were not specifically for PWLD. Sarah attended mainstream school for a short time but when she was diagnosed as having a learning disability she had to then change schools in order to attend a school specifically for PWLD:

> *Sarah went to a 'normal' school from the age of five to seven years old when she went to a school 'for learning disabilities'. The change in school was as a result of going to the doctors when she was seven years old where she was told she had learning disabilities. She remained at the school for people with learning disabilities until she was sixteen years old, at which time she went to a training centre.*
> *R: And how did you feel about having to move from South Parade to your new school?*
> *P: I first thought I had a learning disability and I didn't quite feel good, I didn't feel right, I didn't feel, you know...I felt a bit on edge.*
> *R: About what you'd just found out, or going to the new school?*

P: Yes, yes, what I found out… [At this point Sarah changes the subject abruptly.]

The actual move to a school for PWLD did not appear to cause Sarah distress, but finding out that she had a learning disability did seem to, and continues to, distress her. She is aware that she is different to other people, focussing on her twin sister who does not have a learning disability as a comparison to herself.

Tia also demonstrates an understanding that she has a learning disability and, like Sarah, an understanding that this is seen negatively by other people. The potential negative consequences of PWLD attending mainstream school is detailed in the 'What about us?' research (DoE, 2008), where it was found that PWLD are in favour of greater inclusion in mainstream school, finding young people are in favour of government policy goals in relation to inclusion within mainstream schooling. However, without the inclusion of measures to aid this and decrease the prospect of bullying, such as the inclusion of safe areas and greater supervision, this inclusion is thought to potentially have negative consequences for the individuals, as bullying is a key concern. In addition, Mencap (2007) found PWLD to be twice as likely as those without learning disabilities to be bullied. Such issues were addressed by Tia, who appears to think it is better for PWLD to attend special schools as the prospect of being bullied in mainstream schools is so great.

In relation to this, Tia and I discussed the school for PWLD that her nephew, Jason, and friend, Hannah, both attended, contrasting it with a state secondary school that Hannah previously attended that Tia believed to be inappropriate for her. She implied that she does not feel it an appropriate place for PWLD generally:

Tia explains that she suggested Hannah attend the same school as Jason as she had been removed by her mum from school as a result of being bullied. Hannah changed school, was no longer bullied and was much happier there as she was able to play with other children again, rather than being around adults at home all the time. Tia was really happy about this change as she believed Hannah was in the best place for her:

P: The funny thing is, she used to be bullied at her school and they were trying to send her to the other school where she would have been totally picked on and beaten up so badly at it.
R: Where was she at and where were they going to send her?
P: To a school further up, er, up [location].

R: Oh, right.

P: There were a school up there, a really big school, a big high school. She wouldn't have coped well there, so they had to fight to take her out of school cos she was being picked on and thumped in her tummy, and that could have affected her if she were ever wanting to have children. Her mum was getting worried about her cos she was being hit there.

R: Right, and at the school that she was at that was what was happening.

P: Yeah, and if it was happening there, imagine what would have happened if she got to the other one.

R: Where did she go to?

P: Ha! My school. [school name].

R: Ohh.

P: She got sent there so she was happy. She got on with everyone and no one hit her in the tummy after that. it was the best place to send her. She got taught at home for a bit and then it started going down hill so she managed to get into the other school.

R: Hmm.

P: She was spending more time with grown-ups -

R: Hmm.

P: - than being with kids her own age. And they mentioned it to the teacher that she spending more time with the grown-ups and she's not really playing with other kids her own age, so she was talking like she was about 20 years old, she was. And it took her a while to finally start interacting with children.

As mentioned in the previous chapter, Tia has looked after her nephew often and feels that she is better able to understand him than his mum because she sees them as having similarities even though they have different disabilities:

Tia feels that she is better able to understand Jason because they both have disabilities of some description:

P: Yeah. With me having a disability he knows that I understand him -
R: Yeah.
P: - where his mum can't understand him so much. I understand what he's on about and what he's saying, where she can't. With me having my disability I understand why people sometimes don't listen and just think he's making things up all the time...

Tia feels that she can understand Jason because they both have disabilities. She puts herself in the same group as Jason even though she also points out that their disabilities are very different and that she is far more able to do many things that he is not.

I do not conclude that Tia seeing a difference between PWLD and people who do not have learning disabilities as a negative necessarily, but I do feel that from the data, as well as from speaking to Tia outside of the research environment, she does see a separateness between herself as a person with a learning disability and those who do not have a learning disability. This understanding is then applied to her own life, and the lives of her friends and family, and is illustrated in her conclusion that a mainstream school would be inappropriate for her friend Hannah, as it was for Jason, based solely on the assumption that she would be bullied due to having a learning disability. The situation Hannah has experienced does illustrate the move to a school specifically for PWLD was beneficial for her.

Hannah told me a lot about her experiences of being bullied in mainstream school. Her account corresponded with that which her friend, Tia, had already discussed with me. Hannah was often picked on both verbally and physically; with her mum removing her from the school and teaching her at home when she was hit in the stomach [issues with the MP3 player meant much of this discussion failed to record].

James talked quite a lot in reference to school but in relation to a specific activity (music), but did not discuss anything else about school, such as friends, his experiences or feelings about it:

> R: Do you remember that time.
> P: Yeah, I remember school, yeah.
> R: How did you feel about going to school. ... Can you recall?
> P: I don't know, I've no idea.
> R: Long time ago, wasn't it?
> P: It was a long time ago. I remember I went to school when I was young, about 17, then I went to [school name], I went to [?] high school, I used to play music and sing songs and that.
> R: Did you.
> P: That day when I was, my father used to say, do that if you want to do it, so I did.
> R: Yeah.

P: Yeah. [?] He says that James is a very good sing, he can sing. He says, well I didn't know James could sing. Well he's starting to sing. I could get a few word out of my mouth.

R: Yeah. Is that something that you enjoyed doing?

P: Yeah.

R: Yeah, I can tell.

P: Yeah. Then I used to play piano, guitar, instruments, all sorts. I used to do that. you know what I mean?

R: Yeah.

P: I used to play piano, sing a song. And then they'd clap [?]. Yeah [claps], to me. It were alright.

It was notable that my attempts to discuss participant's experiences of school did not elicit very much data; it did not appear to be something they were interested in discussing. The participants who attended 'special' schools did not seem to feel a sense of exclusion from, nor did they report a desire for participation, in mainstream schooling. This became evident especially when looked at in relation to other institutions such as the workplace and the family where many of the participants did feel that they were excluded and did wish to participate to a greater degree. It seems important to illustrate the feelings – or lack thereof – that the participants had about school as within policy this is considered a key portal in relation to inclusion within society (DoH, 2009), with the government making clear their goals to work towards including PWLD within mainstream schools.

6.4 Work

The redefinition of PWLD as capable of making choices and being independent, as identified by Redley and Weinberg (2007), and as evidenced in government policies (Kings fund, 1999; DoH, 2001; DoH, 2009) means PWLD now have different expectations placed on them to those of the past where they were understood as vulnerable and in need of care (Gilbert et al., 2005). Gilbert and Powell (2008) explain PWLD, whilst once seen as welfare subjects, are:

> …no longer perceived as passive and dependent but constructed as having the capacity to make choices in a market orientated welfare system and therefore active citizens in their own right. (p. 188)

The redefinition of PWLD as capable and potentially independent individuals brings forth new expectations (Redley and Weinberg, 2007). Such expectations are felt by service providers who must follow government objectives, and as such care providers can be seen to mediate the citizenship experience of PWLD as they attempt to facilitate the goal of inclusion in the workforce (Gilbert and Powell, 2008).

A shift in discourse has been recognised, with a move away from the rights of the citizen, towards a citizen being understood as an active consumer with responsibilities in relation to the rest of society (Gilbert and Powell, 2008). This move was identified by Gilbert and Powell in neoliberal terms, with responsibility being moved from the state onto the newly defined self-managing individual. By creating a discourse of PWLD as empowered, self-managing citizens, it is argued by Gilbert and Powell, that not only can the state then reduce its responsibilities towards PWLD but it also facilitates the creation of particular identities. They ask, how do PWLD act as citizen-consumers and make market based choices, under what conditions do they participate – as is expected of a citizen – and, finally, what are the consequences for the individuals as PWLD now have greater choice and rights? The introduction of personal budgets means PWLD are positioned as consumers, able to make choices in relation to their support. As a result of such, as well as the changing representations of PWLD within policy and rhetoric (DoH, 2001; DoH, 2009) Gilbert and Powell refer to PWLD as 'new citizens of the C21' (p. 193).

Therefore, taking part in paid employment poses unique issues in relation to PWLD as they are simultaneously expected to take part in the labour market and positioned as in need of care (Gilbert et al., 2005; Redley and Weinberg, 2007). Gilbert et al (2005) observe a level of 'functional integration' as more PWLD are living and working in their communities, whilst at the same time noting large scale exclusions as PWLD inclusion is often voluntary and mediated by support/care organisations:

> Regardless of which conceptualisation of citizenship we might take, people with learning disabilities have some way to go before it can be claimed that citizenship has been achieved. (p. 293)

Sarah, having worked full time for seventeen years, can be seen as an example of this functional integration to which Gilbert et al refer. Aged eighteen, Sarah moved to a village specifically for PWLD. Here she worked on the farm:

Sarah feels like she deserves her retirement as she often talks of how hard she worked when she lived on a farm for 17 years, and how she now has a bad back and has 'never been right since':

P: And there I used to work on the land. I worked on three farms a day...Oaken Farm, High Farm and Honey Bee Nest.
R: Right.
P: And I used to do the chickens and the cows on Oaken (Falcon) Farm, and hay-making for the cows – hay – what we did in summer, I used to do every job.
R: Sounds like you had a busy time at the farm.
P: I was. And it gave me a bad back. And ever since I've been having wear and tear on my body, ever since, back, bad back ever since. And now I've been told by the doctors and the physios that I do very well at this age and I ave to keep moving, if not I'll be in a wheelchair.

Sarah talks a lot about her working life, placing a great deal of importance on work. She takes great pride in the idea of working. She also refers to knitting as her job. I have the impression that Sarah believes it is very important to work and to earn a wage; she offers to iron for a fee and is constantly knitting and selling her wares to people:

P: Yea. And she said to me I could iron them.
R: Oh brilliant.
P: She's going to ask Owen as well, if I could hand them into Owen on Monday, and I can do them here in the centre.
R: That's good.
P: And earn a wage on it.
R: Hmm. You're always keen to earn a wage, aren't you?
P: Yes.
R: You know when you used to work at Botton Hall Farm, did you earn a wage then?
P: No, I didn't. No, no I didn't, it was all voluntary.
R: All voluntary.
P: Everywhere. Household jobs or farming jobs, the garden anything. Workshops – it was all done freely.
R: Right. Was it that you lived there and - everyone lived there and worked there as

well?

P: Yes, Yes.

R: What did you think about that? Did you think that was-

P: It was alright for me.

R: Yeah.

P: But I been working too hard in my life and it has an effect on me now.

R: Yeah.

P: As I get much older. And this wear and tear back I've got. And arthritis.

R: Yeah.

P: After what I've been doing all my life. And it happened. There.

Gilbert and Powell (2008), in their research with care providers, found many of the disabled people in employment did not actually receive a wage because work was done voluntarily in order that it did not negatively affected their benefits, or the work was for a charity. Although the potential integrating factors of employment, as expressed in VPN were noted, it was concluded that work for PWLD being facilitated by charity care organisations, with the individuals working on a voluntary basis, positioned the PWLD as both volunteer and object of charitable work as many support organisations, such as the organisation where I conducted the research, are charities.

Sarah was in this position for 17 years of her life. She understood that she was working hard but was not rewarded as one generally is on the completion of work; she is very aware that she has a learning disability and that she worked in this capacity because of this. This awareness in terms of her work situation seems evident in her unprompted use of the terms 'freely' and 'voluntary'.

The other five participants who also had experience of working in a voluntary capacity were: Hannah, Chloe, Ellan, Katherine and Mark. Hannah, Chloe, Ellan and Mark were currently volunteering when the interviews took place, with Mark also holding a paid position elsewhere also. Additionally, Tia, Donald and Gerald had worked in a paid capacity in the past.

Of those who had worked voluntarily, only Sarah had done this full-time and only Sarah appeared to hold negative feelings about this, with no one else discussing that they had "worked freely", for example. In the past, Ellan has told me how much she enjoys volunteering at the charity shop, sentiments echoed by Hannah who also volunteers at a charity shop:

On Thursdays, Hannah works in a voluntary capacity for three hours at the RSPCA charity shop in town. Hannah enjoys working in the shop; she works on the till and on the shop floor. She explains that the items in the shop are all two for £1, except for children's coats and shoes, which are £1 each. Children's clothes are expensive; when Hannah is buying Christmas and birthday presents for children she particularly notices this. After she has done her shift at the RSPCA Hannah will go home and have a rest before going to Thursday Club at the day centre in the evening.

Hannah was very enthusiastic about her volunteering, although she would prefer to work in a paid capacity in childcare and is hopeful that her volunteering will stand her in a good position in terms of paid employment:

Hannah would like to go to college to take a childcare course as she would like to be a nursery nurse. When Hannah was at school she did her work experience at an infant and nursery school, after not being able to find a place at a hairdressers, and really enjoyed it; so much so that she would return for one day per week following her work experience.

She is currently waiting for the college to get back to her as she went for an interview and was told that she needs to go on an IT and maths course before she is able to undertake the childcare course. There is a chance she will not be able to go on the childcare course in the end anyway because she is 21 years old and thinks the course is for people younger than this. She will find out more information when she has completed the maths and IT courses. She is waiting for the college to get back in touch with her about when the courses will start.

Hannah not only wishes to work in child care because of her desire to do something that she enjoys, but also because she wishes to live on her own someday; something she would not be able to do was she unable to secure a position in paid employment:

R: Erm, do you think you'll like here for quite a long time, you were saying that you can't afford to move out?
P: Yeah, I think I'll be here for quite a while.
R: Yeah. Have you, erm, do you think, would you like to move out? Is it a money thing?
P: Yeah, I'd like to live on my own but it's just money.

R: Yeah.

P: Money issues that I don't have enough to live on.

Interestingly, this desire is not one shared by the majority of participants, with only Katherine also wanting to live more independently than she currently does. This desire is discussed in greater detail in the previous chapter and the following section, 'Community Involvement'.

Mark is alone in that he is currently in both paid and voluntary employment, and has been on several different courses that aim to prepare PWLD for the workplace. Currently, he works voluntarily in the café at the organisation where I carried out the research, and in a paid capacity at a café in a park near where he lives. Mark, although not a greater talker in the interview situation, was very talkative when it came to a topic he was interested in, such as animals and books. He particularly liked the work experience he did in an older people's residential home, as well as his current jobs where he works in cafes, because of the opportunities to chat to people about things he is interested in:

> *After spending a year on the 'Workwise' course Mark got a job in a residential home for older people. Here his role was to help to make and then serve food. He enjoyed working there because of the different people he was able to meet and talk with; he liked the different personalities he would encounter:*
>
> > *R: Yeah. So, work-wise, can you remember what you did after Workwise?*
> >
> > *P: Then, er, then I worked at, erm, [organisation name]*
> >
> > *R: Oh, right, I don't really know [location] that well.*
> >
> > *P: It's erm...*
> >
> > *R: What sort of a place is that?*
> >
> > *P: Like an old people's home?*
> >
> > *R: Oh right, OK.*
> >
> > *P: Yeah.*
> >
> > *R: Yeah.*
> >
> > *P: I enjoyed that.*
> >
> > *R: Oh, did you?*
> >
> > *P: Different, you know, different personalities.*
> >
> > *…*

> *R: Was it a residential home?*
>
> *P: I think it was, yeah.*
>
> *R: Yeah. And you enjoyed that -*
>
> *P: Yeah.*
>
> *R: What did you like about it?*
>
> *P: Just talking to different people.*

Unlike Sarah, Mark does not feel negatively about the voluntary work that he does, seeming to view both voluntary and paid work equally. However, he does like to have money as he enjoys going out with friends and buying books. Therefore, how Mark would feel were he not able to access this money may be very different as it seems the money equals freedom and opportunity for him.

As already noted, PWLD are seen to be framed as capable workers, consumers and members of the community, whilst in the not so distant past being constructed as dependent and in need of care (Gilbert et al., 2005). Mark, as the only participant who is currently a paid employee, could be evidenced as proof of this capable, consuming member of the community. In line with Somers' (2008) understandings of citizenship, Mark is fulfilling his contract with the state and other citizens by both contributing economically, as well as possibly being seen to be 'giving back' through the volunteer work that he does (Gilbert et al., 2005; Somers, 2008). However, if Mark is seen to be fulfilling not only his duty but his potential then the question arises as to, if viewed as a member of a group of PWLD, does this potentially entail that other PWLD who do not 'succeed' in this way are understood to be failing (Lewis, 1998; Turner, 1997; Vorhaus, 2005; Redley and Weinberg, 2007; Chappell and Gifford, 2011)? To draw on Somers, this may contribute towards the positioning of those who 'fail' as 'contractual transgressors'.

Tia, Donald and Gerald, who had worked in a paid capacity in the past, reflected on their experiences of this throughout the interviews. Tia is in her 40s and Gerald and Donald are now both of retirement age. Tia has worked in two places, the first she did not like at all, but enjoyed working in the second:

> *Tia lived with her brother in Huddersfield for a time and then moved to Newbury with him. Tia's brother took care of her and also got her a job sewing net curtains, although she did not enjoy the job at all. She did not like the type of work she had to do:*

P: A sewing job doing net curtains and that for sending out two firms [?] You put the net curtain bit and you've gotta put the thread all the way down. And you've got to be careful and you've got to pull the thread out and then you snip up the gap where the thread you've taken out. That was horrible job.

R: Was it? Didn't you like it?

P: No cos I [?] half way up and you've got to fight to get the [?] it's like hmm and you pull the other bit slowly it's like…

…

Whilst living in the residential home in Wales Tia started working in a bakery nearby. She was offered the job as she would often walk past the bakery and became familiar with the owner. She would clean, do a little bit of cooking and serving the customers. Once there was a really nasty customer in the shop:

P: Because I've got a disability, and because she could hear the speech impediment in my voice, she goes, 'Oh we have people what are quicker than you', she went – well [the owner] says 'if you don't like it here and everything you can go somewhere else, this lass turns up when anyone else doesn't! And if I need her she's there', he went to them, he went, 'and if you don't like it you can go somewhere else'.

R: Is that to customers or her?

P: To customers.

R: Aw.

P: I was there, like, gobsmacked, [the owner] stuck up for me and he was really nice. He had people what come into the shop what worked for him, right, but some days they don't turn up. And then cos I didn't live far away from the shop he used to ring up and go 'can Tia come in and help out?' He used to pay me a bit of money on the side what I weren't supposed to be getting.

He also would give her bakery goods to take home with her that he could not sell the following day. She would take them home and eat all of them, not offering one to anyone else. Looking back she now regrets this and thinks she must have seemed like a 'bitch' for doing that. She said she just didn't think at the time:

P: They treat you like children so you act like a kid, so you think like a kid…

Tia seems proud that she is able to do more than some PWLD, often referring to herself and other PWLD in distinctive terms. As detailed in the previous chapter, it is important to her to

be able to navigate her life in a way that she chooses and this is reflected by her openness of what she likes and dislikes. She spoke of an alignment with support workers, detailing times when she, as a service user, was asked to take a supporting role with other service users:

> *As Tia was a lot more able than the people she lived with, members of staff at the home would sometimes ask her to help them out. At Christmas when, as usual, there should have been two members of staff working in the home, there would be one member of staff and Tia – who they has asked to help out. Tia was entrusted with taking some of the other residents to the pub. She felt good about this, as well as recognising the difference between herself and the other people who lived in the house with her. Tia understands that she is not disabled in the same way as the other people she lived with.*

Gerald has had many different jobs; if he did not like a particular job that he was doing he would simply leave it and go to get another somewhere else:

> *Gerald has worked in many different places around the town over the years, including in a warehouse, a mill, and as a bin man. He moved on from the different jobs in order to earn more money and because he wanted a change. He used to like working in the mill because he used to chat up the women in there.*
>
> *P: He's worked all over like me – I've had jobs – loads of jobs*
>
> *R: So you've worked*
>
> *P: I've worked at (?) – wood place, you know, where they make coffins and stuff?*
>
> *R: Right, OK.*
>
> *P: I've worked there, yeah.*
>
> *R: And in a mill?*
>
> *P: Yeah.*
>
> *R: On the bins?*
>
> *P: Yeah, I've worked all over, I've worked all over.*
>
> *R: You've had a fair few jobs. Can you remember how old you were when you had your first job?*
>
> *P: No. (laughs) No, I can't.*
>
> *R: Were you young?*
>
> *P: I was about seventeen then, I think. I was still living with my mam then. I've had a load of, a load of jobs man. I've had loads of jobs. you know what I mean? I left*

didn't I?

R: Why did you leave?

P: I got fed up didn't I? I got stalled. Got stalled

R: It seems like it was a lot easier to get jobs than nowadays.

P: I couldn't do with, I couldn't do with, I couldn't do with the noise in the mill. It got on my nerves. You know what I mean?

R: Yeah.

P: It's like coming here, they all carry on here sometimes, don't they? So bloody noisy. (Name) does. She int' in today. She screams. Screams bloody place down. You have to cool her down sometimes. She can get nasty. She can flare out like (name). No, you've got to be careful with (name) these days, or else he'll land you one. He landed his carer one didn't he? He put one on his nose, Friday.

Gerald's last job was as a bin man, from which he was retired early by the doctor. He looks back fondly on the time when he worked but says that things have changed for the worse now and the procedures when working on the bins has changed a lot.

R: Did you like working?

P: Oh aye. Yeah, I'd to give up hadn't I? Had to give up. I shouldn't of been on the bins. No. I enjoyed it. Miss the lads. 'Cos they're all new uns now aren't they? Some of 'em are dead some of 'em now.

R: Which is this – is this people from the bins.

P: Hmm, they're all dead some of 'em. Some of 'em left, got another job. I don't blame 'em. Well, there's only two lads now int there? On the wheelie bins now.

R: Is there?

P: Hmm, there used to be five with the driver, the driver's in charge. They have cameras in.

R: Do they?

P: Yeah. Make sure you're putting the wheelie bin on right.

R: Really?

P: Yeah, they have cameras, yeah, you're ont' camera.

…

R: How did you feel when they retired you?

P: Nowt. I was glad, they didn't want me anymore so…that were it, wasn't it? Yeah,

yeah. They didn't want me no more, do you know what I mean? They made it down to two men now. And the driver. Yep, they didn't want me anymore.

Although Gerald did seem unhappy about his early retirement, he seems to look back fondly on his working days. It seems that he had the control over his life in relation to this; he made the decisions as to whether to start or leave a job. This seems to be an example of a true feeling of inclusion in relation to work, seemingly facilitated by the control Gerald had over the situation. He was not merely 'functionally integrating' in the terms that Gilbert et al. (2005) speak, rather his sense of inclusion seems to have arose from both his willingness to engage with working life and the genuine opportunities for him to do so.

6.5 Community

Participants who need support when outside of the home were less likely to participate in the local community than those who did not need this support. This lack of participation can be seen to be linked to a lack of resources, as opposed to desire, as many of the individuals did wish to go out into the local community more but were unable to do so as they were restricted by the amount of support they had access to.

Simon, for example, would like to have more support so that he can go into town more often:

P: And also I want some more support from, erm, catching the bus on my own.

R: Right, yeah.

P: I want to know, I want to do that more than anything else in the whole world.

R: Right.

P: I've got a bus pass as well, you see, haven't I?

R: Yeah. So, do you mean you could catch the bus from home on a morning to here?

P: Yeah, it's not far from Newsome.

R: No, it's not at all.

P: Or go into town. Hmm.

R: Do you feel like you would feel OK being alone?

P: What do you mean?

R: If you were to come on your own on the bus, or would you want somebody to be with you to support you?

P: Yeah, yeah.

R: Some support?

P: Hmm.

Although Simon has recently started to live independently in his own flat and feels good about this, he still both lacks and desires a greater involvement in the local community. Although this move to living alone has fulfilled one of his wishes, the desire for increased access to the world is unachieved. Further to this, he now lives around the corner from his girlfriend but is neither able to visit her nor have her visit him. It seems that he is in an isolated position from both friends and the wider community by living alone. Although Simon wanted to live independently, the goal of 'living in the community' and the implied social benefits as detailed in Valuing People Now (DoH 2009) seem unachieved as Simon is isolated, although he is understood to be achieving in relation to Valuing People Now objectives.

Observing Simon's situation calls the goal of living in the community, with its implied community involvement, into question. This is compounded when observing Ellan's situation. Ellan, choosing to reside in a residential home, illustrates the varied ways one can be part of a community as she explains that she 'loves it'. She also frequently refers to herself and the organisation as 'we' implying that she really feels a part of the organisation.

Ellan gets on well with the support workers as well as the other residents, and goes out often with her family, her boyfriend, or support workers. As discussed earlier, Ellan chose this way of living; she did have the opportunity to live more like Simon but declined. When comparing the two situations Ellan appears to have the most engagement with the wider community, yet she is living in an 'institution'.

The above examples call into question both our understanding of community as well as the need for a particularist approach in relation to the citizenship of PWLD. In relation to community, Simon would appear to be fulfilling the government objective of community integration, however, Ellan clearly feels a greater sense of community in the way that she lives, in addition to engaging with the community in the normative sense as she goes out far more than Simon is able to do despite living in an institution and having physical impairments that Simon does not. In reference to the need for a particularist conception of citizenship for PWLD, an adherence to a difference-centred approach would mean Ellan's situation would be understood in relation to its own merits and her happiness, rather than set criteria. In this sense,

a person would have the right to live life in a way that differs from the 'normal' way, yet still be valued equally (Moosa-Mitha, 2005; Yuval-Davis, 2006).

With reference to community care setting and institutions, Digby (1996) discusses the flaws in assuming that because a person lives amongst the wider community, rather than in a residential home, that integration and community involvement will occur. Digby states that before this is able to happen, perceptions of PWLD must alter. It seems sensible to extend this point when thinking about the involvement of PWLD in the wider community; even if resources allow, barriers to participation will arguably continue in the form of expectations and assumptions made about PWLD. It is assumed here that, such perceptions are facilitated by government ideology which, whilst seeming to seek to make positive contributions to the lives of PWLD, is underpinned by universalist and neoliberal citizenship understandings that seem to contribute to the further marginalisation of PWLD (Lewis, 1998; Turner, 1997; Oldman, 2003; Gilbert et al., 2005; Vorhaus, 2005; Redley and Weinberg, 2007; Fisher, 2011; Hale, 2011,). This promotion of accepted knowledge – for example, expectations of a person working or somehow 'contributing' to the local community – when unachieved can serve to stigmatise individuals (Turner 1997; Redley and Weinberg 2007).

Tia is illustrative of one of only a small number of participants who, whilst conscious of potential dangers, is sociable and seemingly ready to engage with people in her community. She has a mild learning disability and her narrative, as reflected upon throughout this analysis, illustrates her having confidently pushed the boundaries on many occasions in order that she live her life the way she chooses. Tia seems to gain strength from achieving self-government. Desirable ways to live are sought via what she referred to as 'manipulative' and 'sneaky' means, as these are viewed as the only way to achieve her goals of autonomy and inclusion in the way that she desires. Examples of this include, as discussed in the previous chapter, her twice creating ways in which she was able to live in the accommodation of her choosing. I wonder, in relation to participating in society, does that Tia feels she has to manipulate the various systems and employ such tactics create a feeling of exclusion from society because she is aware that other people without learning disabilities do not have to do this in the same way.

Together, Tia and Hannah do lots of things that take them into their local and wider communities. They are close friends and attend a book club, a walking group, and healthy eating classes together. Hannah wants to lose weight and attends the classes to get new ideas

about what to eat, whilst Tia is diabetic and attends in order to learn new recipes that she can safely eat:

> *Tia is very aware of her diabetes and carries food around with her to control it. She also manages this by altering her meals so she does not upset her blood sugars. Her neighbour is also going to show her how to make diabetic bread, which Tia understands will be drier than normal bread but it will be better for her so she would like to start making it. To help her with creating other meals she has also started attending a cookery class…*

Hannah has a busy schedule, whereby she is often out of the house in the local community. It was not always the case that Hannah was able to do so many things independently within her community. She used to be quite shy and would like her mum to go places with her and speak on her behalf. This has now changed which has had a lasting positive impact on Hannah:

> *R: You sound like you do loads on your own.*
> *P: Yeah. [Laughs]*
> *R: Always at a group or something.*
> *P: Erm, like, erm, I've been on a course just to get my confidence up a bit more.*
> *R: Oh, right.*
> *P: So, I've got a bit more confidence to go ask for stuff now. Like the childcare course, I did that on my own. Which was...nerve wracking at first!*
> *R: Yeah.*
> *P: But then once I'd given my CV in and stuff I thought, well I've done it now so... [Laughs] Yeah, instead of having to ask my mum all the time to ask for things!*
> *M: I used to have to go with her and say, ''you ask for it!''. But now she can do it herself. [Laughs]*
> *P: So I can like, like, I can like go into shops now and ask for stuff, like, ''have you got so-and-so'', instead of asking my mum! [Laughs]*
> *R: Yeah.*
> *P: Cos at one time I used to say, ''mum can you ask for so-and-so'', but now -*
> *M: I think it's 'cos she didn't know how to word it.*
> *R: Hmm.*
> *P: And now it's like I'll just go and do it on my own. [Laughs]*

R: Yeah. Like you used to go one the bus with her, and then you could go on your own, like it was gradual.

M: Yeah.

P: Yeah. ... So I've got more independence to, like, do it now than not do it. [Laughs]

R: Yeah.

P: Like not hold back, just go and ask and they can only say yes or no! [Laughs]

R: Yeah.

M: That's what I used to say, I'd say they can only say yes or no!

P: [Laughs]

R: Yeah. It's different once you've done something like that isn't it?

P: Yeah, it's fine and you think, yeah, I can do it again now! [Laughs]

R: Like proud.

P: Yeah.

R: Yeah.

P: And I don't have to ask my mum to come out with me to go and ask, and she can just, like, stay at home and do her own thing.

M: I used to try to get her ask for herself, but she wasn't always that confident to ask. But when she goes on these courses I know that she's got to do it herself anyway.

R: Hmm.

P: [Laughs] Yeah, and so then she can, like, just go and do what she wants and I can just go and ask myself for stuff.

In contrast to Tia and Hannah who seem to make their own decisions in terms of their engagement with the wider community, the majority of the participants' participation in society is mediated by those involved in their care and support. Chloe is an example of this:

On a weekend Chloe goes out on one to one sessions, where it is just her and a support worker. She prefers this to being in a group because she has more of a say in what happens.

R: What do you do on an evening and on a weekend?

P: I go out, I go out on a weekend.

R: Oh, Do you? Where do you go?

P: Town.

R: Is that with staff from your house?

P: Yes. And I go out on one to one.

R: Oh, one to one?

P: Yes.

R Do you prefer one to one or groups?

P: One to one.

R: Yeah.

Chloe can only have this support on a weekend because a lack of resources means one to one sessions cannot happen as regularly as an individual may wish. Self-determination is denied due to resources as Chloe needs – and also wants – to be supported at all times when she is not at home, but cannot have the one to one support that she desires. It seems that Chloe's participation, and therefore feelings of inclusion, in family, community and social life is restricted by a lack of resources.

How far a lack of inclusion is a consequence of a lack of resources alone is debatable as policy and perceptions play a prominent role in the marginalisation of PWLD (Pakulski, 1997; Goodley, 2000; Simon, 2001; Stevenson, 2001; Fraser, 2005; Bollard, 2009). However, perceptions and resources can be seen to be two overlapping issues as market-driven politics, which have been seen to result in certain groups being under-resourced by way of the amount of monetary support received and the opportunities for them to take part in employment, have the potential to undermine perceptions of marginalised groups (Fraser, 2008; Somers, 2008). Somers gives the example of the consequences of Hurricane Katrina in 2005, stating the tragedy started decades before the floods when the future victims were viewed through a lens of 'personal blame and…dependent immorality' (p. 11). Somers notes that they could not afford to remove themselves from the situation; this position was then explained by way of pathology and therefore the consequences fell not only on the shoulders of government but on the individuals.

As such, the competitive dialogue of neoliberal economics has been understood to create a narrative whereby individual competitiveness is valued, working against the general acceptance of those who do not fulfil this expectation and succeed in the valued manner (Stevenson, 2001). So too can the participation and inclusion of PWLD be viewed in this light. As discussed in earlier chapters, there has been a visible shift from care to support for PWLD (Gilbert et al., 2005). The previously noted positive consequences of this are evident as PWLD are afforded greater rights, there is a focus on quality of life and policies are inclusive of PWLD

(Race, 1999; Walmsley and Jamesson 2003), however, if a person does not participate in society in the valued ways – ways which are sign-posted in policies (DoH, 2001, DoH, 2009) – and go against the assumed market orientated responsibilities of all individuals, there is potential for perceptions and therefore the inclusion of PWLD, to be negatively affected.

The majority of the participants involved in my research do not adhere to the expectations referred to above in relation to employment, with the majority having never been in paid employment. Employment has been noted in government policy (DoH, 2009) as a key way in which PWLD can feel a part of the wider community. Nor do the majority have an involvement in the wider community that would reflect an involvement similar to a person who does not have a learning disability. VPN (DoH, 2009) refers to the loneliness experienced by PWLD, stating that this is due to their exclusion from the community, listing workplace exclusion first followed by education, clubs, places of worship, and leisure centres.

Tia and Hannah, were exceptions to the above lack of community involvement as they both engage in many activities of their choosing on an almost daily basis. They both seem both willing and able to access their local communities in the same ways that those who do not have a learning disability are able to, whereas Chloe, like many others involved in the research, is restricted to the degree which she is able to participate in the world beyond the confines of the institution in which she lives and the general institution responsible for the care and support of PWLD.

The PWLD involved in my study, others within the organisation, and PWLD generally are encouraged to take part in paid and voluntary employment where possible and where resources and opportunities exist. Chloe, Katherine and Ellan have all volunteered in the café at the day centre. This was set up in order that people are able to get experience in the workplace as well as engage with the wider community. Working as a support worker within such an organisation, I witnessed a clear drive towards enabling people to work both on a voluntary and paid basis. Five of the interviewees had at one time worked in a voluntary capacity, and four in a paid capacity. I actually started working for the organisation in a role of which the purpose was to train and facilitate the creation of a café at a day centre whereby PWLD could gain experience in a workplace setting and work towards a qualification that may help them when seeking employment.

6.6 Conclusion

This chapter illustrated the experiences and understandings held by the participants in relation to participation and inclusion, considering these across four areas of life: (1) family; (2) school; (3) work; and (4) community. The present and the previous chapter overlap in many respects as the amount of autonomy a person has relates directly not only to how far they participate in society, but how far they feel a sense of inclusion. The feeling of inclusion seemed to arise from participation in a *chosen* area. Examples within this chapter have illustrated that there is no ideal in terms of how far the participants participated in society, but rather that a sense of being in control and making your own choices in relation to this resulted in the participants feeling satisfied, with the feeling of true inclusion rather than just going through the motions of participation.

In terms of family life, there is a link apparent in the data between feelings of participation and inclusion in relation to how far many of the individuals feel they have a say in this participation, with many feeling a sense of exclusion from their families and a lack of power to change this.

Secondly, and in contrast, although the majority of participants did not attend mainstream schools, they did not feel a sense of exclusion and none reported a desire to be included in this way. This is even more interesting when we reflect on government initiatives as this is considered a key portal in relation to inclusion within society.

Thirdly, the PWLD involved in my study, as well as others within the organisation and PWLD generally, are encouraged to take part in paid and voluntary employment where possible and where resources and opportunities exist. Several of the participants had worked in a paid as well as voluntarily positions, however, there were also those who wished to work or volunteer but were unable to acquire a position. As discussed throughout the chapter, the redefinition of PWLD as capable of making choices and being independent, which then sees them framed as active consumers with responsibilities, is potentially problematic as if people do not wish to work, or are not able to, they may be viewed as deviant.

Finally, in terms of taking part in and feeling a sense of inclusion in the community, as you might expect, participants who needed greater support were less likely to participate in the local community than those who did not need this support. Many of the participants voiced desires in terms of participation in areas which can be termed community, with a lack of resources, mainly inability to have one to one support, noted as the key barrier here. Discussions in this

area brought me to question the way in which community is understood by the participants in comparison to what is valued in policy. For example, living in a residential home for some participants was seen to offer a greater sense of community than those individuals had who were living 'independently' in the wider community. The data indicates that that a sense of inclusion could be facilitated by greater resources being available in order to allow people not only to live in the wider community, but participate in ways which they value and desire.

I have used theories of citizenship as a lens through which to analyse and question the data in relation to the autonomy and inclusion of PWLD. Based on the data and the aims of the research, I have observed how PWLD may possess the same citizenship rights all others in society but this does not result in inclusion as their particular needs are not necessarily addressed; as such I contemplate the type of citizenship that would be best suited to PWLD. In direct relation to this, I have considered how the framing of PWLD as capable citizen consumers, with both rights and responsibilities in relation to normative neoliberal values, may result in an individual being viewed as deviant when they do not achieve to a certain standard. In relation to the identified resource related issues, I found this to be a key facilitator or – as was frequently the case – inhibitor of both a sense of autonomy and a sense of inclusion.

Chapter 7: Redistribution, Recognition, Representation

7.1 Introduction

The two previous analysis chapters have analysed several interrelated issues in relation to the data. In the first analysis chapter, I illustrated findings in relation to independence and autonomy; here I observe how independent people were in terms of the normative assumptions of independence, as evidenced in various policy documents in relation to PWLD (DoH, 2001; DoH, 2009). I found the participants placed a greater emphasis on a sense of autonomy, rather than the 'doing' of independence; having the power to choose the life they wished to lead was valued. For example, this may have been a stereotypically 'independent' one or one that was less so but was of value to them. The key concern and desire here was real choice and control.

In the second analysis chapter, I illustrated findings in relation to participation and inclusion; here I observed how far the PWLD involved in the research participated in the world in terms of normative assumptions of participation. As discussed within this chapter, I found that participation in society was to differing degrees; however, this participation did not necessarily encompass a sense of inclusion. In turn, a sense of inclusion did not lead to participating in society in normative ways, but rather was dependent upon whether an individual had experienced choice and autonomy in relation to this. All feelings here were dependent on choice; agency was an overarching priority.

I felt deeply saddened many times throughout the research process by issues I had previously encountered and had seemingly become somewhat hardened to working as a support worker. This happened again when I went back to the data some time later – I had not looked at the interviews for some time, and it was quite emotional reading over it when I was so removed from both it and the participants, having not worked at the organisation for some years now.

Chloe's inability to acquire a far from elusive object such as a mobile phone seems for me a symbol of a deep and very real divide between many people who do not have and people who do have learning disabilities. A mobile phone may read as a trivial issue when compared to other resource related issues suffered by the participants, such as being unable to go out when they choose, not being able to live where they would like, and wishing to be able to enter the valued arena of paid employment like others who do not have learning disabilities. The list could continue. However, Chloe lacking a mobile phone because she did not have the money

was hard-hitting and symbolic because of the insignificance of this purchase to so many others. Chloe's circumstances do not seem likely to ever change in order to permit this. This seems unreasonable at the very least. Following Fraser's (2012) premise that injustice is a process of negation, whereby we identify injustice, rather than define justice, it seems wrong that an individual is unable to acquire a mobile phone as a result of having a learning disability.

When observing the data it seems that there should be prompt address of resource related issues because here is an area where greater resources could quickly facilitate the improvement of the participant's wellbeing. Following Fraser (2003, 2010), I shall discuss this in relation to the participants in an effort to highlight the effect on PWLD, supporting Fraser's premise that this be considered and addressed independently as well as in relation to the other issues of exclusion. These considerations come at a time when government cuts are acutely affecting disability claimants (Kaye et al., 2012; Beatty and Fothergill, 2013; Glasby, 2017), adding to the inequality and difficulties suffered by the participants here, whose marginalisation was found affected by a lack of economic resources. In terms of recent cuts, the 2016 budget (HM Treasury, 2016) saw a reduction of £4.4 billion to social care, followed in the 2017 (HM Treasury, 2017) budget by the promise of £2 billion for social care to be released over a 3 year period. Dan Scorer (2017), Head of Policy at Mencap, whilst welcoming this pledge and the recognition of the crisis facing social care, stated that this is not enough to improve lives. Such concerns regarding resources and a lack of funding for PWLD run alongside this group having the lowest employment rate when compared to other groups in society; in 2009 (DoH, 2009) less than 10% of PWLD were in paid employment (the majority only working a few hours per week). More recent estimates find this has fallen to 6% – this is in comparison to the UK population average of 74.5% in work (PHE, 2016).

Therefore, this third chapter will centre on Fraser's theory of social justice in relation to her three dimensional framework, with a focus on redistribution as an essential element. In responses to critics, and proponents of solely one of these three dimensions (i.e. Honneth, 2003), Fraser maintains that to think in such monistic terms in the present era is a 'false antithesis' (2003 p 9), recommending that the three be incorporated into one normative theory of justice (2010). In relation to the data, I look at how aspects of Fraser's work, as well as others working within this field, is useful when discussing the position of the participants; the direct results of a lack of access to material resources being the main point of discussion here. I will reflect upon what the PWLD involved in this research can tell us about recognition based

theories. This chapter does not discount the recognition/identity based theories covered previously, but instead sees recognition as part of a larger whole which encompasses redistribution as an equal factor that must be observed in its own right – arguably, a capitalist society cannot do otherwise (Fraser, 2003).

7.2 Fraser' social justice

In line with the data, and following on from reflections previously, the lack of access to material resources faced by the PWLD involved in the research is understood to be a key issue in terms of general wellbeing, as examples of the data later will illustrate, indicating the necessity to include materialist reflections.

In the previous two analysis chapters, I have drawn heavily on the works of cultural rights and difference centred theorists (i.e. Pakulski, 1997; Moosa-Mitha, 2005; Lister, 2007; 2009; Pfister, 2012), thinking about how far the PWLD involved in my research feel included in society, how autonomous they feel they are, what they value, and what they expect from society. What people value leads on to a discussion of justice, and what a person should expect from a society in whereby much of their lives are out of their control. For example, a person may participate in certain aspects of society, but feel a sense of exclusion based on their lack of access to other areas; or they may experience independence in the normative sense, but lack feelings of autonomy because such independent actions do not come with a sense of choice or self-government. This 'doing' participation and independence has been described as 'tokenistic' (Aspis, 2000; Walmsley and Jamesson, 2003).

It is because of this need to address economic structural concerns that I am aligned with Nancy Fraser's (2003, 2010) understanding of social justice, which encompasses three distinct yet interrelated concepts: (1) maldistribution, (2) misrecognition, and (3) misrepresentation. Fraser (2010) describes her theorising of society as 'Zeitdiagnose'; she aims to capture how society 'is' and relate this to how it 'ought' to be. Although Fraser largely neglects disability in her writings, her conception of justice is a useful tool when discussing disabled people and justice (Lister, 2003). Fraser (2012) encourages us to think of justice in terms of negation, rather than in terms of a definitive concept. She explains:

> …we do not need to know what justice is in order to know when something is wrong.
> What we need, rather, is to sharpen our sense of injustice, to cut through obfuscation

and ideology…activate the concept of justice, redeem it from the realm of abstraction, concretize it, enrich it and make it fruitful for this world. (p. 50)

Fraser goes on to advise that in relation to this we must be aware of the framing of some individuals or groups as essentially different to others in order that we are able to see the injustice as it is. Linked to this, and as discussed earlier, the framing of individuals as less moral than others, whereby structural issues are presented as individual issues, should not be tolerated, as this is creating a divide, 'misframing' individuals, and moving them away from considerations of justice and towards the familiar 'rights and responsibilities' agenda whereby rights are seemingly reserved for those who fulfil their 'responsibilities'. This seems to be the position of PWLD. As detailed in Chapter 3: Citizenship and Social Justice, misframing adds a further dimension to our theorising of citizenship and marginalisation as it allows for a discussion of how people are viewed within society; not just in relation to their formal rights but how expectations in relation to valued norms results in some people being overlooked in terms of justice. I use the concept of misframing when looking at the data as it seems that many of the participants represent a group of people who are addressed within policy and have services provided in order that their care and support needs are met, but they are restricted as a result of being unable to contribute economically within a society that expects citizens to do so as a matter of course. Such 'contractual transgressors' (Somers, 2008) are then unable to acquire and live in ways others who fulfil their duties do.

Fraser (2012) understands injustice to be 'a matter of objective victimization, a structural relation in which some exploit others and deny them the moral standing as subjects of justice' (p. 45). She notes the compounding affect when the exploited group are unable to interpret their situation as such. This resonates with the position of the PWLD involved in this research; my participants often seemed accepting of their situation, if unhappy in many respects, they did not interpret their position as unjust. This is a noteworthy point because it follows that if a person does not know that they are being treated in an unjust manner, it will therefore be unlikely that they will seek changes to their situation even if they are unhappy (Fraser, 2012).

In relation to the 'voice' of participants, it is often said that speaking on behalf of a marginalised group, such as PWLD who have little voice, is detrimental to the cause of empowerment and that individuals should be supported to voice their own positions (Gilbert, 2004). I detailed my position in relation to emancipatory and participatory research, whereby research participants control the research process or play a greater part in it, in detail within the Methodology chapter

where I explained why I do not aspire to carry out such research here. Whilst employing the narrative approach is useful in order to give voice to the participants (Lesseliers et al., 2009), it is also a methodology which places great importance on the researcher's interpretations (Silverman, 2010).

There are organisations, such as People First, whose aim is to allow PWLD to make a stand for the issues that they view as relevant to their lives. However, this does not, in my view, remedy the issue of some of my participants, who are seemingly unable to see an alternative to the situation in which they are unhappy, and therefore it seems unlikely that they will make a stand against it. I see it as a necessary step between understandings of what the participants desire, and making recommendations in order that lives can be improved, that I think about the choices the participants feel they have. The finding that participants desired control over their lives and the opportunity make choices that others currently often made for them led to me contemplate the options they were choosing from.

Fraser's (2012) understanding that some individuals and groups may be 'misrepresented', leading to their being overlooked in terms of justice, and structurally placed outside of the realms in which they would be considered for such, is useful here. Fraser explains the two ways in which she identifies social injustice taking place as: (1) by deliberate manipulation, whereby the injustice is understood by the perpetrators but is hidden from the exploited. It is not difficult to hide this from PWLD who are often institutionalised to some degree. I do not claim that the voice of the participants should be overlooked but a focus on this here may detract from highlighting the problems with giving people 'choice' when the options are limited. Fraser critiques the 'narrative turn' for eclipsing materialist concerns; in a similar vein, I think a focus on 'voice' and 'choice' has the potential to have the same effect on justice. And (2) in more subtle ways whereby

> …the public sphere in a seemingly democratic society is dominated by individualizing, victim-blaming discourses, while structural perspectives are absent or marginalized. (p. 45)

This latter understanding is evident in that government policy as discussed earlier in relation to framing the worthy citizen as one who participates in normative, market orientated behaviour (Gilbert et al, 2005; Redley and Weinberg, 2007; Chappell and Gifford, 2011). VPN (DoH,

2009) for example, whilst advocating choice and control for PWLD, focusses on ways in which people can access education and employment.

7.3 Redistribution and recognition

The findings illustrate that the experience of a lack of disposable resources is 'an impediment to parity of participation in social life' (Fraser, 2000 p. 5). This came in two main forms: (1) the participants were unable to acquire – or have any prospect of acquiring in the future – things that are arguably more accessible to those who do not have learning disabilities; (2) a lack of material resources had a direct impact on the support the participants received – this lack of support then served to exclude individuals from participation in various respects, such as being able to leave the house and meet with friends.

Resonating with Somers's (2008) understanding of a society controlled by market fundamentalist ideology, Gilbert et al. (2005) conducted research with those providing services for disabled people, finding opportunities for participation in society to be framed in consumerist terms; the respondents citing money as a gateway to participation by PWLD. This was echoed within my data as participants discussed instances where certain desires were constrained by resources. For example, Gerald talked about how he no longer drinks alcohol:

P: Yeah. I don't drink it, don't mention beer, I don't drink the stuff, too expensive. I go out now and have a shandy.

R: Well you can still go out and see people can't you.

P: Or a coke.

R: Yeah. Would you say, do you go to, you know how you come here? Where else do you go?

P: Nowhere else, I just come here.

R: Do you go to the pub though if you do go out?

P: No, Yeah, sometimes, I do at Christmas.

R: Yeah.

…

P: I got drunk here didn't I? (laughs) With (name – support worker). We fell down the steps here, me and (name – support worker).

R: Last Christmas?

P: Last Christmas, yeah. We got drunk. They had a do on didn't they?

R: And the one before.

P: Eh?

R: And the one before?

P: Yeah, I've been drunk loads of times here. When (support worker name) has dos on. Sometimes he has dos on doesn't he?

R: Yeah.

P: Only £2 last year.

R: Was that at Christmas?

P: Yeah, a do, yeah. I got drunk there an' all (laughs). I'm always getting drunk.

R: But not anymore, eh?

P: No, can't afford it now, man. Too expensive. If I go in a pub I have a coke or an orange.

Gerald does not go anywhere other than the day centre, which he once attended five days per week, and was in the process of cutting this down as he says that it is too expensive to attend now. I remember a time when he would regularly come into the day centre on a morning and talk about how he had been to the pub the night before. I do not know exactly what has changed economically for Gerald but he no longer does this because he cannot afford. It seemed clear when he spoke of going to the pub and getting drunk that he missed doing this and often referred to being unable to go because he has less money now than he once did. Why Gerald should be denied that which he views as a pleasure was my immediate thought, and this question has remained with me throughout the research in relation to many of the participants. In terms of maldistribution, Fraser (2000) explains that some individuals 'lack the necessary resources to interact with others as peers' (p. 5) as Gerald now appears to. Even if we were to accept that distribution is derivative of recognition as Honneth (2003) asserts, and that the recognition of PWLD would result in greater value being placed on Gerald's wellbeing, resulting in both a change of status and finances for Gerald, it is difficult to believe that this would counter the socio-economic gap that has been recognised as increasing (Piketty, 2014). In the immediate Gerald is restricted because he does not have enough money which could be remedied by more immediate action: a fairer distribution of resources.

Furthermore, in terms of recognition/identity based theories, the issue of Chloe not being allowed a mobile phone may be remedied in time if PWLD were removed from a subordinate position in society, viewed as 'differently equal' and deserving of the artefacts that

'contributing' members of society often take for granted. This is in line with identity based theorists working in relation to 'cultural citizenship', 'inclusive citizenship' (Lister, 2007), and 'difference centred' models (Moosa-Mitha, 2005). As discussed in greater detail in previous chapters I do not discount the importance of such theorising for the lives of PWLD, but the data has lead me to believe that more immediate materialist changes would result in the participants being able to lead more fulfilling lives. Such redistributive measures which will see Chloe having a mobile phone before society's institutionalised cultural norms are replaced by ones that value individuals regardless of their economic contribution to society. This is an example of why following Fraser's premise that materialist concerns are essential to a discussion of social justice, instead of seeing them as a derivative of recognition is important for PWLD.

For Chloe, having a mobile phone and being able to contact her family would be more than just fair, it would allow her to feel more involved in her family as this is the reason she wishes to have one. When listening to the interview with Chloe, as well as others, Fraser's (2003) worry that identity based theories have displaced materialist concerns is pertinent and her premise that labour market values deprive some individuals of full participation resounds.

As discussed previously, Simon now lives alone in his own flat, with support workers visiting him on a morning and evening to help him make meals and take his medication. He attends the day centre Monday to Friday and has support on a weekend, when he also spends time with his family. As detailed in Chapter 6, Simon told me that he feels more independent now that he lives on his own and that he likes this feeling. However, he does wish that he could get out more as he needs to be accompanied by a support worker or family member and this is not always possible:

> P: Well...I want to get more and more, I want to get more and more involved.
> R: Right. What sort of things would you like to do?
> P: What we're doing now. This.
> R: Oh, OK.
> P: Hmm.
> R: With what we're doing here?
> P: Hmm.
> R: What other things would you like to do?
> P: Well. You know I'd like to go out more often, you know what I mean.

If Simon were able to access greater economic resources this would mean that he would be able to achieve this goal and, I assume, feel a sense of fulfilment from this. In terms of Fraser's (2003; 2012) theory of social justice, and in line with recognition based theorists (Pakulski, 1997; Simon, 2001; Honneth, 2003; Lister, 2003; Moosa-Mitha, 2005; Lister, 2007; Bollard, 2009), recognising that Simon should have this right is important. Lister (2007), for example, theorises about the possibilities of 'inclusive citizenship' whereby citizenship theory can be used as a tool to aid the cause of social justice as such contemporary citizenship studies interrogate the meaning of citizenship/membership by focussing on identity and recognition. Used in this way, and as noted in previous chapters, theories of citizenship allow us to contemplate how PWLD are excluded and how this can be remedied. The inclusion of Fraser's theory regarding maldistribution and misrepresentation allows me to contemplate both long and short-term remedies to the marginalisation and inequality suffered by the participants.

Resource related issues also appear to impact the care and support many of the participants receive. For example, due to a lack of places available at the local respite centre, Pam is unable to secure a place in order that her elderly mother can have a break from supporting her. The places at the respite centre are limited and therefore are located to people who have more severe learning disabilities than her. Pam and her family have been in contact with a support worker that may start to support Pam for a little while each week; this is not what they wanted but they have been forced to compromise:

> R: Hmm. Erm, I was just in the office and somebody was saying they're going to
> Cherry Trees this weekend. Have you ever been up there?
> P: I've been to have a look, but they said they can't take me cos I aren't bad enough.
> R: Right, OK, so did you go to have a look with your mum?
> P: Yeah.
> R: Yeah.
> P: Hmm.
> R: Have you looked at anywhere else?
> P: Well, I've got this, er, care worker at [place name].
> R: Oh, OK.
> P: Lorraine, they call her.
> R: And what does Lorraine do?

P: Not sure.

R: I mean, what does, what will she be doing with you?

P: Well, she hasn't got in touch yet.

R: Right.

P: So, I don't know.

R: Is it something like she'll be supporting you -

P: Yeah.

R: - when your mum isn't?

P: Yeah.

R: Have you met up with her and -

P: Oh yeah, I've met her.

R: How do you feel about having her to – well whatever she might be doing with you, supporting you.

P: I think it's good.

R: Yeah.

P: Yeah.

R: Like you mentioned your brother saying, erm, if he wasn't there your mum wouldn't get out, is the support worker to help with that?

P: I think so.

Somer's (2008) discussion of the 'contractualization of citizenship' (p. 44) whereby people are rewarded in relation to their ability to take part in income generating activities is pertinent here. If individuals were granted Somer's 'citizenship livelihood', which would be money granted to all, on a non means tested basis, inconsequential of paid employment, they would arguably be in a better position to hire the help they required. Pam and her mum would have a livelihood and would be better placed to arrange the support they needed. This would be an extreme alteration to the way in which society currently operates, with an individual's quality of life not being based on their economic contribution. Whilst in discussion of Marshall's understanding of citizenship, Pateman (1989, 2003, 2004) – a Basic Income proponent – observes that living standards should be separated from employment as there are not enough job opportunities for all the people who require them. This is compounded by the acknowledged impact of automation in reducing jobs (Somers, 2008; Brynjolfsson and McAfee, 2014). If machine increasingly substitutes for the human, Autor (2015) points out that the dilemma will not be scarcity as the machines employed would be able to outperform the

human they replaced, the dilemma would be how to decide entitlement to the wealth that is created by the machines.

The 'citizenship livelihood' or 'basic income' discussed by Pateman (2004) and Somers (2008), as detailed in Chapter 3: Citizenship and Social Justice, would be granted to all individuals in a society, on a non-means tested basis, with individuals in total control of how they used it. In relation to this final point, it has similarities with personal budgets where individuals in receipt of government support have control over their allocated money and are able to choose their own support and care providers. Although the Personalisation Agenda, which this is a part of, appears to be a positive step for PWLD, giving greater choice and control to individuals it is allocated on a means tested basis and does not to provide adequate money in order that individuals can direct their care in the best way (Slasberg et al., 2012). Slasberg et al. note:

> If and when adequate levels of funding are also provided, there may be the real prospect of enabling all to live their lives on the same terms as others who do not need social care support. (p. 161)

Whilst I support the scrutiny and deconstruction of the concept of independence, I also see the merit in a model that advocates the increasing of support in order that people able to lead more fulfilling lives. As such, the independent living and feminist ethics of care models are often used in opposition to one another (Shakespeare, 2000), with a choice of either/or, similarly to recognition and redistribution whereby some theorists believe one derives from the other (Honneth, 2003).

The concept of redistribution is seen here in relation to the independent living movement and personal budgets, as these would encompass practical measures by which the lives of PWLD would be improved in the immediate materially. Recognition based theories, including, Fraser's Status Model (2012) as well as identity-based understandings, link to the feminist ethics of care model. Both of these approaches aim to create structural and cultural changes in order that we speak a new language and alter our thinking in relation to the expectations we have of people in a society. The data exemplifies a society which values 'contributing' members over others is problematic for the participants. Valued contributions such as being in employment and being self-sufficient are goals that a person with a learning disability is unlikely to be able to achieve.

Pam's predicament in terms of her support was not an isolated case within the data, as Simon and Gerald illustrate. Tia is a further example of the constraining effect of resources on care and support. In previous chapters I have discussed the lengths to which Tia has had to go to in order that she receive the type of support that she feels she needs. Her current living situation is as a result of her having persuaded her doctor to advise that she live in accommodation usually reserved for people older than Tia, or for people with physical impairments, which Tia does not have. Previously, she has had to, in her words, 'manipulate' people, such as the doctor in this case, in order to be able to get her way.

Tia is seemingly quite adept at creating a life that she wants. It seems other participants are not as capable of doing this. Sarah, for example, would like very much to have a bedroom on the ground floor of the home in which she lives. Before my conversation with Sarah about this, she had spoken to me and other support staff about this on many occasions throughout my time working there:

> *R: And do you like it there?*
> *P: I do, yes. But there I've not got a bedroom downstairs because one day I might need one. When I get older.*
> *R: Yeah, you've worried about this before haven't you?*
> *P: I have, yes.*
> *R: But what have they said at home?*
> *P: I've been told from home it's up to the physios.*
> *R: Right.*
> *P: But I can't have one yet, until I need one, when my health gets worse. But now today, last Tuesday I was told that at the doctors I went to this month – last week – and guess what? I've been told that my eyes are deteriorating...now.*

Sarah has fallen on many occasions that I am aware of and have witnessed. She has said that she loses her balance, especially if someone startles her. It seems that when this happens it reignites her desire to have a bedroom on the ground floor but until she is assessed as requiring a bedroom on the ground floor, this is not possible. Thinking about this in relation to Fraser's theory of social justice, I can see that redistribution, recognition and representation could all be usefully employed here.

The one to one support which Pam will have for a short time is a rarity amongst the participants. Previously, I discussed Simon who lives independently but does not go out on his own very often as he would need to have a support worker with him. He explained that he would like to do more things on his own but cannot for this reason. This was echoed by Diane who would also like to do more things on her own, such as catch the bus to town and meet her friends, but again cannot because this would require the one to one support that resources deny her.

The support which is often required in order that people are able to go out and do things that individuals who are not disabled arguably take for granted, is limited by resources as well as the institutionalised Patterns of cultural value to which Fraser (2003; 2010) refers, whereby such circumstances are deemed acceptable because of the way PWLD are misframed and regarded as different from others. It seems that if all those who needed support were to have it in order to participate in activities others take for granted, for example, this would be less of a problem and would facilitate the participation of individuals in society, family life, social life, etc. This is an example of how maldistribution marginalises PWLD. If redistribution does not remedy status subordination (Honneth, 2003), it is difficult to argue that it would not immediately improve the lives of the participants.

I have discussed various examples of where the participants were restricted by resources that people without learning disabilities would arguably not be, or would have more of an opportunity to challenge/change. This lack of an opportunity to challenge is an important point in relation to Fraser's (2012) understanding of justice and sees PWLD's experience of injustice as especially acute. Fraser explains that we should not assume that because there is no obvious protest that injustice is not occurring as a person or a group may not be able to articulate their issues or interpret their experiences in a way that allows for this. This resonates with the participants involved in my research whereby there seems to be an acceptance of situations that they are clearly unhappy about.

Data in relation to Tia are further examples whereby a lack of protest does not mean a person is not experiencing injustice. As previously discussed, Tia had to manipulate the system in order to live in a place of her choosing. She persuaded her doctor to write a letter to say she needed a ground floor apartment as steps would be too difficult for her because this is what she preferred. Tia saw this as a great triumph and was proud of her ability to bring this about:

P: And then I got sneakier 'cos I wanted to be closer to my mum and they mentioned about this place. So I went "Yeah!" You're not supposed to move into this place until you're at least forty and I wasn't forty. They went: "The only way you can get into this place is if you get, if a Doctor thinks your legs is bad enough to move in here''. And I'm pestering my doctor every time I went up. I went "Oh I don't want to stay there". Someone tried getting in the back door when you go out and I caught this-

R: Did they, at Lawton Street as well?

P: Yeah I caught this Asian guy coming round the back and I thought "who is he?" and I went "hiya" not thinking of anything. This older Asian guy strolling away, he went "hiya" and he was trying to get in and that.

R: So is everybody here over forty?

P: Yeah so my doctor says "I'm not supposed to!" and he signs this piece of paper what got me into this place.

As a result of taking steps to ensure that on this occasion she moved into a place of her choosing where she felt comfortable, Tia has lived in her flat for a long time compared to other places that she has lived. In other places she has only stayed there for one birthday, but has spent several birthdays in her current flat – she is not sure how many exactly. Tia is very proactive it seems and as a result of having negative experiences in other places that she has lived decided it was necessary to take these 'sneaky' steps in order to secure her flat. Although admirable, and possibly a form of protest against a situation where she is provided with little choice, Tia does not appear to see the way she has been moved to places that she did not choose as wrong, but rather just how things are. This resonates with Fraser's (2012) warning that a person may not have the tools to articulate their issues, or view their situation as unjust; instead of seeing her actions as taking a stand against the injustice of being given little or no say in where she lives, with her lack of economic resources seemingly removing this right, Tia describing her actions as 'sneaky' seems to imply that she is doing something wrong. This is further articulated when she talks of having 'manipulated' staff in previous residential homes into giving her snacks. Rather than seeing making the choices to eat certain foods as her right, she appears to accept this as her doing something underhand.

Whilst many of the participants wish to work, the majority currently do not participate in paid employment and have never worked in either a paid or unpaid capacity; their capacity to earn a sufficient amount to meet their material needs is therefore limited. I have discussed the

participant's relationship to work previously, illustrating the different views and experiences in relation to this. PWLD are in a position whereby they are framed as capable within policy (DoH 2009, Gilbert et al 2005), but the opportunities for them to actually take up paid employment are limited with only 6% of PWLD in paid (in the main, part time) employment (PHE, 2016). Hannah, Chloe, Ellan, Katherine and Mark are all currently in voluntary jobs, with Mark also holding a job in a paid capacity, and Tia, Donald and Gerald, have worked in a paid capacity in the past. As we have seen, the participants who work voluntarily all wish to work in a paid capacity but are unable to find positions.

7.4 Conclusion

As the analysis progressed it became apparent that I failed to focus enough previously on resources as an underlying necessity in order that individuals could experience the autonomy and inclusion that were found to be desired. From Chloe being unable to have a mobile phone because of resources, to Hannah wishing, but being unable to, foresee a time when she would be able to move out of her family home and live on her own, the analyses illustrated the constraining effect of resources upon the participants' lives as an important and immediate concern which required address before anything else. This seems of greater significance because I/they cannot foresee a time when this will change.

That is not to discount the work of such theorists as discussed previously (i.e. Digby, 1996; Turner, 1997; Shakespeare, 2000; Redley and Weinberg, 2007; Gilbert and Powell, 2008) who are challenging the positioning of PWLD within a market-orientated world. Instead, I contemplate here how using elements of Fraser's (2000, 2003, 2008, 2010, 2012) conception of social justice whereby redistribution, recognition and representation are understood as separate as well as mutually reinforcing, as a helpful lens through which to contemplate the resource issues specifically, and build on these alternative citizenship models and critiques of a society dominated by neoliberal values.

The data therefore indicated a need for materialist understandings to take a lead role in contemplations of a type of citizenship appropriate for PWLD. Fraser's understanding of social justice as three separate and interrelated parts made sense for the data and the lives of PWLD. Further to this, her understanding that contemplations of social justice are a process of negation was useful in order to assess PWLD as both individuals and as a marginalised group; as the analysis illustrates, the individuals I interviewed led very different lives, at the same time as having many issues in common.

The data indicates the necessity to include materialist theorising when contemplating the citizenship of PWLD. This is a discussion of true inclusion within society – for immediate improvement of the participant's lives it is not enough to change hearts and minds, to change the perceptions and understandings of PWLD; there are practicalities which are overlooked if this is all that is done. People should not be suffering because they lack the economic means to make their lives better in a society that demands a person must 'contribute' and have an amount of independence in order to be 'rewarded' with the material.

Chapter 8: Conclusion

8.1 Introduction

This thesis has explored the citizenship of a group of PWLD, observing perceptions and experiences in relation to the hegemonic neoliberal settlement that has been identified in contemporary society. Employing citizenship theory as a lens through which to contemplate the inclusion of PWLD revealed its flaws as a facilitator of inclusion, marking it instead as potentially aiding the exclusion of those who are unable to meet neoliberal expectations. In seeking to contribute to the development of a citizenship theory that can help facilitate the inclusion of PWLD, the research explored how far normative understandings of independence and inclusion were desired by the participants, alongside how far they were included in these terms.

In looking to citizenship theories and critiques, discussions ensued with regards citizenships potential to both include and exclude members of a society that are subject to the same rights. These discussions incorporated theories which advance the need for more than universal rights, but rather, the need for a focus on the position of an individual or a group because 'having' rights is separate to the rights being felt or implemented. This application of citizenship theory revealed the flaws of current understandings of citizenship when applied to marginalised individuals, leading to contemplations of what a citizenship theory in relation to PWLD would entail. Differentiated forms of citizenship have been developed by theorists who are also interrogating citizenship's promise of inclusion (Pakulski, 1997; Stevenson, 2001; Isin and Turner, 2002; Moosa-Mitha, 2005; Yuval-Davis, 2006; Turner, 2007), arguing that more than formal rights are required. Observing the position of marginalised groups illustrates citizenship failing in its universal promise as well as highlighting the need for more than the granting of rights but measures to facilitate their implementation. These theorists have therefore suggested ways in which citizenship theory can be adjusted in order to offer greater inclusion. Such alterations centre on recognition and identity based solutions. For example the removal of institutional disrespect within society in order that marginalised groups are recognised as equals alongside others. A further example being positive representations of stigmatized groups such as asylum seekers and young, single mothers. These efforts are discussed alongside questioning the normative understandings upon which such institutional disrespect and negative stereotypes are created. The research led me to ask,

how can PWLD be valued citizens when normative understandings centre on that which the majority of the participants will never be able to achieve or do not desire?

Such interrogations of citizenships inclusionary and exclusionary potential fuelled the research. As many researchers have done before, I questioned how far dominant citizenship discourses potentially further exclude those who are unable or somehow blocked from being able to fulfil their perceived responsibilities as citizens. Previous research in this area is minimal in relation to PWLD who are often left out of citizenship theorising. When citizenship is employed in the analysis of the inclusion of PWLD, the exclusionary potential is highlighted. The research here sought to understand the ways in which people were excluded, as well as an understanding of the value placed on normative notions of citizenship.

8.2 Chapter overview

This final chapter draws the research together, summarising the main findings, the contribution the research has made, the limitations of the research, and recommendations for future research. The following section discusses the aims and the main findings, bringing these together into a general discussion of the implications in relation to citizenship theory and the possibilities for citizenship as an inclusionary tool in relation to PWLD specifically. I ask here, how PWLD can experience inclusion in a society whereby citizenship is predicated on values such as self-sufficiency, normative independence and contributing economically to society? This is followed by considerations of the research contributions. These are broken down into the (1) empirical; (2) theoretical; (3) philosophical; and (4) methodological contributions made by the research. The limitations of the research are then detailed. These are in relation to methods and methodological approach employed. Finally, in light of the findings, contribution to knowledge and identified limitations of the research, the final two sections make recommendations as to the course of future research and theorising.

8.3 Main findings

The research aims of this thesis were to: (1) Develop an understanding of participant's perceptions and experiences of 'independence' and 'inclusion' as normatively understood; (2) Contribute to the development of a citizenship theory in relation to PWLD; and (3) Explore the necessary changes indicated by the empirical research to support the inclusion of PWLD in society.

In relation to the first aim, normative citizenship values were challenged by the research. I found that the participants did not value the carrying out of independence and inclusion in the normative sense, instead valuing and desiring that which followed from a sense of autonomy. This sense of autonomy – being allowed to make decisions in relation your own life – was juxtaposed against independence within the analysis because I found that when the participants spoke of independence, much of the time they were referring to the ability to direct their lives. This is in contrast to understandings of normative independence which place value on the 'doing' of independence. In relation to developing an understanding of inclusion, this was juxtaposed against participation within the analysis as I found that the participants generally valued the feeling of inclusion but not necessarily the act of participation in the normative sense. The feelings of autonomy and inclusion were of more importance to the participants than normative acts of independence and participation. Where these acts were valued, they were preceded by a sense of autonomy – the participants valued the choice to engage, rather than being directed to do so by support services or family. Although choice is detailed as a goal within government policy, market driven goals appear to dominate the definition of valued ways of living.

PWLD, as the group experiencing the lowest employment rate, suffer acutely in terms of economic disparities (PHE, 2016). The economic position of this group are affected by the present political climate. The findings here further indicating the contribution a lack of resources plays in the lives of PWLD. Such resource related barriers to participation are compounded by a recognised neoliberal settlement which values the productive, self-managing individual, as well as by the hegemonic discourses which frame PWLD as capable members of society. In combination these factors serve to further exclude PWLD as well as possibly rendering individuals as failures when apparent opportunities for normative participation are not successfully used (Gilbert et al., 2005; Vorhaus, 2005; Redley and Weinberg, 2007; Goodley, 2016). A person that does not contribute within such a neoliberal settlement are then seen to be deserving of their position.

The specific findings here indicate that the participants do not necessarily value normative understandings in terms of inclusion and independence. In terms of these normative notions, the participants faced resource related impediments to normative citizenship participation. It does not seem like enough to challenge attitudes, to represent PWLD positively, to recognise and include difference. These are positive and seemingly necessary, but the data here

facilitated contemplation of a broader dilemma that seemed related specifically to resources. Money would help the participants in terms of their wellbeing, it would make them happier. Importantly, it would not be the 'having' in the literal sense, but the doors that having greater resources would open, what it would allow the individuals to do with their lives. For example, having a mobile phone, and being able to access to one to one support in order that they are able to better direct their lives. These choices were evidenced to centre not on extravagant activities but what may be understood as the everyday, the mundane; going to town, visiting their family, visiting friends, *making* friends, buying a mobile phone in order to contact family when they chose.

The research here has therefore added to a theoretical discussion of normative understandings of citizenship, highlighting the need to address representation, recognition and redistribution as separate concerns when thinking about inclusion. Interrogating the citizenship of a group of PWLD has illustrated this necessity as resource related issues were found to be a key concern for those involved in the research. The promises of universal citizenship, alongside normative citizenship expectations are not making PWLD's lives better, but nor, it seems, would differentiated citizenship based on these same normative ideals as these were not found to be valued by the participants. PWLD neither wholly desire them nor have access to the potential to achieve them if they did value them. In terms of recognition, difference appears to require representation and redistribution before the value of recognition can be realised.

The empirical and theoretical research indicates the necessity to address resource related issues in order that the participants are able to live in ways they value. Resources were identified as a baseline from which considerations of recognition – incorporating autonomy – could follow. Following Fraser's (2003) contemplations of citizenship in relation to social justice, I found that for PWLD, the lack of access to resources cannot be overlooked. It is not possible to begin a discussion of issues in relation to identity or recognition in isolation when the effects of economic disparity are so apparent amongst all of the participants. PWLD are not alone as a group suffering this, however, the lives of this group of individuals are affected uniquely in that they have little control or opportunity to change their situation if they wish. They are both limited in their capacity to change their situation in relation to their economic position within labour markets and excluded because of their lack pf participation within it. This exclusion is understood to be to be validated by a neoliberal social settlement whereby

those who do not contribute - 'contractual transgressors' (Somers, 2008) – are seen to be not fulfilling their obligations as citizens, and as a consequence deserve their position. Citizenship when aligned with neoliberal values is a problematic concept because a member of society should be independent in the normative sense and fulfil obligations to contribute to society in economic ways.

Findings in relation to resources ran alongside the need to address issues of representation and recognition – for example, the misrepresentation of groups (which render them overlooked), and institutionalised disrespect (negative stereotypes). My understanding that there exists a hegemonic neoliberal settlement means I believe that more than an increase in funding for individuals and services provided for PWLD is necessary to remedy this. It is about the questioning of normative assumptions which have come to dominate understandings. Whilst such suggestions require further research and conceptualisation, issues of recognition and representation seem likely to continue whilst a neoliberal social settlement leaves PWLD in a position where they are not valued as a result of their lack of economic contribution.

In relation to the second aim of contributing to the development of a citizenship theory in relation to PWLD, the relationship between citizenship and disability studies more often sees the incorporation of theories of citizenship by disability theorists, rather than disability being discussed within broader contemplations of citizenship. Alongside theorists advancing the rights of other marginalised groups, disability theorists have employed citizenship with the goal of highlighting the disparities between rights being held by an individual and these rights being accorded and felt in practice. Having rights therefore does not necessarily lead to feelings of inclusion or autonomy. Viewing the participants through the lens of citizenship has illustrated the injustice of this concept in its current understanding.

As such, Fraser's justice as negation is found to be useful when contemplating the citizenship of PWLD, instead of defining justice and applying this to individual positions, or adapting citizenship rights in order that marginalised groups are offered greater inclusion, identifying injustice seems a more plausible way to address exclusion and marginalisation. This will then lead to looking to the causes of exclusion, from which follows considerations of representation, recognition and redistribution.

The research indicated that although emancipating the voices and opinions of the participants, and making suggestions for change in relation to their specific circumstances and desires was a goal of the research, many of the participants were unaware of the potential choices they had, injustices they are subject to, and their right to protest against their situation. The injustices suffered by the participants in relation to a lack of resources and recognition is compounded by this inability of most to recognise that their situation is unjust or to know the alternative ways of living that may be possible. This observation adds to research that has questioned the goal of research that attempts to include PWLD, asking does it really seek to improve lives and does it go far enough in its efforts. Criticism centres on research being tokenistic or selfish – carried out in order to state that inclusion of PWLD has been sought and the individuals have exercised autonomy, or to gain opinions about service provision in order that improvements can be made, respectively. Such goals fail to address the issue of real choice and voice being facilitated. In relation to this, Fraser's discussion of a lack of protest by the marginalised should not be mistaken for justice being present:

> …we should not assume that the absence of explicit critique or overt protest means that injustice does not exist. We should understand, rather, that organized opposition to injustice depends on the availability of discursive resources and interpretative schemas that permit its articulation and open expression. (Fraser, 2012 p. 51)

This is an important point in relation to the current research. It struck me that whilst the participants would point out things they were unhappy about, there was a general 'absence of explicit critique or overt protest'. This was an important finding in relation to methodological implications as it questioned the usefulness of the more 'inclusive' emancipatory and participatory research methods which are revered for allowing the participants to either control the process or have a greater influence in the shaping of it. This will be discussed further in the research contribution section below.

The data illustrated a lack of overt protest at the position that the participants found themselves in in terms of a lack of resources and agency, whilst further finding the value placed on autonomy was paramount – above valuing 'doing' independent things. The feeling of directing their own lives and/or having choices. This can be seen not as a form of protest at the current situation, but it is seen as dislike for the current confines. Like autonomy, feelings of inclusion were valuable to the participants – regarded above 'doing' participation. That is, the feeling that they were included in something that they valued was more important than

carrying out participative acts. This valuing of a feeling of inclusion was often preceded by the need for an individual to feel that they had a sense of autonomy.

8.4 Research contributions

Firstly, whilst disability studies theorists have employed a citizenship lens in order to highlight the exclusion of disabled people, citizenship theorists have notably excluded disabled people, particularly PWLD, from their theoretical, and particularly empirical, research. This research conducted qualitative interviews with a group of PWLD, specifically in relation to their experiences and understandings of citizenship. I have contributed empirically and theoretically to a research area that has been noted to be theory heavy and exclusionary (Lister, 2007).

Secondly, whilst those theorising in relation to disability have incorporated citizenship theories within their research in order to highlight exclusion, it is rare that citizenship theorists include disabled people, particularly PWLD. Where citizenship theorising does include PWLD, it is more often within this broad category of disabled people and does not account for the particular needs of this group, instead attempting to find ways to allow PWLD to participate in the normative sense. By including PWLD in this research, I have contributed to the evaluation of citizenship, questioning its inclusionary potential. In relation to citizenship theory generally, applying the lens of citizenship to PWLD highlights flaws in relation to inclusion.

Thirdly, as a philosophical contribution, the research has added to a body of work that is returning to materialist considerations in relation to citizenship and social justice (Offe, 1996; Fraser, 2003; Somers, 2008). In theorising in relation to citizenship of PWLD, the research has questioned and critiqued the normative neoliberal assumptions of current citizenship understandings. It has asked how and why PWLD should be included, pointing to the need for materialist concerns to be uncoupled from the value of a citizen. This is an ideological and philosophical debate. In contemplating PWLD, current normative understandings of citizenship are understood to promote an ontology that is both damaging to those who do not achieve hegemonic goals, alongside not necessarily being valued by those being excluded as a result of a lack of adherence to these valued outcomes. The research contributes to a growing body of work that challenges this social settlement.

Finally, in relation to methodology I have contributed to a body of research which seeks to include PWLD as participants in research, recognising that this group as underrepresented in research both generally and in relation to issues which specifically affect their lives. This is an important contribution and I am pleased that the research was able to do this. This was compounded by the reactions of many of the participants when I asked them if they would like to take part in the research as individuals were generally pleasantly surprised to being invited to be part of the research.

This was often coupled with confusion as to what research was, what it would involve, and what they would have to do to be part of it. This led to issues being highlighted in relation to informed consent, as a continued lack of understanding meant it was necessary to take further steps in order that the research was conducted ethically. I have detailed this extensively in Chapter 4: Methodology and Methods. In terms of a research contribution, my experience of conducting informed consent as an ongoing process provides useful insights for informed consent generally, as well as in specific relation to instances where understanding and agreement are questioned.

Participatory and emancipatory research are revered in research with PWLD. It took some time to align my methodology and methods with my understandings of the position of PWLD in relation to their marginalisation and inclusion. Participatory and emancipatory research are often offered within research as inclusive methodologies, and their merit to the lives of PWLD is well evidenced. Indeed, within the present research the reactions to research being done 'on' the participants is testament to how the further step of the PWLD being in greater control of the research process would be potentially beneficial to the participants feelings of liberty, inclusion and autonomy. However, the aims of the research as well as, crucially, my understandings of the misrecognition and misrepresentation encountered by PWLD meant that I was not only interrogating the participant's understandings and experiences, but also using these to inform my understanding of normative understandings of citizenship and critiques of this.

In terms of the narrative methodology employed, the research contributes to a small body (e.g. Booth and Booth, 1996; Owens, 2007; Baldwin, 2008) of work which challenges the traditional exclusionary tendencies of narrative research with regards PWLD with its call for 'articulate subjects'. As detailed in Chapter 4: Methodology and Methods, the present

research sought pragmatic ways in which to facilitate the inclusion of the participants, reconfiguring the narrative approach in relation to the PWLD who took part in the research.

8.5 Limitations and future research

In relation to the aims of the research, whilst this thesis did fulfil the aim of contributing to its development, it does not offer a clear demonstration of a form of citizenship appropriate for PWLD. Based on research with 18 PWLD alongside normative theorising in relation to conceptions of justice, I have offered empirical findings and theorised as to how better to facilitate inclusion. Further research in relation to the research aims here would be carried out on a larger scale in order to better inform such contemplations. Secondly, I would suggest that research be carried out across more than the one organisation in order to gain a greater variety of experiences. Finally, in relation to the methods employed, it would be useful and ethically sound for further research to be carried out with people with more severe learning disabilities. People with more severe learning disabilities were explicitly excluded from the present research as I did not have the time nor resources to include people with greater communication issues in the research. This further research should look to learning disability communication aids in order to explore the possibilities for greater inclusion.

8.6 Final thoughts

Throughout the research process, and particularly in the beginning, I battled with the desire to make grand normative statements about how I thought society should be, statements in relation to social justice and conceptions of citizenship. Incorporating Fraser's justice as a process of negation occurred to me as a valuable strategy and a useful lens through which research can assess citizenship. In terms of the positions of the participants in the present research, instead of seeking to make claims as to how things should be, it was empirically and theoretically manageable to instead identify how things should not be. The data from interviews with the individuals combined with my understandings of their position therefore found that the participant's citizenship was impeded by economic barriers and this should not be the case.

This research therefore supports the understanding that the creation of a truly just and inclusive society will be aided by the decoupling of income from work. The PWLD involved in the research can be viewed as a case study in support of the argument for universal basic income as central to new forms of citizenship. In relation to normative theorising, I think it essential that future research contemplates the citizenship of PWLD in relation to discussions

of a climate in which some forecasters believe automation is going to lead to reduced employment opportunities. PWLD are already in a position where they experience excessive marginalisation in terms of employment. If these forecasts are correct, coupled with further predictions that we are in the process of moving towards greater inequality as the socio-economic gap widens, I do not think it is possible for PWLD – or anyone who does not adhere to the norm – to experience the recognition or to access resources that will facilitate inclusion.

The developments I experienced during the research in terms of understandings and values led to an interest in the idea of a 'universal basic income' (Offe, 1996; Bauman, 1999; Pateman, 2004; Somers, 2008 Parijs, 2003; Wright, 2011; Bregman, 2016). Wright has discussed universal basic income as a 'real utopia', explaining that this is an ideal and feasible solution to exclusion and poverty, if only we question normative assumptions. Wright encourages us to make real that which has been constructed as the impossible. In line with this, Bregman (2017) has argued for a 'utopia for realists', explaining the economic feasibility of implementing basic income if we question our assumptions – or social settlements – about work and income. As a final example, Bauman (1999) talks of removing 'the awesome fly of insecurity from the sweet ointment of freedom' (1999, p.188) when advancing the idea that income is separated from employment. Bauman, in support of the vision of a basic income, states that besides discussions around the economic viability of a basic income, we also need to have a grand vision; we need to think about the society that we want in the future in order to seek ways of achieving this. He is aligned with those who detail the economic ways in which a universal basic income can be achieved within the current capitalist economic reality, but is critical of focussing too ardently upon how it is economically viable without giving equal attention to a critique of normative assumptions and expectations. I agree with the theorists referred to here who are of the position that it is necessary to challenge normative assumptions about work and income in order to make the world a better place. Universal basic income is not new idea (e.g. More, 1516; Mill, 1949; King, 1967), but is currently experiencing a revival.

The research findings challenge normative assumptions regarding independence and inclusion; greater value was often placed on feelings and understandings rather than normative performative acts. As such, independent acts are juxtaposed with a sense of autonomy, and participative acts with feelings of inclusion. A lack of resources were found to impede these

feelings of inclusion and autonomy, highlighting the necessity to look to resources as a central matter when contemplating the citizenship of PWLD. For example, one participant wanted a one to one support worker in order that she was able to make decisions about what she did and where she went, rather than having to go out with a group of PWLD and having little or no choice in what she did with her day. Another participant wanted to spend some time in respite care in order to give her family some time where they did not have to spend all their energies supporting her. These were examples of the participants wishing for autonomy but being blocked by a lack of resources. If they had access to money in order to pay for these services they would have had greater autonomy.

The participants not having the resources to realise these desires leads to questions of whether they experience the choice that they necessarily should. This is highlighted as especially true when thinking about the specific ways in which resources limited their choices – ways in which people who do not have learning disabilities are able to take for granted, such as being able to decide what you are going to do with your day. The research found it is essential not only that the opportunity to be make decisions and be heard be available to individuals, but also that the scope of options available be interrogated as well as the individual being supported to question this scope. It is notable that the research found that although the desire for autonomy was paramount, and despite unhappiness being voiced, there was a lack of overt protest. If options are very limited, or agency is not felt or facilitated, how can an individual really be said to have choice? And if an individual or group are not provided with the information to challenge their position how is this true choice?

In addressing the goal of exploring understandings and expectations in relation to normative citizenship concepts, and discussing what the PWLD involved in the study actually desired regarding these, the findings here demonstrate that it is essential that redistribution be central to discussions of the citizenship of PWLD.

Appendix 1: Consent form

CONSENT FORM

Title of Research Project: Promoting independent citizenship among people with learning disabilities

- It is important that you read, understand and sign the consent form.
- It is your choice if you would like to take part and you do not have to take part if you do not want to.
- If you have any questions please just ask.

I have been told about the research and why it is being conducted ☐

I agree to taking part in it ☐

I understand that I have the right to stop taking part in the research at any time ☐
without giving a reason

I give permission for my words to be quoted (by use of a different name) ☐

I understand that the information collected will be kept in secure conditions ☐
for a period of five years at the University of Huddersfield

I understand that no person other than the researcher/s and facilitator/s will ☐
be able to see the information provided.

I understand that my identity will be protected by the use of a different name in the ☐
report and that no written information that could lead to my being identified will
be included in any report.

If you are happy that you understand the information and would like to take part in this project please put a tick in the box next to each sentence and write your name and sign below.

Signature of Participant:	Signature of Researcher:
Print:	Print:
Date:	Date:

Appendix 2: Information for interview participants

Research purpose

The reason I am doing this research is to find out how you feel about the following things:

Where you live

Living with other people or living on your own

What you do in your spare time

Doing things on your own

The support you have from other people

Being independent

I will be using what I find out as part of my university studies – I am doing a PhD. I want to do this because it is important to find out your opinions about the services you use and the way you live to see if you are happy. I think it is important that people are able to voice their opinions.

It is you decision if you take part and you do not have to if you don't want to.

If you do decide to take part but then decide you don't want to you can stop at any time.

If you are happy to talk to me I would like to record a conversation with you. No one else apart from me and my supervisors at university will be able to listen to the recording, and when I write about you I will use a different name so that when people read my work they will not know it was you.

When I have finished my research and written about what I have found I will show or read it to you to see if you are happy with what I have done.

If you want to talk to me about the research afterwards then please contact me and I will meet you. My telephone number is 01484 472745 or you can ask a support worker, family member or carer to arrange for me to meet with you if you would prefer.

Appendix 3: Information for families, carers and support workers

For people with learning disabilities, an independent life, whereby they are able to take part in 'normal' society, appears to be framed as ideal within government policy. I am going to look at how people with learning disabilities wish to be included in society, and the influence previous life experiences have upon their opinions. Also, relatively little research has been conducted with people with learning disabilities in reference to the 'personalisation agenda'.

With the service users who agree to take part I am going to carry out interviews, hold group discussions and make observations for approximately four months.

The following is a copy of the information sheet which has been read and/or given to the people who have agreed to take part in my research:

Research purpose

The reason I am doing this research is to find out how you feel about the following things:

Where you live

Living with other people or living on your own

What you do in your spare time

Doing things on your own

The support you have from other people

Being independent

I will be using what I find out as part of my university studies – I am doing a PhD. I want to do this because it is important to find out your opinions about the services you use and the way you live to see if you are happy. I think it is important that people are able to voice their opinions.

It is you decision if you take part and you do not have to if you don't want to.

If you do decide to take part but then decide you don't want to you can stop at any time.

If you are happy to talk to me I would like to record a conversation with you. No one else apart from me and my supervisors at university will be able to listen to the recording, and when I write about you I will use a different name so that when people read my work they will not know it was you.

When I have finished my research and written about what I have found I will show or read it to you to see if you are happy with what I have done.

If you want to talk to me about the research afterwards then please contact me and I will meet you. My telephone number is 01484 472745 or you can ask a support worker, family member or carer to arrange for me to meet with you if you would prefer.

Appendix 4: Interview guide

Interview Guide

- Understandings of the move to more independent lifestyles.

- How much control they feel they have in relation to independence. For example, where they live.

- Explore understandings of employment and the importance this holds

- What being independent means to them.

- How important being independent is.

- Their ideal situation.

- Thoughts and feelings about living with people that they have not chosen to live with/generally living in shared accommodation/living with friends/alone.

- How they spend time away from their homes/How they would like to spend time away from their homes.

- Concepts of normality/Feelings of difference and marginalisation.

- Understanding power imbalances

Appendix 5: Participant information

	Has worked in the past or present Yes = Y No = N paid capacity = p voluntary = v	No. of interviews conducted	Estimated age range	Ethnicity
Chloe	Y (v)	1	30 – 39	White British
Diane	N	1	40 – 49	White British
Donald	Y (p)	1	50 - 59	White British
Ellan	Y (v)	2	30 – 39	White British
Gerald	Y (p)	1	50 – 59	White British
Hannah	Y (v)	1	20 – 29	White British
Jade	N	1	30 – 39	White British
Jane	N	1	40 – 49	White British
James	N	1	40 – 49	White British
Katherine	Y (v)	2	20 – 29	White British
Mark	Y (p)	2	20 – 29	White British
Mary	N	1	60 – 69	White British
Pam	N	1	50 – 59	White British
Rebecca	N	1	30 – 39	White British
Sarah	Y (v)	3	60 – 69	White British
Simon	N	3	20 – 29	White British
Tia	Y (p)	2	40 – 49	Mixed ethnicity – White British and Black British
Tricia	N	1	30 – 39	White British

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