WHAT DOES LEARNING DISABILITY MEAN IN THE ‘REAL WORLD’? RE-EVALUATING CONCEPTIONS AND DEFINITIONS OF LEARNING DISABILITY

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Dedication

This thesis is dedicated to my Mum (1947-2012).

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Abstract

What does learning disability mean in the 'real world'? is a qualitative sociological thesis that explores the discursive resources used by different groups of people in relation to the term learning disability. Learning disability is a term that can mean different things to different people. It is also a term that can be seen from a variety of theoretical standpoints. Indeed, the term learning disability exists within a semantic tangle of definitions, concepts, colloquialisms, politics and attitudes that is fraught with historical, social and political tensions. While this is a feature of many terms, how learning disability is understood is of direct consequence to people with learning disabilities and the lives they live. This thesis aims to address this confusion and to work towards a re-evaluation of concepts and definitions of learning disability.

The empirical work undertaken for this thesis is based on two philosophical positioning statements that emanated from the literature review: that learning disability is both an embodied reality *and* a social construct; and that people's views, perceptions, and understandings are meaningful reflections of social reality. In order to obtain the perceptions of people experiencing the 'real world' of learning disability, a combination of focus groups with people without learning disabilities and photovoice sessions with people with learning disabilities were used. The resultant findings have been analysed using a combination of discourse analysis and interpretive engagement. From this data, it is concluded that dominant models of disability, found in current learning disability policy and research as well as in the research participants' talk, result in the (mis)representation of learning disability. In order to redress this issue, it is argued

that the body, including the brain as a bodily organ, must be reoriented to a position of influence within understandings of learning disability.

Contents

Chapter 1: Introduction

Learning disability has been described as the UK's official term (Walmsley and Johnson 2003) to refer to people who have 'significantly reduced ability to understand new or complex information, to learn new skills' and a 'reduced ability to cope independently which starts before adulthood with lasting effects on development' (DoH 2001 p.14). Defined in this way learning disability is a heterogeneous label that covers a continuum of ability which includes what are referred to as mild, moderate, severe and profound and multiple learning disabilities (Hardie and Tilly 2012). The term learning disability has been in common and accepted use among people with and without learning disabilities for over 20 years (Walmsley and Johnson 2003). Despite this, the term learning disability exists within a semantic and theoretical confusion that in turn has resulted in the situation whereby learning disability can mean different things to different people (Hardie and Tilly 2012).

It is important to note that the UK is the only country to use the term learning disability in this way (Emerson and Heslop 2010). Other English speaking nations such as the USA, Canada and Australia use the term 'intellectual disability' (Emerson and Heslop 2010). In the USA, The American Association on Mental Retardation, made the decision to replace its use of the term 'mental retardation' with the term 'intellectual and developmental disabilities' in 2007, so that it is now known as the American Association on Intellectual and Developmental Disabilities (AAIDD) (Schalock 2007). Following from this, and in conjunction with the AAIDD's adoption of the term intellectual disability, internationally-used diagnostic manuals are also working towards changing their terminology from the radically out-dated mental retardation to the term intellectual and developmental disability. The Diagnostic and Statistical Manual of Mental Disorders (DSM) V (American Psychiatric Association 2013), for example, is now using the term ‘intellectual disability (intellectual disorder)’ and the World Health Organisation ICD-11, to be published in 2017, is thought to be adopting the term ‘intellectual developmental disorder’ (Higgins 2014). Consequently, the term intellectual disability is now increasingly used within medical settings in the UK. Mansell’s (2010) report for Mencap, *Raising our Sights*, for example, adopts the term profound multiple intellectual disabilities instead of the previous and more commonly used term, profound and multiple learning disabilities. Further to this, the term learning disability is used by other nations, such as the USA, to refer to what is known as ‘specific learning difficulty’ within the UK e.g. Dyslexia. In contrast to learning disability, specific learning difficulties refer to particular aspects of learning and are independent from intellectual ability (Hardie and Tilly 2012).

While learning disability is used consistently within Department of Health (DoH) policy (DoH, 2001, DoH 2009, DoH 2012), this is not the case across UK public policy as a whole nor is it the case within learning disability practice or everyday language. Learning disability is frequently replaced or used interchangeably with other terms, such as intellectual disability, mental handicap, mental capacity, cognitive impairment, learning difficulty, developmental delay and in some instances mental ill health. Within the Department for Education, for example, the (SEN) Code of Practice (DoE 2015) refers to moderate, severe and profound and multiple learning *difficulty* to mean the same as the DoH definition of learning *disability* (Emerson and Heslop 2010). In addition to this, the term learning difficulty is often referred to as people with learning disabilities' term of choice (Goodley 2001) following its use by self advocacy groups such as People First.

The replacement of learning disability with other terms is also readily found within academic and professional literature: Simons (1992), Harris (1995), Goodley (2001), and Race (2002) use the term learning difficulty; while Rapley, Kiernan and Antaki (1998), and Pilnick et al (2011) use intellectual disability; Antaki et al (2007) use intellectual impairment, ICD -10 (2000) still uses mental retardation; Olney and Kim (2001) and Roll-Peterson (2001) use cognitive disability; and Cannella et al (2005) use developmental disability. Researchers seldom explain what they mean by the term they are using but rather assume that the reader is sharing the same thought process (Carlson 2011). With so many terms, each with their own nuances, this is a risky assumption to make.

The fluctuating use of learning disability and its replacement terms cannot be separated from its complex sematic and social history. While academic and policy literature, from ancient Greece to the present day, illustrates the presence of people with learning disabilities as a constant, terminology has been subject to frequent replacement (Scheerenberger 1983, Rix 2006). The turnover of labels has accelerated over time, reflecting the increasing pace of social change. Terms in common use have included: natural fool, idiot, person of weak intellect, mental imbecile, mentally infirm, simpleton, feebleminded, moral imbecile, mental defective, mentally deficient, subnormal, mental retardation and mentally handicapped. Many of these terms derive from the language of medics and others involved in the care and treatment of people with learning disabilities.

The social history of learning disability (see Scheerenberger 1983, Digby 1997, Race 2002 and Rix 2006) serves to highlight the sociocultural basis (Scheerenberger 1983) of its semantics. Demonological explanations popular in the middle ages, for example, gave way to scientific explanations following the enlightenment (Neugebauer 1996). Those referred to as natural fools and idiots in the 13th to 17th centuries, for example, although still associated with demonological explanations (Scheerenberger 1983), were generally found to be included in community life (Ryan 1980). In contrast to this the sociocultural changes that were taking place in the 19th century, such as the industrial revolution and the popularity of the eugenics movement, resulted in the active segregation and stigmatisation of people who were now referred to as feebleminded (Race 2002). However, people we now refer to as people with learning disabilities are supported to live independently within the wider community, in line with popular moral values such as equality and fairness (Carlson 2001).

Of particular interest within this history is the rapid and consistent translation of medical and legal terms into lay terms of abuse. Each of the labels highlighted above have been, and many continue to remain, pejorative terms. Perhaps the earliest example of this is the use of the still popular phrase ‘village idiot’. The first references to this can be found in the 13th century when idiot was used as a legislative term (Rix 2006). Contemporary lay language, moreover, reveals the current abusive use of a wide spectrum of redundant terms, such as: idiot, moron, spastic, retard, fool, dunce, imbecile and basket case. Further to this, children are now heard using learning disability as an abusive term in playground bullying. Learning disability, thereby, is a term that has a long history of stigma attached to it. This stigma has been exacerbated across the developed world as a consequence of industrialisation (Digby 1996) and the more recent dominance of a neoliberal political economy (Goodley 2014). As Edgerton (1967 p.vii) states, 'of all the attributes of man, mind is the quintessence; to be found wanting in mental capacity – in general intellectual competence – is the most devastating of all possible stigmas'.

In addition to this, the language used to refer to people with learning disabilities in the UK is underpinned by a theoretical tension between medical and social conceptions of disability. Such models and theories are associated with disability studies. Moreover, the social model, often defined as disability studies' 'big idea' (Shakespeare and Watson 2001), critiques the perception that disability is a product of individual biology (as ascribed by the medical model) and instead argues that disability is a social construct, a product of disabling social and environmental barriers. The social model provided an alternative way of seeing disability that in turn impacted upon the language used to refer to it, particularly among disabled people themselves. It has been argued, however, that neither model provides a useful framework for understanding learning disability despite their discursive influence on lay, policy and academic understandings of the term (see Goodley 2001 and Shakespeare 2006). These debates will be explored further in the literature review. The point to be made here is that dominant theoretical models of disability that can be found to underpin conceptions of learning disability found within social policy, research and lay language can be problematic when used to make sense of learning disability.

Consequently, the use of and theorisation of the term learning disability is neither globally nor nationally universal. While the use of differing terminology among other nation states is to be expected, due to unique histories and cultures, the use of differing terminology within a country can and does result in confusion. The fundamental point is that learning disability can and does mean different things to different people. It is a term that exists within a semantic tangle of definitions, concepts, colloquialisms, politics and attitudes that is fraught with historical, social and political tensions, which in turn can impact upon the lives of people with learning disabilities and those working in learning disability practice. Indeed, when working in public health I frequently encountered confusion surrounding the term learning disability. One example that sticks in my mind is a sports project for isolated mental health service users, Sporting Change. To access the project individuals needed to be referred either by a mental health professional or any other health or social care practitioner. Sporting Change repeatedly received referrals for people with learning disabilities who did not have a history or current diagnosis of mental ill health. These people had to be turned away from the project.

While the use of differing terminology to refer to the same thing is not always problematic, for example I can call the thing I sit on in my lounge a sofa, a couch, or a settee without being misunderstood, confusion and tensions arise when replacement terms are value laden or mean something different entirely. While some terms can be accurately used interchangeably without too much confusion, for example learning disability and intellectual disability, others cannot. Use of terms that have different connotations and definitions to learning disability, such as developmental delay, mental ill health and learning difficulty, can and do result in confusion. Such confusion, moreover, makes talking about learning disability a difficult task within any social, political or practical setting.

This semantic tangle, although repeatedly found within academic research, everyday talk and professional practice, is rarely addressed and remains relatively unquestioned. On the surface this might not seem problematic. Learning disability, however, is not just a term that can be replaced without thinking: as seen, replacement results in confusion. In addition to this, learning disability refers to lived realities. The terminology used is value laden, politically imbued and socially constructive. As Wendell (1996 p.32) tells us, 'how a society defines disability and whom it recognises as disabled are of enormous psychological, social, economic and political importance, both to people who identify themselves as disabled and to those who do not but are nevertheless given the label'. With this in mind, in order to clarify and understand learning disability as both a term and a lived experience, it is important to address the seldom-acknowledged confusion which surrounds the term.

A number of researchers have addressed the meaning of the term learning disability and other associated terms by situating it within theoretical debates (Maldenov 2014), historical context (Klotz 2004), and by asking people with learning disabilities (Goodley 2001) and without learning disabilities (Danforth and Navarro 1998) what they think. It is fair to say, however, that the majority of social scientific research addressing learning disability, uses the term or its associated terms without question. Consequently, as will be seen in the literature review, learning disability is frequently misrepresented.

What does learning disability mean in the real world? seeks to address the confusion highlighted above by exploring the discursive resources used by people experiencing the 'real world' of learning disability to make sense of the term learning disability. The ‘real world’ is used here to refer to the experiences and practices of people with and without learning disabilities who encounter the reality of learning disability first hand or who have the potential to influence this reality. In exploring ‘real world’ constructions of learning disability, moreover, the project aims to establish a clearer understanding of learning disability as perceived by people with and without learning disabilities in order to re-evaluate sociological perspectives of learning disability. To do this the project asks the following research questions:

What does learning disability mean in the real world?

(a) How is learning disability theorised and conceptualised in sociological and policy discourse?

(b) How is learning disability understood by both people with learning disabilities and people without learning disabilities who work in learning disability practice or who have the potential to influence this practice?

(c) What is the relationship between the constructions of learning disability produced by participants with and without learning disabilities and how can this contribute to a re-evaluation of sociological perspectives of learning disability?

The empirical and theoretical evidence presented as a consequence of answering these research questions will be used to re-evaluate sociological perspectives of learning disability. In this way, the thesis makes a sociological contribution to disability studies. The work carried out to make this contribution is structured as follows.

Chapter 2 provides a review of the relevant literature in order to answer research question (a). Specifically, the social and the medical model of disability are discussed in relation to their theoretical underpinnings and the challenges faced when learning disability is applied. The recontextualisation of the discourses associated with these models is then presented within a social policy and learning disability practice context. In order to re-evaluate these models, theories of embodiment are then reviewed and used to redress some of the theoretical tensions highlighted. Consequently, the argument made in the literature review forms the epistemological and ontological basis of the thesis, namely that: learning disability is both a social construction *and* a material reality and that people's views, perceptions and understandings are meaningful reflections of that social reality.

Chapter 3 addresses the research design chosen to answer research questions (b) and (c). Here the project's ontological and epistemological starting points are outlined in order orientate the project with a qualitative approach and to justify the choice of the specific methods and modes of analysis used. The research methods and modes of analysis chosen, namely: focus groups and photovoice; and discourse analysis and interpretive engagement, respectively, are then described. This is followed by a discussion of the practical application of these methods and frameworks of analysis. In addition to this, the sampling strategy, access, inclusion of people with learning disabilities as participants, ethical considerations and my own positionality within the research process are all considered here.

Chapter 4 provides an introduction to the analysis with a particular focus on the discourse analysis of the focus groups. In conducting the discourse analysis, three repertoire pairs were identified to be used extensively across the focus group talk: *I know what learning disability is/learning disability is a confusing term; I don't like labels/labels are useful*; and *people with learning disabilities are different to me/people* *with learning disabilities are the same as me*. In addition to these a number of commonalities characterised the focus group talk. This chapter discuses these commonalities in order to contextualise the interpretive repertoires discussed in the following three chapters.

Chapters 5, 6 and 7 all present the discourse analysis of the focus group talk in order to show how learning disability is understood by people without learning disabilities working in learning disability practice and/or with the potential to influence learning disability practice. Each of the three chapters addresses a specific repertoire pair. Chapter 5 addresses the *I know what learning disability is/learning disability is a confusing term* repertoire pair. Here it is argued that the participants use this repertoire pair to construct a particular identity, that of the 'good person', that they work hard to maintain throughout their talk. It is further argued that in doing this the participants necessarily both (mis)understand learning disability and avoid talking about the body. Chapter 6 addresses the *I don't like labels/labels are useful* repertoire pair. Here it is argued that the participants draw on the discourse of labelling theory to maintain their 'good person' status and thereby 'pass off' their labelling behaviour in terms of equality. Chapter 7 addresses the *people with learning disabilities are different to me/people with learning disabilities are the same as me* repertoire pair. Here it is argued that once again the participants avoid talking about the body in order to maintain their commitment to equality; a commitment they frame in terms of sameness.

Chapter 8 then presents the interpretive engagement analysis of the photovoice findings in order to show how learning disability is presented and discussed by people with learning disabilities. Here it is argued that the learning disabled body plays a significant role in these understandings. Consequently, in response to research question (c) it is argued that there is a disjuncture between how learning disability is constructed by people with and without learning disabilities that is based on the location of the body.

Following the discussions presented in the analysis chapters, chapter 9 concludes with a summary of these findings. This summary is presented in relation to the original research questions and the contribution to disability studies that can be made. A threefold contribution is presented that involves an epistemological, a theoretical and a practical contribution. It is ultimately concluded here that the body is essential to sociological understandings of learning disability. This conclusion is discussed in relation to the limitations of the research project and suggestions for further study are made.

Chapter 2: Literature review

In order to answer research question (a) *how is learning disability theorised and conceptualised in both sociological and policy discourse?*, a review of academic and policy literature addressing learning disability has been conducted. This review reveals three fundamental and interlinked issues that help to untangle the discursive confusion presented in the introduction and also highlight the need for further exploration. The three issues will be discussed in the following order:

- Models of disability.
- The role of models of disability in the construction of learning disability within social settings.
- The learning disabled body.

The final section of the literature review concludes by positioning the thesis philosophically. Indeed, the research design discussed in the following chapter is premised upon this position.

Models of disability

This section of the literature review addresses models and theories of disability. Academic literature within this field of study is used to argue that models and theories of disability are reflective of the language changes highlighted but also influence the discursive construction of learning disability as a term, a lived experience and a social issue. In order to understand this claim, it is necessary to outline what these models and theories are and how they construct particular discourses.

A wide variety of models and theories of disability are used within academic research, including: the social model (Oliver 1990), the medical model (Mladenov 2014), social constructionism (Rapley 2004), critical realism (Shakespeare 2006), feminist disability theory (Morris 1997), phenomenology (Hughes and Paterson 1997, Hughes 2004, Maldenov 2014), post-structuralism (Corker 1998), symbolic interactionism combined with embodiment theory (Coleman-Fountain and Mclaughlin 2013) and dis/ability studies (Goodley 2014). Of these models and theories, the social model and the medical model are the two dominant, and contrasting, constructions of disability in the UK (Shakespeare 2006). It is these models that are most influential and visible within the contemporary language of learning disability. While feminist disability theory, poststructuralism, phenomenology and social constructionism are well represented within academic research, it is possible to argue that only the social and the medical models have visibly penetrated social policy, practice and everyday language and perception (Shakespeare 2006). Consequently, this section of the literature review will focus on the medical and the social models of disability. Other approaches will be discussed when the learning disabled body is explored in the final section.

Each theory or model constructs disability in different terms. The language used to refer to disability, therefore, will differ depending on the model/theory being used. It is important to note that outside of academia and disability movements, the model or theory of disability being used is unlikely to be a conscious decision and is more likely to be a reflection of the intertextuality of the normative values contained within the dominant models of disability. For example, it is now unproblematic to think of environmental or physical barriers as disabling. It is unlikely that anyone would disagree that steps into shops, workplaces etc. make access for wheelchair users difficult, nor that libraries with only small print books are inaccessible to visually impaired people. This normative way of seeing disability is a reflection of the social model of disability as a discourse at work. Equally, the medical model is also apparent when the everyday conception of disability is thought about. For example, it is socially expected that a parent of a child with Down Syndrome, for example, will seek diagnosis and remedial advice from medical professionals; failure to do so would be widely viewed as bad parenting. Models and theories of disability, moreover, are perhaps better understood as discourses at work within particular settings. This perspective will be illustrated in the following two sections when constructions of learning disability within social policy and research are discussed.

The medical model is discussed first for the reason that it is frequently cited to be the hegemonic model of disability (Oliver 1990, Preistely 1998, Rapley 2004, Swain et al 2004, Arehart 2008). To describe the medical model of disability as something that has been explicitly defined and something that operates within definitional boundaries is somewhat problematic. It is perhaps easier to outline the medical model as paradigm of thought or a discourse that penetrates talk and perception of disability (Areheart 2008). As Areheart (2008 p.185) tells us 'this model does not so much reference an intellectual position advanced by contemporary scholars as it provides a way of describing the norms that have traditionally governed disability in Western society'. Oliver (1996 p.31), for example goes as far as to claim 'for me, there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalisation is one significant component'. The medical model of health is often described as the absence of disease (Aggleton 1990). As Baum (2008 p.4) tells us, the medical model presents healthy bodies operating 'efficiently like a machine…any breakdowns in the body system mean that it is not healthy'. By implication, if the body is not diseased, it is therefore healthy. The medical/individual model of disability operates the same logic and relies on normative categories such as the disabled and non-disabled body (Areheart 2008). Fundamental to the medical model is the location of the individual body, 'the individual is the locus of disability' (Areheart 2008 p.186). The medical model, constructs the individual problem of disability as having a biological cause that requires medical remediation (Areheart 2008). As such the medical model imposes a particular way of being onto the 'disabled'.

When applied to learning disability, the medical model positions the individual with a learning disability both as one of life's unfortunates and as someone who is expected to comply with the latest medical guidance. Rapley (2004 p.8), for instance tells us that, 'intellectual disability is constructed in both 'official' discourses and everyday common sense as an irretrievable 'disorder' of competence afflicting individual subjects, requiring professional diagnosis, treatment and management'. Rapley (2004 p.14) uses Rose's concept of the psy-complex (that psychiatric medicine and psychology has colonised intellectual disability and thereby constructs it as something that maintains the power of psychiatric and psychological diagnosis and treatment) to explain the progress of the medical model into an 'unspoken screen on which contemporary action-in-the-world is made intelligible as such'. In this way the psy-complex exemplifies the internalisation of medical ways of seeing the world and the construction of disability as other. Furthermore, Rapley (2004 p.14) argues, 'psychology then, has come to offer the ubiquitous vocabulary of our present and a series of techniques whereby we make ourselves into self-governing subjects'.

The preoccupation with normality and the construction of disability as an individual pathology (Fisher and Goodley 2007) that requires diagnosis and treatment is visible throughout medical discourse and social interaction, as will be shown in the following two sections. In addition, medical diagnosis, for example, has wider implications than locating and labelling pathology. For people with a learning disability, medical diagnosis results in a label that both shapes the identity of the person so labelled and affects how other people respond to them (Edgerton 1967, Simons and Carter 1992, Gillman et al 2000 and Harris 1995). Much research has been carried out to explore the impact of this system of diagnosis and labelling, (see Harris 1995, Fisher and Goodley 2007). Scior (2003), for example, highlights the medicalisation of emotion when talking about Marie, a woman with learning disabilities and primary carer for her mother. As is the case for many people without learning disabilities, Marie found caring for her mother very stressful. Marie's overdoses, however, were treated as indicative of her learning disability rather than her social context. As Scior (2003 p.791-792) tells us 'Marie is positioned as the site of 'pathology' and her distress is largely isolated from the wider social context'. Such research has parallels with labelling theory, whereby, labels are positioned as both socially produced, and socially shaping (Becker 1963). Labelling theory, however, has been widely applied to mental ill health (Goffman 1963) and various forms of crime and deviance (Becker 1963) but less so to learning disability specifically.

Within the social model of disability, the dominance of the medical model and its power to produce labels is seen to uphold a system of social oppression (Swain et al 2004, Oliver 1990, Abberley 1987, Donoghue 2003). Unlike the medical model, the social model can be talked about in terms of a description of disability rather than a normative set of ‘truths’. The social model emerged as a reaction against the historical dominance and all-pervading nature of the medical model, in particular, the medical model’s construction of disabled people as tragic victims and abnormal citizens (Swain et al 2004). Fundamental to the social model is a redefinition of disability that reframes disability. In 1976 The Union of the Physically Impaired Against Segregation (UPIAS) reformulated the word ‘disability’ in terms of society rather than body, stating, 'in our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairment by the way we are necessarily isolated and excluded from full participation in society' (Barton p. 286). Following the UPIAS definition, Mike Oliver, a disabled person himself, alongside other disabled academics and activists developed ‘the social model of disability’.

This social model builds on the UPIAS definition and uses a structuralist understanding of society to explain the social position of disabled people and the route out of oppression (Finklestein 2004). For Oliver, the definitive cause of disability is the prevailing political economy and its relationship with rational truth. Indeed, Oliver (1990 p.21) tells us ‘there are… strong economic reasons for the exclusion of disabled people and it is the embodiment of these social and economic relations under capitalism which has led directly to the exclusion of disabled people within capitalist societies’. His argument works as follows: within a capitalist system, science and economics as rational truths collaborate to create disability as an individual, biological problem, inherent within disabled bodies. Work is constructed in such a way that disabled people are excluded and forced to be dependent upon others for economic survival (Terzi 2004). Working from this perspective, social model rhetoric argues that there is no such thing as people with disabilities; instead, disabilities are socially constructed and imposed upon people with impairments (Corker 1997).

The social model, moreover, is predicated on an impairment/disability split whereby disability is prioritised and impairment is marginalised (Corker and French 1999). Disability is redefined as a social construct that is experienced by all people with impairments, creating a united, disabled identity. As Arehart (2008 p.188-189) tells us 'the experience of disability is not inherent or inevitable given a particular medical condition; rather it depends upon the particular social context in which one lives and functions'. Causation is relocated from the individual to society as a whole, thereby constructing disability as an experience that can be removed. Impairment, on the other hand, is used to define individual, bodily conditions that have personal rather than collective consequences. As Shakespeare (2006), describes, the impairment/disability split can also be understood in terms of an individual (impairment)/social (disability) dichotomy. The social model's focus on disability (society), however, sidelines bodily impairment (Corker and French 1999). As Oliver (2004 p.8) argues, 'the social model is not about the personal experience of impairment but the collective experience of disability'.

Social model rhetoric, therefore, positions people with learning disabilities as members of a collective group of people with impairments who are disabled by social barriers. Possession of a learning disability is only considered important in that it allows such people access to this collective identity. As people who are disabled by social barriers, people with learning disabilities, according to the social model, are ideally located to rise up against oppression and eliminate these disabling barriers. The social model, moreover, has received much criticism relating to its body/society dichotomy and the assumptions that it brings. In reducing impairment to an issue of individual biology, it has been argued that the social model is utilising the hegemonic language and normative categories that it seeks to avoid (Shakespeare 2006). The social model's construction of disability, thereby, retains a mind/body meta narrative, re-labelling it as impairment. As Hughes and Paterson (1997 p.326) state, the social model 'concedes the body to medicine'. The social model despite itself, moreover, is unable to escape the hegemonic language of the medical model.

The combination of the mind/body dualism implicit within the social model and the positioning of impairment as a 'devalued other' (Finklestein 2004 p. 18), is particularly problematic for people with learning disabilities. A learning disability is unlike a physical or a sensory disability, in that the impairment is principally cognitive (Niedecken 1999). In the case of cognitive impairments, the part of the body which is impaired is the brain; this may cause further or secondary impairments in the functioning of other parts of the body. Added to this, learning disability, as a category, is a continuum that includes a wide variety of abilities. Some people with learning disabilities may not be able to conceive of social barriers let alone express thoughts about them. While this rhetoric is undoubtedly inspirational and as Shakespeare (2006) tells us, liberating for some, the relegation of the body is problematic for people with learning disabilities. While a rhetoric of unity and collective action might fit for people who experience certain disabling barriers and can articulate this experience, for people with learning disabilities, such a rhetoric can be disabling in itself. Oliver's desire for collective action among people with disabilities, moreover, relies on the use of the brain; the bodily organ which is the locus of impairment for people with learning disabilities.

By way of neglecting impairment, the social model, moreover, is guilty of creating a potential hierarchy of disability, whereby those that can shout loudest are given precedence. Shakespeare (2006 p.4) recognises this hierarchy and asks for the origins of the social model to be considered, suggesting 'perhaps disabled scholars often emphasise the dimension of disability which they most directly experience'. An emphasis on physical and sensory disability is implicit throughout social model discourse. As Goodley (2001 p.212) tells us, 'while the social model is not reserved for people with physical impairments, it may often seem that way'. Finkelstein's (1975) imagined village provides a useful example of this claim. Finkelstein (1975) imagined a village in which 'normal' people would experience disabling barriers and people with impairments would be free from disability. All village residents are wheelchair users, the village is organised around this so that when people who aren't in wheelchairs visit, it is they who experience disabling barriers. While accessible living, shopping and mobility may significantly reduce disabling social barriers for cognitively able wheelchair users, as Shakespeare (2006 p.49) tells us 'short of a global catastrophe which returned western society to medieval levels of economic and social organisation, it would be impossible to recreate a world in which literacy and numeracy were not important attributes for economic independence and advancement'. Even in Finkelstein's 'barrier free' village, people with learning disabilities would still be as disabled as ever. Consequently, as Inglis and Swain (2013 p.340) tells us, 'it is often difficult to equate the writings of the disability movement with the lives of people with a learning difficulty'.

The social model outlined above is often described as the strong (Race 2006), or the first wave social model (Rapley 2004) and, as shown, has been subject to critique. Such questioning generally concerns the emphasis on structuralism (Terzi 2004, Corker 1998), the dichotomies that this emphasis necessitates (Hughes and Paterson 1997) and separation of impairment from disability (French 2004, Thomas2004). Following such criticism, this strong version of the social model has been subject to a number of on-going revisions (Thomas 2004, Hughes and Paterson 1997, Hughes 2004, French 2004, Terzi 2004 and Corker and French 1999). Indeed, disability studies as a whole is currently experiencing an expansion whereby critical and sociological theory is gaining prominence (Goodley 2014).

Revised versions of this strong model adopt a slightly different discourse of disability that is characterised by a commitment to the social origins of disability and the need to include impairment in this. French (2004), for example, calls for impairment to be considered as something more than individual. French uses her visual impairment to highlight the fact that no amount of barrier removal will allow her to see. Thomas (2004) approaches this by introducing the concept 'impairment effects'. For Thomas (2004), the consideration of impairment effects allows for individual limitations that arise from impairment to be taken into account. For Hughes and Paterson (1997), impairment cannot be reduced to the biological body. For them the body is also social; impairment, therefore, cannot be side lined as a product of individual pathology. They claim that, 'impairment in other words is a product of discursive practices' (Hughes and Paterson 1997 p.33). Indeed, Hughes and Paterson (1997) call for an embodied rather than disembodied notion of disability. For Hughes (in Swain et al p.67 2004), the acceptance of impairment as socially constructed 'extends the principles of the social model beyond its original boundaries and in doing so manages to strengthen rather than compromise itself'.

This revised version of the social model, moreover, constructs both disability and impairment as socially produced. Learning disability, if approached from this version of the social model, is talked about as something that is entirely socially constructed. Rapley (2004) uses discursive psychology to highlight the social construction of learning disability as what the strong social model would define as both an impairment and a disability. For Rapley (2004), the consideration of learning disability is not just about getting the terminology right, it is about recognising that learning disability is interactionally produced and actively negotiated. The idea that learning disability is an interactional product removes considerations of individual biology. To present learning disability as something that is entirely socially constructed, however, can be just as problematic as constructing disability as something that is different to and separate from impairment. As Terzi (2004 p.152) states 'there certainly is a causal relation between oppression and disability, when society plays a strong role in excluding and marginalising impaired people. But in maintaining that disability is squarely socially caused, the social model theorists are over-socialising their position'. In relation to learning disability specifically, further problems arise. Indeed, Goodley (2001 p.209) warns that, 'a worrying omission in the 'turn to impairment' is the distinct lack of focus on learning difficulties'. Although learning disability may certainly be lived as an internalisation of social norms, it is founded upon a material/biological reality that both shapes and is shaped by its social context (Shakespeare 2006). This argument will be developed further in the final section that addresses the learning disabled body.

In summary, the social model and the medical model of disability are representative of linked approaches to understanding disability that have wide reaching consequences for how learning disability is both understood and lived by those so labelled. Their influence upon the way disability is constructed in social policy and other social settings.

The role of models of disability in the construction of learning disability within social settings

In order to understand how those working in learning disability practice or experiencing learning disability in other ways might come to generate their own understandings of the term, it is necessary explore a range settings in which learning disability is currently defined and that are encountered within the social worlds of the research participants included in this project. The sources discussed here include: diagnostic manuals, education manuals, and UK social policy. Research settings are also discussed in the methodology.

With regards to the participants who will encounter learning disability most frequently in a medical setting, the definitions provided in diagnostic manuals are likely to play a role in their understanding of learning disability. Those that are influenced by such manuals might include: GPs, Paediatricians, Clinical Psychologists, Psychologists, Carers and indeed, people with learning disabilities themselves who are subject to such definitions. The diagnostic manuals most commonly used in the UK are the DSM V (American Psychological Association 2013) and the World Health Organisation

International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) (WHO 2016). Both manuals reflect the dominant language used to refer to learning disability in the USA discussed in the introduction. Consequently, neither manual uses the term 'learning disability'.

DSM V (APA 2013) uses the term intellectual disability (developmental delay) and defines it as 'a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains'. ICD -10 still uses the (generally thought to be outdated) term mental retardation to refer to people with learning disabilities. Here mental retardation is defined 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' (ICD-10 2016). Further to this definition ICD-10 goes on to subcategorise mental retardation based on IQ score. Someone with mild mental retardation, for example is said to have an approximate IQ range of 50-69. Such definitions can be seen to represent a particularly medicalised approach to disability, whereby the 'condition' or 'disorder' is located in the individual's 'mind' and is said to affect individual abilities. ICD-10's definition particularly focuses on deficit and the categorization of ability through the application of objective measures. There is no mention of social, environmental or cultural factors in either of the definitions.

For those working in educational practice in the UK, and also those in receipt of such practice, it is likely that the definitions contained within the Special Educational Needs and Disability Code of Practice (DoH 2015) will be of consequence to how learning disability is understood. Here learning disability is found within the wider concept of learning difficulty. A child with a learning difficulty is defined as having ‘a significantly greater difficulty in learning than the majority of children of the same age’ or as having ‘a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area’ (DoH 2001 p.6). As with the definitions found in the medical diagnostic manuals, the SEN code of practice definition takes a predominantly deficit focused approach to learning disability, in that the ‘disability’ is framed in terms of preventing the affected child from performing in the same way as a child without such a condition. Once again there is no consideration of cultural, environmental or social factors.

Despite the medical focus contained within the definitions likely to be encountered by some of the research participants in this project, UK social care policy has sought to promote a cross-sector approach to learning disability practice, service provision and service experience. For this reason the use of the term learning disability and its associated definition, contained within *Valuing People* (DoH 2001) is also likely to be influential across all people experiencing learning disability either as part of professional practice, caring responsibilities or as a lived experience.

As seen in the introduction, UK social policy uses the term learning disability and defines it as ‘a significantly reduced ability to understand new or complex information, to learn new skills’ and a ‘reduced ability to cope independently which starts before adulthood with lasting effects on development’ (DoH 2001 p.14). This use of the term learning disability ‘officially’ replaced the previously used term mentally handicapped which was associated with a medicalised approach to learning disability. The change to learning disability and its constituent definition was positioned as a radical departure from such an approach.

Valuing People (DoH 2001) was the first white paper to address learning disability in thirty years; its update, *Valuing People Now* (2009) remains the most recent. Throughout the social history of learning disability very few government policies and white papers have addressed learning disability as a distinct subject matter. *Valuing People* (DoH 2001) changed the way learning disability is talked about in government policy; indeed, its legacy is reflected in the current UK Government's social care rhetoric. On the surface its approach mirrors the principles of the social model. Indeed, *Valuing People's* four key principles; rights, choice, independence and inclusion, represent identifiable cornerstones of the social model. If *Valuing People* is looked at more closely, however, it becomes clear that such principles also share similarities with the ideals of neoliberalism, whereby increased choice and independence are key priorities (Goodley 2014). Neoliberalism strives for a reduced state supported by rational citizens who are able to take responsibility for themselves (Goodley 2014). While the language of the social model and the language of neoliberalism share many similarities, as discourses they function very differently. Consequently, it has been argued by some (Redley and Weinberg 2007, Shelley 2008, Cumella 2008 and Goodley 2014) that current social policy rhetoric addressing learning disability is dominated by a neoliberal agenda with an ablist focus rather than social model principles. This argument is also made strongly about social care more generally (see Ferguson 2007).

Learning disability is represented as a relatively homogenous experience within social policy. People with learning disabilities are generally represented in accordance with the principles of liberal citizenship (Redley and Weinberg 2007), i.e. given the opportunity for independence, the voice for change and the freedom to choose, people with learning disabilities can be active citizens like anyone else. Such an approach, as will be illustrated, is aided by the discursive influence of both the social and medical model of disability. To illustrate this argument examples from recent policies, namely *Valuing People* (DoH 2001) and *Care and Support* (DoH 2012), will be provided and discussed.

When the *Valuing People* definition of learning disability is examined closely (see p.10 for the full definition), it is clear that while social issues are addressed, learning disability is identified as an individual issue that impinges on ability to participate. The thing that 'started before adulthood' results in reduced abilities and 'has a lasting effect on development' (DoH 2001 p.14). This is not a social constructionist definition; rather it is a medical construction, based on individual pathology and dependent upon normative ideas of ability/inability. Race's (2002 p.30) critique of the definitions contained in the 1913 mental deficiency act can be similarly applied to the *Valuing People* definition: 'all [definitions] contain descriptive statements which are totally bound up with the transitory norms and understandings of a particular society'. The *Valuing People* definition is clearly bound up in the neoliberal priorities that structure our current society such as, personal autonomy and rational thought. As Goodley (2014 p.28) tells us, 'the functioning neoliberal self is an able bodied and minded one'; people with learning disabilities must be supported to strive for this.

The neoliberal rhetoric of independence, inclusion, rights and freedom of choice, also found as *Valuing People's* four key principles, frames people with learning disabilities as rational beings who, although limited by their individual pathologies, are able to make choices for their own benefit. When explaining one of the key principles, choice, *Valuing People* (DoH p. 24) states 'this includes people with severe and profound disabilities who, with the right help and support, can make important choices and express preferences about their day to day lives'. People with learning disabilities, are moreover, assimilated as people who, with nudges in the right direction can be 'normal'. Morally loaded statements, such as this, appear to be irrefutable. Who would deny a person the equal right to choose, to take control of their own lives, to achieving social acceptance? It is necessary, however, to question the extent to which a generic approach to social care that encourages personal responsibility to make informed life choices is applicable to all people with learning disabilities (Redley and Weinberg 2007). As Fyson and Kitson (2007 p. 434) suggest, 'if people were able to be fully independent and to make important life choices without support then they would not be receiving state-funded services in the first place'.

It is within UK Government solutions to social care services for people with learning disabilities that the neoliberal agenda becomes most obvious. The current orthodoxy upheld within the *Care Act 2014* (HMSO 2014) is that the 'best' way to provide social care services for adults, including adults with learning disabilities, is via individual budgets and self-directed support. Indeed, the *Care Act 2014* (HMSO 2014) developed from the Coalition Government Social Care white paper, *Caring for our Future: Reforming Care and Support* (DoH 2012). This white paper is centred on to two principles: the first being the need to minimise people's need for formal care and support; the second that people should be in control of their own care and support. *Caring for our Future* (DoH 2012 p.3) moreover, states 'things like personal budgets and direct payments, backed by clear, comparable information and advice, will empower individuals and their carers to make the choices that are right for them' (DoH 2012 p.3). Implicit within this orthodoxy is a move towards a rhetorical focus on ability and contribution rather than inability and dependency (Redley and Weinberg 2007). In their forward to *Caring for our Future*, Andrew Lansley (then Secretary of State for Health) and Paul Burstow (then Minister of State for Care Services) tell us (DoH 2012 p.3) 'We need as a society to understand that people with care needs very much have something to offer. Care and support should not just be about making people comfortable but about helping them to fulfil their potential, whatever their circumstances'. Again, such rhetoric appears irrefutable due to its foundation of popular moral values.

Both *Valuing People* and *Care and Support*, however, are illustrative of what Carlson (2001) refers to as 'cognitive ableism'. Cognitive ableism is a product of accepted and unconscious ways of understanding learning disability, characterised by the reification and location of disability within certain individuals (as seen in the *Valuing People* definition and general approach to support); and the privilege of cognitive ability over all other characteristics. Carlson (2001) frames cognitive ableism as a product of social and political circumstance. In this way learning disability is constructed as a homogenous way of being, located within individual bodies, consistent with the medical model of disability. As such, these bodies can be circumscribed into the discourse of liberal citizenship, they can be bodies who can make the right choices, live independently and ultimately strive for normality. As Goodley (2014) tells us, neoliberalism has normalised the desire for similarity. People with learning disabilities are presented as potential candidates for 'normal' society, blurring the difference between people with learning disabilities and people without learning disabilities to the point where difference is almost ignored. While this provides moral shelter by avoiding defining people by their differences, as will be argued in the following sections, difference in cognitive ability is an inherent property of learning disability that needs to be accounted for.

The ideals of the social model that were seen to revolutionise *Valuing People's* approach are displaced by the rhetorical dominance of the medical model within its content. While the semblance of social model principles allows *Valuing People* to be seen as a pioneering approach to learning disability (Burton and Kagan 2006), such principles are not conducive to a neoliberal approach to governance. As, illustrated, the social model strives for the elimination of competition and the achievement of equality, anathemas to neoliberalism. The medical model of disability, however, does not challenge neoliberal ideology and allows it to dominate. The location of disability within individual bodies is convenient for a government that wants its citizens to take responsibility for themselves. Under the medical model, disabled citizens can be shaped and disciplined in a way that the disabled citizens as constructed by the social model cannot.

It is important to recognise that such a turn has explicitly excluded a significant minority of people with learning disabilities. Cumella's (2008) critique of *Valuing People* clearly shows the implicit neglect of people with profound and multiple learning disabilities. Indeed, Cumella (2008 p.183) states, 'the review of currently available data suggests that the person-centred assessments proposed in the white paper as a means of enhancing choice for people with an intellectual disability have probably affected only a minority of those eligible, and may have differentially excluded the most disabled'. Consequently, learning disability is not only inaccurately represented in social policy rhetoric, it is also inappropriately represented at the expense of those most in need. This misrepresentation is also present within social scientific research, as illustrated below.

It is clear that both social policy and social science are influenced by the social and medical model of disability and that the presentation of these discourses in these formats influences how learning disability is constructed on a wider scale. It is difficult, however, to find a place for learning disability within either the discourse of the medical or the social models (first and second wave). The social model's claim to speak as disabled people on behalf of all disabled people, and the medical model's imposition of ways of seeing and experiencing disability, are both problematic for learning disability. It is argued here that learning disability as an identity is based primarily on the presence of the material body that in turn is influenced by the intertextuality and embodied internalisation of normative values and ways of seeing disability as constructed by disability discourses at work within particular contexts. It has been argued here that such discourses are recontextualised within particular settings, namely social policy and learning disability practice. The idea that learning disability is an embodied reality will now be discussed.

The learning disabled body

The literature discussed in each of the previous sections highlights a move towards social constructionism that is problematically underpinned by the hegemony of the medical model of disability and its relationship with neoliberalism. If this transition is examined more closely, however, an implicit dependence upon a Cartesian conception of the self is apparent. Descartes' (1640) statement, 'I think, therefore I am', separates the self from the body. For Descartes, the body functions mechanistically, independent of the self which is located in the mind or the soul. The body is presented as a material object of secondary importance to the mind. Knowledge is constructed as a reaction of the self to pre-existing, external objects including bodies (Edwards 1998). The Cartesian perception of knowledge and being in the world is often referred to as a meta-narrative that dominates Western rational thought (Burkit 1999).

Both the semantic history of learning disability, briefly outlined in the introduction, and the models of disability presented above are characterised by a mind/body dualism. The social history of learning disability reveals an increasing objectification of the body as a consequence of the application of rational thought in the form of medical and psychiatric knowledge (Rapley 2004). Changes in terminology reflected the increasing medical interest in the categorisation and quantification of learning disability (Carlson 2001). As Snyder and Mitchell (2001 p.371) tell us, the medicalisation of disability 'made the body increasingly subject to relegation to predetermined categories of deviance by physicians enabled to act as evaluators of difference'. It has been argued here that this medicalised or Cartesian conception of the body continues to dominate within the use of the term learning disability.

In the discussion of learning disability seen through the prism of the medical and social models of disability, it is clear that the medical model explicitly operationalises a mind/body dualism by positioning disability as a pathological category that can be medically recognised in individual bodies. It was further argued that the social model, in seeking to escape the mind/body dualism of the medical model, dismissed the body as an unnecessary consideration at the expense of its escape. Within the social model, moreover, just as in Descartes' dualism, the self is free from bodily impairment. This is reflected both in the social model's call to arms, that disabled people unite and act as self-advocates for the removal of disabling barriers, and the implicit exclusion of learning disability as an impairment that challenges the mind/body, impairment/disability dualisms the model is hinged upon. The hegemony of mind/body dualism, thereby, has consequently repositioned the brain as part of the self rather than the body. The cognitive ability to establish a collective identity and work towards the removal of disabling barriers is not thought of in terms of bodily action but is thought of in terms of the mind or the self. The normalisation of such a perspective is also reflected in how learning disability is constructed in social policy and social science. People with learning disabilities are presented in terms of people who can make their own choices, be fully involved in the research process and ultimately function in the same way as those who are cognitively able.

It is clear, therefore, that mind/body dualism, as a way of thinking about society, is so entrenched within our conceptions of disability that it is difficult to escape. Williams and Bendelow (1998 p.208) talk about this in terms of duality and dualism, stating 'the transformation of this duality into an ism – one in which the mind/body divide appears somehow natural, rational and unconditional'. The social model provides an excellent example of this; conceived initially from a structuralist perspective, the model continues to implicitly buy in to the mind/body dichotomy.

Owing to their Cartesian underpinnings both the social and the medical models have been heavily critiqued here as ways of seeing learning disability, thus suggesting the need to re-evaluate mind/body dualism and think through an alternative approach. In order to do this it is necessary to bear in mind a question posed by Synder and Mitchell (2001 p.381): 'can stories of disability be analysed without recourse to the pathologising discourse of interventionist medicine, on the one hand, or to the grotesque, on the other?' This is not intended to be pessimistic but rather to be mindful of how Cartesian hegemony structures our use of language and ways of seeing the world. As Synder and Mitchell (2001 p.385) state, 'the disabled body cannot simply be fashioned anew out of whole cloth because its cultural situation finds it embedded within objectifying and objectionable languages of the body'. Consequently it is easy to either forget the body or over emphasise it. As Freund (2001 p.699) points out, the body is generally 'absent in 'consciousness'. When tensions occur between body, material artefacts and social material space or when pain, fatigue and difficulties with the body occur, the body becomes present in consciousness and experienced as an object'.

Despite a Cartesian dominance, the development of post-structural, phenomenological, symbolic interactionist and feminist perspectives have resulted in the repositioning of the body as a site of sociological analysis (Watson and Cunningham-Burely 2001) and the dominance of a Cartesian epistemology has now been widely criticised (Turner 2008, Watson and Cunningham-Burley 2001, Burkitt 1999, Edwards 1998, Leder 1990). While such criticism has been readily applied to medicine (Leder 1990), mental ill health (Foucault 2001), women's health (Butler 1993, Garland-Thompson 2003, Wendell 1996) and perceptions of disability in general (Wendell 1996), there has been less of an interest in its application to learning disability (see Edwards 1998 and Hughes and Paterson 1997 for examples). As shown, the hegemony of the mind/body dualism, however, is particularly problematic for learning disability, due to its cognitive and chronic nature. Unlike mental ill health, people with learning disabilities do not have bodies that fit within a discourse of recovery. In order to develop this argument it is necessary to outline some of the criticisms of and alternatives to a mind/body dualism. Feminist, post structural, symbolic interactionist, and phenomenological theories will be presented as alternative ways of seeing learning disability that seek to overcome the prevailing mind/body dualism.

As Edwards (1998 p.48) tells us 'the Cartesian view of the self prohibits any constitutive role for the body in accounts of the self'. Phenomenology reclaims the body while dissolving dualistic conceptions of the body as an object. Phenomenology, moreover, is what Nettleton and Watson (1998 p.4) call an 'embodied perspective'. For Merleau-Ponty (1964 p.3), the point of phenomenology is to 're-establish the roots of the mind in its body and in its world'. Merleau-Ponty (1964) called for a rethinking of perception, not as something that results internally as a reaction to external objects, as in the Cartesian conception, but as something that is embodied. The phenomenological body represents mind and body as one; this non-dualistic body is positioned in the world and represents the site of perception (Williams and Bendelow 1998). In this way, the body is ontologically repositioned as the locus of experience. Because the body is positioned in the world, embodied perception is always situated (Morgan 2008). The body, thereby, is not reduced to a pre-social object but is just as much part of the world as it is constructed by the world (Nettleton and Watson 1998). Merleau-Ponty's 'sentient-body-subject', positions bodies as the sites of meaning via individual perception and experience within a shared world (Williams and Bendelow 1998). As Edwards (1998 p.53) tells us 'The self as subject, is not construed as something purely mental. Rather it is understood as necessarily embodied. The self as an acting subject is inseparable from and identical to the body'. The body, moreover, is formulated as an active agent (Morgan 2008).

Hughes and Paterson (1997 p.335) use the language of the social model (in that they differentiate between impairment and disability), to apply a phenomenological perspective to the theory of disability and tell us that 'impairment and disability meet in the body not as the dualistic clash of inner and outer phenomena, but insofar as impairment structures perceptions about disability and disablement is part of the felt world'. For Hughes and Paterson (1997) phenomenology allows the impaired body, to view the world and perceive disablement. This perspective, they explain, allows the body to be reclaimed as part of disability rather than discarded as secondary, stating, 'in this context impairment escapes the habitual. It enters the realm of signification and its meaning arises from a symbiosis of personal embodied knowledge (personal knowledge about pain) and abstract cultural beliefs (social knowledge about pain)' (Hughes and Paterson 1997 p.335). Hughes and Paterson's application of social model rhetoric, however, is problematic. It has already been argued that the social model's dualistic approach to disability and impairment constructs a Cartesian conception of the body. To use this epistemology in combination with a non-dualistic phenomenological approach is contradictory.

This is not to say, however, that as an ontology, phenomenology cannot be useful for thinking about learning disability. Edwards (1998) makes a clear argument for the use of the phenomenological body when thinking about disability and seeking to escape the dominance of mind/body dualism. For Edwards (1998) phenomenology's conception of the body as an integration of mind and body that positions the self as an embodied subject allows disability to be thought of as constructive. The phenomenological body can both represent and know the world, as Edwards (1998 p.54) states, 'the nature of the subject's experience is determined by the nature of the body'. Here it can be seen that phenomenology allows us to think about experience as wholly embodied which further allows the development of the idea that learning disability is not homogenous, as it is often portrayed to be, but is dependent on both bodies and their social interaction.

The implementation of phenomenology as a research practice rather than a philosophy, however, has been subject to criticism (Morgan 2008 and Williams and Bendelow 1998). If Hughes and Paterson's (1997) argument is applied to learning disability research practice, phenomenology is revealed as an ableist discourse, rooted in the assumption that non-dualistic bodies are non-learning disabled. Hughes and Paterson (1997 p.335) use a phenomenological approach to argue for 'the realignment between, body, self, and society' that they claim results from the presence of impairment and the ability of the impaired body to experience disability and therefore make sense of the impaired body's position in the world. As a philosophy, social model dualisms aside, this as Edwards (1998) states, sounds 'plausible'. In practice, the experiences of learning disabled bodies situated in the world and the meanings that these experiences create are seldom taken into account (Walmsley 2001). Furthermore, for some bodies with learning disabilities, the phenomenological language of perception and interpretation that generate the desire to represent lived experiences as conceived of by able minded researchers (Morgan 2008) is not suitable. As outlined, the lived experience of people with learning disabilities presented in academic research tends to represent only the relatively able end of the learning disability continuum, resulting in the exclusion of those whose voices are least heard.

Judith Butler applies a post-structuralist feminist perspective to bodies that goes some way towards untangling the problem that a phenomenological perspective creates when applied to learning disability. Butler's arguments refer to the female body but can just as easily apply to any other marginalised body, including the learning disabled body. Butler's (1993) primary argument, in *Bodies that Matter*, is that regulatory power constructs bodies but that in doing so, a constitutive outside is also created. The constitutive outside represents marginalised bodies. Butler (1993 p. 1) tells us, 'the category of sex is from the start, normative; it is what Foucault has called a regulatory ideal. In this sense then sex not only functions as a norm but is part of a regulatory practice that produces the bodies it governs, that is whose regulatory force is made clear as a kind of productive power, the power to produce – demarcate, circulate, differentiate – the bodies it controls'. If Butler's sex is replaced with ability, disability can be seen as a constitutive outside, that Butler (1993 p3) frames as an 'abjected outside, which is after all, inside the subject as its own founding'. The inside subject (the able body), thereby, is dependent upon the existence of an outside (the disabled body). While phenomenology and post-structuralism represent different ways of seeing the world, Butler's idea of a constitutive outside can be used to explain the problematic application of phenomenology to learning disability. Phenomenology while asserted as non-dualistic, does not account for the constitutive outside that learning disability represents to the phenomenological embodied subject.

This said, Butler's concept of bodies is not without problems. Post-structuralist accounts of bodies have been criticised for rendering the body 'both everywhere and nowhere' (Williams and Bendelow 1998 p.1). For Butler the material is produced and reproduced through the power of discourse (McLaughlin and Goodley 2008). Consequently, Bigwood (1991 p.59) tells us that 'the poststructuralist body…is so fluid it can take on almost limitless embodiments. It has no real terrestrial weight'. As McLaughlin and Goodley (2008) present, other feminist's addressing disability have sought to highlight the relationship between the material and the discursive in ways that avoid these criticisms.

In general, feminist theory of the body, like phenomenology, constructs the body as an experiencing fusion of body and mind, where subjective realities and personal bodily experience are rendered ontologically important (Morris 1993). Broadly speaking, for feminists, the body is culturally constructed according to normalising standards that are organised patriarchally (Wendell 1996). The general argument is that the gendered body is a cultural construct. Gender is not an undisputable biological certainty; rather it is the product of bodily internalisation of cultural norms (Garland-Thompson 2003). In outlining women as 'other', thereby, feminist theory of the body, as has been argued, lends itself well to the understanding of other bodies thought of as 'other'. Despite this, Morris (1993) critiques feminist theory from a disabled body's point of view. Morris (1993) highlights the ableist underpinnings of feminism, and argues that the female body as perceived by feminism is tacitly able-bodied. Morris highlights examples of feminist perceptions of care whereby women and dependent people are talked about separately. The dismissal of the disabled woman's body, Morris argues, makes it difficult for disabled women to feel included by a movement that is principled on acceptance. It should be recognised that Morris' argument is now relatively dated and there has since been a movement towards feminist disability theory (Garland Thompson 2002, Wendell 2003). Morris' argument, however, should not be discarded. Morris makes an important point regarding abelism and the inescapable bodily norms that Western Cartesian society is based upon.

Wendell (1996) draws on the able-ist construction of the everyday and finds parallels with the feminist approach to the body. For Wendell (1996) the feminist argument that gender is socially constructed as a result of differences between females and males, can be translated to disability, in that disability is constructed as a result of differences between the disabled and the non-disabled. For Wendell (1996), however, the body cannot be entirely socially or culturally constructed. Instead, Wendell (1996 p.45) thinks of the biological and the social as interactive agents that construct bodies and therefore, disability, stating 'I believe that in thinking about the social construction of disability we need to strike a balance between, on the one hand, thinking of bodies' abilities and limitations as given by nature and/or accident, as immutable and uncontrollable, and on the other hand, thinking of them as so constructed by society and culture as to be controllable by human thought, will and action'. To acknowledge that not all social change can eliminate bodily difference, rather than seeming defeatist, is both refreshing and plausible. Wendell (1996 p.168) tells us that bodies have both 'limits and weight'.

What is useful about both the phenomenological and the feminist approaches to the body is that emotions, senses and feelings are seen as part of the body. Unlike the Cartesian separation of the mind from the body, issues often considered to be of the mind are constructed as embodied. As Nettleton and Watson (1998 p11) tell us 'the concepts of the lived body and the notion of embodiment remind us that the self and the body are not separate and that experience is invariably, whether consciously or not embodied'. Coleman-Fountain and McLaughlin's (2013) application of symbolic interactionism and theories of embodiment to the understanding of the role of impairment in how people identify themselves through social interaction seeks to explore how certain performances of embodiment become known to be different. This combination can be usefully applied to the understanding of learning disability in that symbolic interactionism stresses the role of social encounters in the production of selves while embodiment theory provides the body with a material reality. Coleman-Fountain and McLaughlin's (2013) combination of these approaches allows impairment, framed as 'what bodies can do' (p.133), to be seen as more than a discursive product. Impairment can be constructed in this way as a relationship between material bodies and social interactions. Unlike a post-structuralist approach, thereby, the materiality of the body is considered to be an essential factor within impairment. Indeed, Coleman-Fountain and McLaughlin (2013 p.139) state 'the way in which bodies look and function are significant in informing social interactions and are fundamental in deciding how bodies and persons 'fit' within normative frameworks of understanding'. For Coleman-Fountain and McLaughlin (2013), the importance of the body in the understanding of impairment is threefold. First, bodies that exist in the world are argued to be present within discursive practices. Here they give the example of the diagnosis of visual impairment and state 'to talk of a visual impairment implies something about the capacity of that body to see' (2013 p.139). Second, the body and what it can do is positioned as essential to the understanding of why some bodies are stigmatised and others are not. Third, how bodies perform is identified as playing a key role in social interaction and the production of identity. This simultaneous focus on what bodies can do and their role in social interaction allows learning disability to be seen in terms of a co-constitutive relationship between the material and the social and thus avoids the dualisms associated with the medical and social models.

Similarly, when writing about pain, Williams and Bendelow (1998 p.169) highlight the difficulties encountered by approaches that render the material body invisible and call for a sociological approach that embraces the body as the site of feelings and emotion in order to '(re)locate the embodied individual within the broader sociocultural contexts of meaning and action, thereby freeing pain from exclusive biomedical jurisdiction' (Williams and Bendwlow 1998 p.158). What is interesting about the approach to pain that Williams and Bendelow (1998) call for is that it recognises the biological origins of pain but yet avoids dualistic dominance by asserting pain, its origins and its experience, as embodied. Williams and Bendelow (1998) use the example of pain to show that the lived body can be ontologically thought of as a material entity while also being epistemologically thought of as a culturally orientated one. For Williams and Bendelow (1998 p.210), the social constructionist epistemology of culture and social norms fills 'the existential space between the immediate embodiment of disease as brute materiality and its meaning laden character as human experience'. It is important to note that Williams and Bendelow's (1998) suggestion is not hinged upon the dominant Cartesian conception of biology. When outlining their approach to biology they tell us that, 'to claim a biological foundation for the body does not necessarily imply reductionism if the very nature of biology itself is fundamentally rethought within the social sciences. Biology is not simply a limit or constraint. Rather it provides the active basis and transformative potential of our embodied being in the world' (Williams and Bendelow 1998 p.211).

It has been argued throughout the previous sections that, as with Williams and Bendelow's pain, learning disability is both biologically and socially embodied. As Williams and Bendelow (1998 p.212) state, 'stripped of its ideological baggage, biology provides a radical critique rather than justification of existing social arrangements'. Such an approach is useful because it both avoids and rejects dichotomous thinking. While the biological is recognised, it is not prioritised. Further to this, the biological is repositioned as something that can be thought about differently. The body is not posited as a Cartesian object, but as an active subject. As Thomas (2004 p. 59) states, 'such an ontology can, and should, hold to the position that this biological substrata is always and everywhere overlaid with socially constructed ideas about the body'.

The rejection of dualisms, via the reconstruction of biology and the positioning of the body as both ontologically material and epistemologically embodied, allows an answer for Synder and Mitchell's question (2001 p.381) outlined at the beginning of this section; 'can stories of disability be analysed without recourse to the pathologising discourse of interventionist medicine, on the one hand, or to the grotesque, on the other?'. The answer is yes, to understand the body as a biological and a social entity without the dualistic commitment to mind/body, social/biological, allows an alternative space for thinking about learning disability. In this way learning disability can be located in an individual body as a biological construct without recourse to the medical model. It is important here to think of biology in non-dualistic terms, to think of biology as Thomas (2004) encourages us to, as socially layered and as Williams and Bendelow

(1998) state, as without limit or constraint but rather as platform for embodiment. In constructing biology as such, biology becomes not something to be ignored or feared as in the social model, but as Williams and Bendelow (1998) state, a radical critique of Cartesian dominance. Furthermore, it allows the social to have a place within the body and vice versa.

Approaching the learning disabled body in this way positions the thesis philosophically, in that the learning disabled body is presented as both a social construct *and* a material reality. In claiming such a standpoint, people's views, perceptions and understandings of social reality are rendered epistemologically meaningful. These two philosophical positioning statements are discussed in further detail below.

Based on the literature provided and also the researcher's experience of working with people with learning disabilities, this project ontologically positions learning disability as both socially constructed and socially constructing. While this may seem epistemologically contradictory, this is not intended to be a dualistic position; rather, it is a unified one, whereby the body and society are co-constitutive. The learning disabled body is argued to be ontologically material and epistemologically social. In other words, the learning disabled body is fundamentally a biological body; however, its biology and its connotations are known socially, through social interaction, societal norms and their reproduction within social structures. In this way the learning disabled body can be seen to be an object onto which meaning is inscribed through social interaction. Such an approach is consistent with a social constructionist stance. While there are some social constructionists who believe that everything, including extremes such as death and furniture (Edwards et al 1995), are social constructs that cannot exist prior to human meaning making, social constructionism generally accepts the constitutive nature of things. Indeed, when talking about discourses as 'human meaning making', Wetherell et al (2001) tell us that discourse is both socially produced and socially producing. The learning disabled body, moreover, can be seen in the same way; it is both socially produced and socially producing. Such an approach affords both the body and sociocultural constructions a productive role within the reality and the discursive construction of learning disability. In claiming that the material learning disabled body is known through social interaction, it is imperative that people's views, perceptions and understandings are positioned as meaningful reflections of social reality.

Summary

This literature review has presented an answer for research question (a) and has also served as a space to discuss the theoretical limitations and challenges encountered when seeking to re-evaluate sociological perspectives of learning disability. The policy, theoretical and empirical literature presented highlights a number of gaps and shortfalls; namely the failure to acknowledge the semantic confusion that surrounds the term learning disability, the consequent tendency to misrepresent and mis-construct learning disability and the largely unquestioned role of cognitive ableism. It is suggested that a reconstruction of biology and a rejection of mind/body dualism, that the short falls of social policy and research have been shown to be predicated upon, can create a space in which learning disability can be considered more usefully. It is impetrative that learning disabled bodies and the ways of being that they present are afforded importance when seeking to understand and learning disability. Moreover, it is argued that learning disability is an embodied reality composed of biological foundations and social internalisations. It is from this ontological and epistemological starting point that the remaining research questions will be approached.

Chapter 3: Research design

It has been established that learning disability means different things to different people in different contexts; and it has been concluded that learning disability, as both a term and a material reality, is not easily positioned within either of the dominant theoretical conceptualisations of disability, namely the medical and social models. For this reason, it has been argued that a theoretical understanding of learning disability requires an embodied platform as its basis. In order to re-evaluate the theories of learning disability presented in the literature and to add to the theoretical work that has already been done towards this, it will be useful to establish both what learning disability means to different people in different practical contexts and how these understandings are produced. Research questions (b) and (c) address this need by asking:

(b) How is learning disability understood by both people with learning disabilities and by people without learning disabilities who work in learning disability practice or have the potential to influence this practice?

and

(c) What is the relationship between the constructions of learning disability produced by the participants with and without learning disabilities and how can this contribute to a re-evaluation of sociological perspectives of learning disability?

The inclusion of people with learning disabilities in research

As highlighted in the research questions and also the introduction, this research project seeks to include the voices of people with learning disabilities across the continuum of ability contained within its definition. Before the methodological approach and the discussion of the specific methods used is presented, it is first necessary to discuss the inclusion of people with learning disabilities in research and the importance of this, while also being mindful of the challenges this presents and the problems associated with many research projects that claim 'inclusivity'.

Research regarding learning disability is heavily dominated by medical perspectives, in particular psychology and psychiatry (Mladenov 2014); sociological perspectives by contrast are marginal. It is fair to say that even within Disability Studies itself, research that focuses on learning disability has only recently begun to feature. Prior to this, physical and sensory disability dominated the field. Within social science, research that addresses learning disability tends to either focus on service delivery and policy implementation (Rodger et al 2012) or concentrate on the experience of learning disability including the parental and/or care giver experience (Chadwick et al 2013), the social care provider experience (Salmon et al 2014), the medical professional experience (Clayton et al 2008) and increasingly, the personal experience (Povee et al 2014).

Such research is now heavily influenced by the social model's call to conduct inclusive projects. Indeed, inclusive research is now viewed as best practice within the social sciences (Blunt et al 2012). Further to this, inclusivity is now a requirement of major funding bodies such as the Department of Health, the National Institute of Health Research and the School for Social Care Research. 'Emancipatory', 'inclusive' and 'participatory' research are terms that are often used interchangeably and have become synonymous with disability studies. While each term has its own distinct origins, they are often used as umbrella terms to refer to research that involves people with learning disabilities as more than research subjects (Walmsley and Johnson 2003). For Oliver

(1992 p.102), traditional approaches to research such as positivism and interpretivism locate what he refers to as 'the social relations of production' with the researcher. Such approaches, he argues, can only generate analyses of disability that are reflected through the researchers' values and not disabled people's (Oliver 1992). Emancipatory research alters the relations of production by becoming part of the struggle against oppression; participatory research, on the other hand, can be described as research that includes people with disabilities as either co-researchers or participants (Kiernan 1999); while inclusive research is defined by Walmsley and Johnson (2003 p.9) as 'research in which people with learning disabilities are active participants, not only as subjects but also as initiators, doers, writers and disseminators of research', and is rooted in normalisation theory (Walmsley and Johnson 2003). Although there are different ways of defining such research, there is less flexibility in its application. When talking about the submissions received for their special issue on inclusive research, in the British Journal of Learning Disability, Blunt et al (2012 p.83) reported 'we received some papers that had not fully involved people with learning disabilities as researchers, but the authors still called their research 'inclusive'. This worried us as it could mean that some non-disabled researchers believe they are doing inclusive research when they are only involving people with learning disabilities in very small parts of the projects'. The construction of learning disability perpetuated by such research, in particular the research methods generally employed for such projects, helps to explain this tension.

Inclusive research with people with learning disabilities has typically relied on traditional research methods to gather information. Scior (2003), for example, uses semi-structured interviews to investigate the impact of gender on the lived experience of learning disability. Similarly, Salmon (2012) uses semi-structured interviews to address friendship among young adults with learning disabilities and Fitzgerald and Withers (2013) use semi-structured interviews to explore how ten women with learning disabilities identify with their sexuality. Recent examples of the use of focus groups include Chapman et al (2012) who used focus groups to research self-advocacy and Gates and Waight (2007) who used focus groups to understand how people with learning disabilities make sense of their mental health.

While semi-strutured interviews and focus groups are the norm, a smaller number of researchers have taken an ethnographic approach. Oswin (1991), for example, uses an ethnographic narrative approach to explore how people with learning disabilities experience grief. Similarly, both Goodley (2000) and Redley and Weinberg (2006) have used ethnography to explore self-advocacy; and Shelly (2008) has written a reflexive ethnography detailing a year in his life as a personal assistant to a person with learning disabilities. In addition to this, a growing number of researchers are now using arts based and visual methods. Welsby and Horsefall (2011), for example, organised art workshops in order to generate conversation among women with learning disabilities, from which to base their interviews on and Rojas, and Sanahuja (2012) used video to explore the lives of people with learning disabilities. Indeed, photovoice is also gaining in popularity. Examples of photovoice in practice will be discussed later in the research design chapter owing to the project's own use of this method.

The term co-researcher rather than participant is now popular in research projects that seek to be inclusive. People with learning disabilities have been involved as co-researchers in projects using a variety of methods. Oral histories (Atkinson et al 1997) and autobiographies, for example, (Baron 1996, Cooper 1997, Atkinson and Walmsley

1999) are generally considered to be inclusive research methods that empower people with learning disabilities, allowing them to reclaim their history that has previously been told by others (Atkinson et al 1997). David Baron's (1996) autobiography, for example, tells us about his life growing up in an asylum for children with learning disabilities.

In addition to oral histories and autobiographies, an increasing number of studies seek to include people with learning disabilities as co-researchers in an attempt to equalise power relations and avoid the criticism of speaking for or on behalf of people with learning disabilities (Walmsley 2001). Haigh et al (2013) describe their study, *What things make people with a learning disability happy and satisfied with their lives?*, as a fully inclusive research project. People with learning disabilities were included in: the research design, conducting interviews, analysing findings, writing the research paper and making the film that formed the accessible project report. Similarly, Butler et al (2012) involved people with learning disabilities in the planning, implementation, analysis and dissemination of their research project using focus groups to explore the experiences of people with learning disabilities living with someone who has cancer. Welsby and Horsfall (2011) also involved people with learning disabilities as co-researchers in their project to address the experience of women with learning disabilities. Five women attended art workshops and were asked to set the research agenda by talking about whatever they wanted to.

Common to the 'inclusive' studies presented, however, is the involvement of a particular type of person with learning disabilities. People that can verbalise life histories, write autobiographies, respond appropriately to interview questions, engage in art workshops and participate in the research process are generally representative of people with relatively high levels of cognitive ability. The needs of people with learning disabilities, therefore, can prove a challenge for traditional research methods to function as they might be expected to. As Kaehne and O'Connell (2010) tell us, focus group participants 'need to have the ability to: (1) reflect on their own and other participants' views, (2) engage communicatively with each other, and (3) explore a given issue with minimal guidance from the moderator'. The characteristics of some people with learning disability i.e. lack of verbal communication, pre-intentional communication, inability to process abstract questions and limited social interaction, challenge the use of focus groups methodologically (Kaene and O'Connell 2010). Further to this both Fraser and Fraser (2001) and Gates and Waight (2007) have found that focus groups conducted with people with learning disabilities can often lapse into individual interviews carried out in a group setting, losing the group interaction that is key to the focus group method. Gates and Waight (2007 p.114) reflect on their use of focus groups to explore people with learning disabilities' knowledge of mental health services and tell us, 'the facilitator had to provide detailed explanation and as such this had the potential to be construed as leading informants. Sometimes the researchers had to actively steer away from providing an educational service rather than undertaking exploratory research'. While focus groups have and can be successfully used when conducting inclusive research, as in the example of Chapman et al (2012), the participants in successful projects typically have mild to moderate learning disabilities. Chapman et al's (2012) participants were self-advocates and so are likely to have been relatively able.

While the majority of people with learning disabilities fall into the mild/moderate category of ability (DoH 2001), a significant minority do not. Research involving people with profound and multiple learning disability is scarce (Klotz 2004). Of course there is an obvious reason for this marginalisation: people with PMLD are not able to engage in the types of research identified above, they likely cannot verbalise their feelings and require much support for day to day living. Interviews, oral histories and focus groups etc are impossible research methods for this group (Klotz 2004). While this is a fact of their disability, problems arise when research uses the term learning disability without specification. As shown, the term learning disability includes a continuum of ability, and so to claim that research conducted with relatively able people with learning disabilities is representative of learning disability becomes problematic when generalised research claims are made. Welsby and Horsfall (2011 p.796) for example tell us 'we believe that there will be resonances for other women who have an intellectual disability in the western world'. Similarly, Butler et al (2012 p.140) conclude that 'no subject is too difficult for people with learning disabilities to talk about'. Such research, thereby, implicitly constructs people with learning disabilities as relatively able, or 'normal'. This way of seeing people with learning disabilities allows the current language of co-researchers and empowerment to continue. This way of seeing learning disability, however, is again representative of cognitive ableism.

The construction of learning disability that implicitly predominates within inclusive research, thereby, renders it exclusionary, limiting those who can take part to only those who are able. As Walmsley (2001 p198) tells us, 'most people with learning difficulties need allies to do research'. In some cases, PMLD for example, it is necessary to speak for people with learning disabilities because people with PMLD may have no verbal communication and are largely unable to cognitively process abstract concepts/questions for themselves. People with PMLD lead mediated lives; in many cases their life would not be possible without support. A mediated approach to involving people with PMLD in research, therefore, cannot be avoided. This should not be seen as a limitation but rather should be treated as a necessary condition of the research. While emancipatory research as defined by the social model may not be achievable for some people with learning disabilities this is not to say that research cannot be emancipatory in a more traditional sense. There is both room and necessity for a plurality of voices. As Klotz (2004) points out, research with people with PMLD requires a radically different methodological approach.

The application of the aims of inclusive research to research with people with learning disabilities and the tensions that then arise are reflective of the origin of such an approach. The social model, as outlined in the literature review, has only recently moved towards the inclusion of people with learning disabilities (Shakespeare 2010). Despite seeking to reject an individualist approach associated with the medical model, inclusive research often follows the exclusionary discourse of the social model. As has been emphasised, while some people with learning disabilities have additional physical and sensory disabilities, their primary disability is cognitive. Where people with physical and sensory disabilities generally share able-mindedness as a characteristic, people with learning disabilities do not. It is cognitive impairment, moreover, that sets people with learning disabilities apart from other people with disabilities. Consequently, it can be argued that emancipatory, participatory and inclusive research, in the original forms, require modification in order to fit the needs of people with learning disabilities and what their bodies can do.

The inclusion of people with learning disabilities in research requires the use of methods that can be tailored to the participants' range of needs and abilities. Including people with learning disabilities often requires breaking away from the use of traditional research methods or modifying them as necessary (Aldridge 2007). Not to include people with learning disabilities in a project that seeks to gain an understanding of how social actors understand learning disability would result in limited research findings and a weak re-evaluation of current theories. Although people with learning disabilities are included in this project as research participants, I do not intend to promote this project as inclusive or emancipatory research in their current established forms, nor would it be appropriate to do so. As argued here, the inclusion of people across the continuum of learning disability in the whole research process is unrealistic. This research project aims to re-evaluate concepts and definitions of learning disability using the constructions of learning disability generated by those in 'the real world'. As Walmsley (2001) warns, inclusive and emancipatory research risks the loss of theory: 'my fear is that inclusive researchers are so fearful of saying things which people with learning disabilities cannot follow that they say very little, leaving the field of theorising to others, including disabled scholars, with little or no commitment to inclusion'. This is not, however, to say that this research project, its findings and dissemination, are not inclusive or emancipatory in their own terms, rather the opposite will be argued as the methodology progresses.

Based on the project's ontological and epistemological assumptions, that learning disability is both materially and socially produced, as outlined in the literature review, the research methods and the modes of analysis used to answer the questions above were tailored to the particular needs and abilities of the participants involved. For this reason a qualitative research design using two research methods and two modes of analysis was chosen: focus groups and discourse analysis for the participants without learning disabilities and photovoice and interpretive engagement for the participants with learning disabilities. In order to set out this particular approach, this chapter is divided into two sections. The first section builds on the philosophical position . Here, the project's ontological and epistemological starting points are discussed in relation to the research questions and the research design. The second section, methods, outlines each method chosen and details relevant examples of these methods in practice. This section also discusses sampling, ethics and access and provides a reflexive discussion of the methods in practice. The two sections are not mutually exclusive, rather the project's ontological and epistemological starting points provide justification for the use of the particular methods chosen and how they were used.

Section 1: Methodology

The research questions and the research design chosen to answer them are underpinned and enabled by the research project's epistemological and ontological starting points. Grounded in the literature discussed in the previous chapter, the project is premised upon two philosophical position statements. First, that learning disability is both a social construct and a material reality; and second, that people's views, perceptions and understandings are meaningful reflections of the social reality that the project seeks to explore.

To claim that peoples' views, perceptions and understandings of the world are meaningful reflections of social reality is reflective of the ontological and epistemological starting point outlined above and positions the project firmly within a qualitative approach to social science. At face value, however, research questions (b) and (c) could be answered using a variety of research designs. The questions seek to explore a specific instance of social reality – how learning disability is understood by different social actors. As Becker (1996) tells us, the aim of both qualitative and quantitative methodology is to explore social reality, in that they both seek to provide some insight into why and how events occur. At this preliminary level, qualitative and quantitative methodologies are very similar. It is their differing epistemologies and ontologies that set them apart and render one more applicable than the other in specific instances. Generally speaking, quantitative methodologies adopt a realist stance while qualitative methodologies refute such an approach (although the degree of refute varies depending on theoretical position) and adopt a relativist approach whereby the presence of multiple realities is accepted.

The realist stance adopted in a quantitative methodology sets out that objects exist independently of human experience and that objective knowledge of them can be achieved scientifically, through the removal of social and cultural variables from the research process (Benton and Craib 2011). Within the social sciences, positivism is associated with quantitative methodology. For positivist researchers, A always happens when B happens. Knowledge of this truth is achieved using reliable scientific methods. Quantitative methods, therefore, seek to make knowledge claims that are considered to be objective truths (Benton and Craib 2011). Objective truths can be replicated by other researchers simply by applying the same scientific method or by observing the same processes. Alternatively, qualitative methodologies embrace the subjectivity and human experience that quantitative methodologies seek to control (Hammersley 2013).

Generally speaking a qualitative methodology adopts some form of social constructionism in that, objects whether thought to be pre-social or not, are thought to be known socially. Human action is not thought to be explainable through value-neutral methods. Rather than seeking to find replicable 'truths', qualitative methodologies seek to highlight specific instances of social action (Benton and Craib 2011). In addition to this a qualitative research design allows the flexibility to explore people's experiences and understandings of the world (Hammersley 2013). As Becker (1996 p.56) outlines, 'the point of qualitative research is not to prove, beyond doubt, the existence of particular relationships so much as to describe a system of relationships, to show how things hang together in a web of mutual influence or support or interdependence or what have you, to describe the connections between the specifics'. A qualitative methodology, thereby, is inherently relativistic, in that it is accepted that there will be multiple interpretations and accounts of the world, hence the importance of the belief that people's views, perceptions and understandings of the world are meaningful reflections of social reality.

In order to work within the project's specific ontological and epistemological position a complementary research design is required and indeed, certain research designs are rendered unsuitable. A research design that values reality as a static entity that humans respond and adapt to, such as a positivist design, would not facilitate appropriate or convincing research findings for this research project (Morgan and Smircich 1980). Despite acknowledging the material reality of the learning disabled body, this project does not seek to produce social rules or population-wide generalisations, rather it seeks to provide instances of social action in the form of the discourses used by different social groups to produce their understandings of learning disability. The aim is to describe this social reality as observed in the participants' understandings. A methodology that seeks to highlight how meaning is relational rather than to prove or produce laws beyond reasonable doubt is required. It is for this reason that a qualitative research design has been chosen.

A qualitative research design offers a number of methods to be used to explore social realities, including; interviews, participant observation, focus groups, life histories, arts based methods and visual methods (Hammersley 2013). While sharing the same ontological starting point, that social worlds are made up of overlapping and constitutive variables (Becker 1996) each method has its own set of epistemological rules (Kaehne and O'Connell 2010) that render methods useful or not in specific research contexts. It is for this reason that two compatible methods, focus groups and photovoice, were chosen to answer research question (b). In addition to this two complementary modes of analysis were used to analyse the research findings. As stated, discourse analysis, specifically Potter and Wetherell's (1987) concept of interpretive repertoires, was chosen to analyse the focus group talk and Drew and Guilimen's (2014) interpretive engagement was chosen to analyse the photovoice findings.

The decision to use two separate methods and frameworks of analysis is informed by the project's ontological claim that learning disability has a non-dualistic biological basis that has a direct impact on what a learning disabled body can do. While the aim of the project is to establish how different groups construct their understandings of learning disability it was decided that the ontological differences experienced by people with learning disabilities necessitated a research method that does not rely on verbal communication. An alternative mode of analysis that reflected this was, therefore, chosen. Although nearly all of the participants produced talk as part of the research methods used, the structure of the talk provided by the participants with learning disabilities differed significantly to the talk provided by the participants who did not have learning disabilities. This was a consequence of what the two groups of participants' bodies could do. In the case of many of the participants with learning disabilities, their talk was often limited to short sentences and in a number of cases was structured in a way that talk is not generally expected to be structured. As examples: some participants mixed what they were talking about with other topics; some participants stuttered or slurred very significantly; many of the participants' answers were limited to short sentences; and many participants talked about other things entirely. In addition some participants did not talk at all. Further to this the participants also produced visual representations of learning disability as part of the photovoice method. For this reason it was decided that the cognitively ablest parameters of discourse analysis did not fit the photovoice findings. The choice of research methods and modes of analysis are further related to the project's philosophical basis in the second section below.

Section 2: Methods of data collection and methods of analysis

This section builds on the methodological discussion above and outlines the practicalities of the research methods used to answer research questions (b) and (c). In order to provide further detail about the methods chosen, a description of each method and mode of analysis is provided and examples from other research studies that have used these methods are given. This is followed by a description of the conduct of the research including: sampling, access, ethics and the use of each research method in practice. Finally a reflective discussion of the research process is provided.

Focus Groups

Focus groups were chosen as the most appropriate method to explore different lay and professional groups' constructions of learning disability for the reason that focus groups allow the discursive interaction between participants to be seen. As Kitzinger (1994 p.117) states, 'when researchers want to explore people's understandings it makes sense to employ methods which actively encourage the examination of the social processes in action'. It is this interaction, how the group constructs its own particular understanding of learning disability, that is of interest to this project.

Morgan (1999 p.130) describes focus groups as 'a research technique that collects data through group interaction on a topic determined by the researcher'. Furthermore, focus groups allow the investigation of the meanings that people attach to a prescribed topic via the observation and encouragement of their discursive interaction. When talking about her use of focus groups to explore the effects of media messages about AIDS, Kitzinger (1994 p.107) tells us, 'when group dynamics worked well the co-participants acted as co-researchers taking the research into new and often unexpected directions and engaging in interactions which were both complementary and argumentative'. It is for this reason that focus groups can yield data on 'sensitive' topics that might not otherwise be accessible in a one-to-one interview. While talking about learning disability might not seem like a sensitive topic, as has been established, learning disability is a politically loaded term that can mean different things to different people.

When explaining why focus groups were used to explore people with learning disabilities' attitudes to disability, CorrMcEvoy and Keenan (2014 p.222) state 'we decided to do focus groups because they are more open and people mightn't be as nervous or shy to speak up'. In addition to removing the potential intimidation of a one to one interview, focus groups allow the conversation to flow in countless different directions as the participants respond to one another (Kitzinger 1994). The interaction within focus groups creates a space for broad discussion (Barbour 2008) where participants can both agree with and contradict each other.

As seen in the literature review, focus groups have been widely used within learning disability research to explore a variety of research topics (Chadwick et al 2013, Chapman et al 2012, Gates and Waight 2007). Employing a similar rationale to this research project, Chapman et al (2012), used focus groups to explore how the term 'advocacy' is understood by four groups of stakeholders: people with learning disabilities, family carers, direct support workers and service managers and commissioners. As with this project and the term learning disability, Chapman et al (2012) recognised that advocacy means different things to different people and that this can result in various uses of term. When carrying out the focus groups, Chapman et al (2012) structured the groups differently according to need. For those with learning disabilities, a more interactive approach was taken, including group exercises, art work and drama, while only a topic guide was used for the focus groups of stakeholders without learning disabilities. Despite Chapman et al's (2012) effective use of focus groups with people with learning disabilities, the people they included were not people with severe or profound and multiple learning disabilities. As seen in the literature review the epistemological parameters of focus groups do not hold up well for all people with learning disabilities. It is for this reason that an alternative method was chosen to include people with learning disabilities in this study

Photovoice

In an attempt to overcome the repeated challenges of including people with learning disabilities in research, highlighted in the literature review, photovoice has been chosen as an accessible method to allow the inclusion of people with learning disabilities with a full range of abilities. Photovoice is one of a number of photography based visual methods including auto-driven photo elicitation, whereby participants' photographs are used to facilitate discussion (Pink 2006) and photo elicitation, whereby photographs taken by the researcher or pre-existing photographs are used to facilitate discussion (Stanczak 2007). Photovoice was originally developed by Wang and Burris (1997) as an action research tool to be used within health promotion research. Following Wang and Burris' pioneering use of the method to explore women's experiences of health in rural China, Wang (1999) outlined nine prescriptive steps for delivery. These are: 1) selecting a target audience, 2) recruiting participants, 3) educating participants about the photovoice method, 4) gaining informed consent, 5) brainstorming the project focus with participants, 6) distributing cameras, 7) providing time for participants to take photographs, 8) meeting with participants to talk about their pictures using the SHOWeD method of questioning (**W**hat do you See here? What is really **H**appening? How does this relate to **O**ur lives? **W**hy does this problem or strength really exist? What can we **D**o about it?) and 9) planning how to share this information with the target audience.

While retaining its general structure, Catalani and Minkler (2010 p.448) tell us that over time Wang's nine steps have been adapted by other researchers to meet the needs of their research project and participants so that photovoice can now be described as 'a flexible tool….It can be altered to fit diverse partnerships, community contexts, participant characteristics and research or intervention interests'. Further to this a number of researchers have sought to expand the photovoice method to include researcher analysis within the process (Drew and Guilemin 2014, Carlson et al 2006 and Baker and Wang 2005). Drew and Guilemin's (2014) interpretive engagement, used to analyse the photovoice findings here, is an example of this.

Generally, in photovoice, research subjects are given cameras to take photographs of either a negotiated subject or a subject of the researcher's choice and are given a time period in which to take the photographs. The photographs taken are then discussed informally either in a group setting or individually. As Booth and Booth (1997) tell us, in photovoice participants are able to take control of the aspects of their lives that they choose to reveal to the researcher. In turn the researcher is allowed entry into the lives of the research subjects in a depth that likely could not have been achieved otherwise. Booth and Booth (1997 p.432) go on to state: 'photovoice is all about point-of-viewness: it sets out to capture and convey the point of view of the person holding the camera. Photovoice invites us to look at the world through the same lens as the photographer and to share the story the picture evokes for the person who clicked the shutter'.

Photovoice is a seldom used method within research involving people with learning disabilities. Despite this three notable studies have used photovoice: Booth and Booth

(1997), Jurkowski and Paul-Ward (2007) and Povee et al (2014). Each of these studies found photovoice to be an accessible method that could be adapted to the needs of their participants. Booth and Booth (1997) worked with 16 mothers with learning disabilities who regularly attended a parenting support group to gain an insight into the experience of being a parent with learning disabilities. In their project participants were asked to take photographs of anything they associated with their life as a parent. For Booth and Booth (1997), the combination of participants' photographs and their explanations allowed an insight into the experience of parenting that semi-structured interviews would not have been able to access. One mother's photographs, for example, on first viewing appeared to be of empty street scenes. Booth and Booth (1997) describe the images on first appearances as a 'puzzle' and wondered why there weren't there any photographs of the child. When asked to talk about the images, however, the mother revealed that the photographs were of places on the way to the support group that her son liked. Her son had recently started school and so no longer accompanied her to the group. The mother was feeling lonely without her son. As Booth and Booth (p.438) state 'these are not lifeless street scenes after all. The images have a totemic significance as material representations of a phase in their mother–child relationship'.

Jurkowski and Paul-Ward (2007) used photovoice with four Latino adults with learning disabilities to explore how people with learning disabilities make sense of their health and wellbeing. Participants were asked to think about what hurt or helped their health and to take photographs of these things. Jurkowski and Paul-Ward (2007) found that the images enabled abstract concepts to be addressed. One participant for example, had asked his mother to take a picture of him in bed. This allowed him to talk about air pollution and how this affects his asthma. In contrast to traditional research methods, Jurkowski and Paul-Ward (2007 p.363) found that photovoice, 'provides something concrete; photographs that promoted participants to talk about their perspectives'.

In their 'This is me' project Povee et al (2014) asked their 18 participants to take photographs of things that represented who they are and things that they valued as important in their lives in order to explore identity and social roles among people with learning disabilities. Povee et al (2014) found that the photovoice method allowed them access to areas of their participants' lives that other methods likely wouldn't such as visualisations of their homes, workplaces and holidays. Indeed Povee et al (2014 p.901) state, 'using photovoice, researchers are able to obtain a more rounded insight into how the world is perceived and experienced by people with intellectual disabilities as they are granted access to their homes and community'.

In addition to allowing the inclusion of a diverse range of participants, photovoice also allows for innovative dissemination of findings. While traditional means of dissemination often involve publishing in locations that the research participants do not have access to or knowledge of, academic journals, trade magazines and institutional reports, photovoice allows the benefits of the research findings to be shared more equitably. Booth and Booth (1997), for example, posted their participants' photographs on a website and Jurkowski and Paul-Ward (2007) produced a photo album for each participant to keep. The photographs taken for this project will be displayed in two public exhibitions. Povee et al (2104) also chose to exhibit their participants' photographs publically. The exhibitions will be discussed in more detail when the practical application of photovoice is addressed.

While the term photovoice, etymologically, may imply an emphasis on visual and verbal communication, the method allows participants the opportunity to voice their worlds visually, opening up the method to people who may not be able to articulate themselves verbally as is the case for many people with learning disabilities. Booth and Booth (1997 p433), for example, tell us 'by combining visual images (the photo element) with individual and group discussion (the voice element), it helps to include people who lack verbal fluency. Photography as an activity emphasises action over cognition (we 'take' photos after all); it provides a means of concretising issues and concerns in a way that corresponds more closely to the thinking of people with learning difficulties than other more abstract modes of expression'. Similarly, Jurkowski and Paul-Ward (2007 p.363) state, 'photovoice allows people with intellectual disabilities to express their real life experiences through photographic images that represent their perspective as they interact socially within their home, agency and neighbourhood'. In sum, photovoice provides an accessible method that allows an insight into the lives of people who often cannot communicate their experiences via more traditional research methods. Importantly, it can be tailored to the participants needs without breaching its methodological parameters.

The use of two methods and two modes of analysis

Epistemologically, the use of photovoice and focus groups is both compatible and complementary. Both methods share the same epistemology that in turn fits with the epistemological underpinning of the research project: that people's values, opinions and experiences are meaningful reflections of social reality. Both methods involve group sharing, allowing the construction of meaning generated by specific groups to be explored. This combination of methods brings a fundamental benefit to the project. The use of photovoice and focus groups allows the inclusion of people with learning disabilities without challenging the methodological underpinnings of more traditional research methods which are implicitly designed with the cognitively able in mind. In order to re-evaluate sociological perspectives on learning disability via ‘real world’ constructions, the perspectives of people with learning disabilities are equally as important as those of people without learning disabilities. Not to include people with learning disabilities because a research method that is suitable for those without learning disabilities would be compromised by the characteristics of some people with learning disabilities would result in limited research findings that uphold a medical model of disability. Similarly, the two modes of analysis employed also begin with the same epistemological starting point: that social worlds are a product of social interaction and social structures. Indeed, the choice of two methods and modes of analysis is principally driven by the project’s ontological claim that the learning disabled body is of relevance to the social construction of learning disability and its epistemological claim that this material body is known socially. The choice is also driven by the project’s aim to reveal how different groups construct learning disability and the resources they draw on to do this. In making these claims, it is sensible to choose methods that reflect what the individual bodies involved can do in order to allow their access to the project and the inclusion of their voices.

Analysis

As stated, Potter and Wetherell’s (1987) concept of interpretive repertoires was used to analyse the focus group talk and Drew and Guilemin’s (2014) interpretive engagement was used to analyse the photovoice findings. Each of these modes of analysis are discussed below.

Discourse analysis

Broadly described, discourse analysis looks at patterns of language within and across texts as well as taking account of the social and cultural contexts in which the texts occur (Wetherell 2001). Potter (1996) outlines two primary assumptions within discourse analysis: that discourse is a social practice; and that linguistic resources facilitate this social practice. Rather than simply reflecting reality, language, via the use of linguistic resources, is seen as having an active role in its construction (Bowker and Tuffin (2002). For discourse analysts 'how we choose to position our experiences is intrinsically connected to the ways in which our understandings are linguistically presented' (Bowker and Tuffin 2002 p. 331). Discourse analysis, moreover, applies a social constructionist ontology and epistemology – social reality or meaning is constructed through language in use and, consequently, is also known through language in use. The aim is not to identify permanent attitudes or truths but rather to highlight how language is both constituted by social reality and constructive of it (Vehkakoski 2007). As Tuominen et al (2002 p.273) identify, discourse analysis focuses on 'discourse as the vehicle through which the self and the world are articulated and on the way different discourses enable different versions of selves and reality to be built'.

Potter and Wetherell (1987) use the analogy of a ship in a bottle to describe their approach to research. Like ships in bottles, people's worlds are made up of parts – society, selves, material objects etc. – that are taken for granted as having always been there, ‘their presence is unquestioned and miraculous’ (Potter and Wetherell 1987 p.181). In this way, discourse analysis renders the process of ‘manufacture’ important. In the case of learning disability for example, as highlighted in the literature review, learning disability is a material and social reality that is often used un-problematically in discourse. This unquestioning use is underpinned by a variety and combination of discourses at work. Like the ship in the bottle, understandings of learning disability aren’t just there, they are manufactured by discourses that are part of social life that in turn is impacted upon and produced by material learning disabled bodies.

Although the project acknowledges the presence and role of the learning disabled body, it is the social construction of how these bodies are understood that is the primary research interest. It is for this reason that discourse analysis’ social constructivist focus provides a compatible tool for analysis of this data. Indeed, when discussing the uses of discourse analysis within disability studies, Grue (2010 p.533) tells us, ‘while disability has a material component that is inextricably linked to individual bodies... the consequences that the biophysical has for the individual in question is to a huge extent a matter of socio-political dynamics’. It is the function of discourses at work, both in terms of how discourses shape learning disability, and how the materiality of learning disability shapes such discourses, that are necessary to answer the research questions and ultimately contribute to a re-evaluation of theories of learning disability. The purpose of analysing the talk generated in the focus groups and photovoice sessions is not to seek out objective truths, but to highlight the meanings given to learning disability and the ways in which such meanings are constructed.

Interpretive repertoires

Interpretive repertoires are identified by Potter and Wetherell (1987 p.149) as a linguistic resource used in language to construct meaning. Interpretive repertoires are defined as 'recurrently used systems of terms used for characterising and evaluating actions, events and other phenomena' that are 'constituted through a limited range of terms used in particular stylistic and grammatical constructions'. Potter and Wetherell (1987 p.149) further tell us that 'a repertoire will be organised around specific metaphors and figures of speech'. Indeed, Edley (2001 p.202) likens interpretive repertoires to 'repositories of meaning: that is distinctive ways of talking about objects and events'. Interpretive repertoires, therefore, are one of the linguistic resources Potter (1996) referred to when outlining the two principles of discourse analysis. Interpretive repertoires are resources that allow the speaker/writer to construct meaning and consequently manufacture subject positions, identities, selves and understandings of the world. They are active entities; they represent language in action and can be used flexibly to achieve this (Potter and Wetherell 1987).

As a linguistic resource that can be drawn upon to make sense of events, actions and other phenomena, interpretive repertoires are embedded within the societies and cultures which they are used to understand. As Edley (2003, p.202) states, 'in becoming native speakers, people are encultured into particular, even partial ways of understanding the world'. Indeed, Edley and Wetherell (1999) talk about interpretive repertoires as socially and culturally produced resources that allow individuals to engage in, share, and comprehend common understandings of the world. Consequently, there are many and evolving interpretive repertoires that can be drawn upon in any given situation. As Edley (2003, p.202) states, 'interpretive repertoires offer speakers a whole range of different rhetorical options'. Potter et al (1990) liken this range of options to the positions available to a ballet dancer. Just as a ballet dancer can chose from a variety of moves depending on the context in which s/he is dancing in, a speaker can choose different repertoires and moves within the repertoire, such as metaphors and terms, to suit the context in which they are speaking. The interpretive repertoires used by individuals to construct meaning, therefore, can be many and varied. Different repertoires can be used to perform different tasks. Indeed, Potter and Wetherell (1987 p.156) tell us 'people go through life faced with an ever-changing kaleidoscope of situations, they will need to draw upon very different repertoires to suit the needs at hand'. Further to this, certain repertoires may not be unique to specific groups of people and may be found to be used across varying groups. They can also work together or in tension. Unlike the themes identified in traditional thematic analysis, interpretive repertoires acknowledge variance as well as consistency in the way that people construct meaning (Lupton 1995). As Vehkakoski (2007) identifies, interpretive repertoires can change, overlap and conflict even within the same conversation with the same person. In summary, interpretive repertoires represent the flexible and ever changing resources available to speakers to enable them to make sense of the everyday (Bowker and Tuffin 2002).

As well as making sense of the everyday, interpretive repertoires also invoke identities and subject positions. Moreover, their capacity for making sense of events and actions is inextricably linked to the creation of selves. As Tuominen et al (2002 p.273) identify, 'different discourses enable different versions of selves and reality to be built'. The multitudinous nature of interpretive repertoires not only allows for varied and flexible accounts of events, but also allows for the construction and reconstruction of individual identities (Davies and Harre 1990). Indeed, Edley and Wetherell (1999) tell us that identity is actively and discursively constructed. Davies and Harre (1990) call this rhetorical identity work 'positioning'. Positioning can be both interactive, where one person positions another, and reflexive, where an individual positions themself (Davies and Harre 1990). As Edley and Wetherell (1999) found in their study of middle class boys' accounts of their potential futures, the boys' uses of different interpretive repertoires allowed them to position themselves with contradictory identities associated with both feminism and sexism. As Davies and Harre (1990p.46) tell us, 'who one is, is always an open question with a shifting answer depending upon the positions made available within ones own and others discursive practices and within those practices the stories through which we make sense of our own and others lives'. Identity, therefore, is constructed as an on-going process and language is positioned as the site of identity construction (Edley and Wetherell 1999).

As linguistic resources, therefore, interpretive repertoires allow speakers to traverse the ever-changing and contradictory landscape that is shared cultural and social knowledge. In drawing on different repertoires at different times according to context, speakers can make themselves understood to their audience and can associate and disassociate themselves with particular identities (Davies and Harre 1990). In doing this speakers can also negotiate what Billig et al (1998) call ideological dilemmas. Like interpretive repertoires, ideological dilemmas are reflective of shared social and cultural beliefs and the history that has produced them (Billig et al 1998). Such shared beliefs contain contrary ways of understanding the world; it is when two contradictory themes conflict that an ideological dilemma is created (Billig et al 1998). For this reason ideological dilemmas are not straightforward, rather they are complex and changeable.

Ideological dilemmas create a situation in which 'people are pushed and pulled in opposing directions' (Billig et al 1998 p.163). This back and forth movement between contradictory repertoires indicates the presence of an ideological dilemma (Edley 2001).

Such an approach enables the complexity of shared social and cultural knowledge about learning disability to be acknowledged and reveals how this knowledge comes to structure everyday understandings of learning disability. In summary, interpretive repertoires have been chosen as the most appropriate approach to discourse analysis for this project for the reason that their identification allows the shared, varied and contradictory nature of learning disability, that often goes unacknowledged or unnoticed, to be seen. In addition to this the encultured (Edley 2001) basis of interpretive repertoires allows the learning disabled body's ties to normative social and cultural expectations to be highlighted.

There is no one prescribed way of doing discourse analysis, instead there are many frameworks and models to choose from (e.g. Potter and Wetherell 1987, Parker 2005, Wodak and Krzyzanowski 2008, Van Dijk 1993). Further to this, when talking about doing discourse analysis Potter and Wetherell (1987 p.169) tell us 'it should be clear there is no analytic method, rather there is a broad theoretical framework, which focuses attention on the constructive and functional dimensions of discourse coupled with the readers [researcher's] skill in identifying significant patterns of consistency and variation'. Despite this, Potter and Wetherell (1987) outline a flexible ten step guide to carrying out discourse analysis. The ten steps include: 1. Research questions, 2. Sample selection, 3. Collection of documents, 4. Fieldwork, 5. Transcription, 6. Coding, 7. Analysis, 8. Validation, 9. Writing up, and 10. Application. Steps 6 and 7 of this process were followed when analysing the focus group talk. Their application will be discussed further when the practical experience of conducting this form of analysis is discussed.

Discourse analysis in learning disability research

While discourse analysis is a well used method within the social sciences and the humanities, there are few examples of its use within disability studies and fewer still within learning disability research (Scior 2003, Antaki et al 2002, Danforth and Navarro 1998, Rapley et al 2010). This is not to say that discourse analysis is not a useful method when it comes to learning disability research. Indeed, further to the evidence provided above, Grue (2010) tells us that disability displays many of the same characteristics of popular discourse research topics such as gender and racism whereby marginalised identities are also explored. A small number of researchers (Danforth and Navarro 1998, Scior 2003), have applied discourse analysis to talk about learning disability.

Scior (2003) used discourse analysis to identify how women with learning disabilities construct their identities in relation to gender and disability. A discourse analytic approach was chosen in order to highlight the linguistic resources used by the participants to generate their understandings of the role of disability and gender within their everyday experiences. Scior (2003) found that a discourse analytic approach revealed the dominance and tensions between unquestioned constructions of women and people with learning disabilities. Indeed, Scior (2003 p.793) tells us that where previously the talk of people with learning disabilities has been viewed with caution due to the presence of contradictions and inconsistent responses, 'discourse analysis provides a beneficial method due to the acknowledgement of contradiction as part of everyday talk'. Scior's work, however, encounters the very problem highlighted in the literature review: her participants only included women with mild learning disabilities.

With similar aims to this project, Danforth and Navarro (1998) used discourse analysis to explore how everyday talk can construct what they refer to as mental retardation as a specific identity. Danforth and Navarro (1998) collected instances of discussions about learning disability that took place in everyday settings such as the home and public places and used discourse analysis to look for common themes throughout the talk. The discourse analysis they carried out resulted in the conclusion that speakers used the term mental retardation as part of their everyday vernacular as a term of expression without the intention to insult individuals who have been categorised as mentally retarded, as in phrases such as: 'you are being retarded' and 'you are such a retard'.

While discourse analysis has proved useful to these projects, common to each of them is the distinct absence of people with severe or profound and multiple learning disabilities i.e. people whose cognitive ability would challenge the use of discourse analysis. By virtue of the range of cognitive difference found within people with learning disabilities as a population category, as already outlined, discourse analysis is not always applicable to their talk that can be structured very differently to that expected in discourse analysis. As stated, it is for this reason that interpretive engagement was chosen to analyse the photovoice findings.

Interpretive engagement

Interpretive engagement is a framework for analysing participant generated photographs developed by Drew and Guilemin (2014) in order to expand the system of analysis included within the photovoice method. Interpretive engagement positions participant generated photographs as both representations of reality and a means for investigating the social construction of this (Drew and Guilemin (2014). For some researchers (Yates 2010), this is seen as an either/or relationship – either photographs are considered to be what Yates (2010) describes as a 'window to the world' whereby images are thought about in terms of objective representations of reality, or photographs are considered to be what he calls a 'window to identity' whereby images are thought about in terms of a means to reveal the sociocultural nature of reality. Indeed, interpretive engagement is based on Bank's (2008) assertion that images have an internal and an external narrative (Drew and Guilemin 2014). The internal narrative emphasises what the image represents and the external narrative focuses on the sociocultural context of the image. Both narratives operate in a co-constitutive relationship. In other words, the reality presented in the image can only be known through social interaction and social interaction would not occur if the object was not present (Banks 2008).

The aim of interpretive engagement, moreover, is not to claim that photographs represent a means to achieving objective truths nor that they present such truths but rather to establish that photographs have multiple meanings that can change over time due to the socially constructed nature of the knowledge of what the image shows (Drew and Guilemin 2014). This ontological and epistemological basis, therefore, renders interpretive engagement a suitable method of analysis for the photovoice findings in relation to both the project's own ontological and epistemological starting points and also the aim of the photovoice method.

In acknowledging that photographs can have multiple layers of meaning, interpretive engagement sets out a systematic, three stage approach to the analysis of participant generated photographs. Drew and Guilemin (2014 p.57) state that it is 'through engaging with, and articulating, a range of potential readings of participant generated photographs, the researcher becomes more accountable for what they think they have come to know, how they have come to know it and what they might still know at the end of their visual analysis process'. Each of the three stages in place to achieve this, are outlined below.

Stage 1: Participant interpretation of meaning

This stage of analysis focuses on what the participants want to show the researcher and how they explain this. At this stage the data to be analysed includes: the participants' photographs; their thoughts about the images and how they came to produce them; and any research parameters under which the photographs were taken (Drew and Guilemin 2014). Due to the sole focus on the participants' interpretations, the analysis of the images produced remains incomplete, indeed, at this stage Drew and Guilemin (2014 p.60) tell us that, 'stage 1 on its own offers relatively limited insights into the greater, or whole, collection of photographs'. The participants' interpretations, however, should not be dismissed for they represent an equally valid layer of meaning.

Stage 2: Researcher interpretation of meaning

Drew and Guilemin (2014 p.60) describe stage 2 of the interpretive engagement process as 'meaning making through researcher driven engagement'. The emphasis here shifts to the researcher's interpretation of the photographs via the close examination of the images and the participants' talk about them. Drew and Guilemin (2014 p. 62) describe this process as moving from 'photographs to findings'. In other words, the representations presented in the photographs are subject to researcher analysis to uncover their sociocultural construction.

In addition to the data analysed at stage 1, this stage also includes the researcher's reflections on participant interactions and explanations and the researcher's detailed interpretation of what is shown in the photographs. Thus an extra layer of meaning is added to the analysis, that of what the researcher thinks is going on as well as what the participant has said is going on in stage 1. In systematically interpreting the images, Drew and Guilemin (2014) suggest the researcher ask a number of analytic questions when viewing the images and the participants' talk about them. Such questions include: what is being shown? What are the components of the image? What do the different components of an image signify? Is there more than one possible interpretation of the image? and how does the image reflect or depart from dominant cultural values?

This stage facilitates the development of themes across the photographs and relationships between them. The themes generated as a result of the researcher's interpretation raises the possibility of alternative interpretations to those presented by the participants. This should not be seen as a problematic occurrence nor as an instance of the researcher's interpretation overriding the participants', rather Drew and Guilemin (2014 p.62) encourage such contradiction by stating, 'we support multiple voices and interpretations'. As with stage 1, Drew and Guilemin (2014) emphasise the incompleteness of the analysis at this stage and note that the analysis at the completion of stage 2 requires re-contextualistion within wider theory in order to generate a robust overall analysis.

Stage 3: Re-contextualisation

This final stage of analysis involves locating the interpretations generated at stages 1 and 2 within the theoretical frameworks applicable to the research project. In order to do this Drew and Guilemin (2014) suggest the researcher ask two questions: what knowledges are being deployed? and whose knowledges are excluded from this representation? Once all three stages are complete the consequent explanations provide a robust and rich reflection of the content of the participant generated photographs that reveal both multiple layers of meaning and the social constructedness of these meanings (Drew and Guilemin 2014).

The practical application of each of the research methods and modes of analysis discussed is detailed below.

Research methods and analysis in practice

Sample

The following two groups formed the sample:

1. **People with learning disabilities**

   Including: people with mild, moderate, and profound and multiple learning disabilities and their carers for support where necessary.

This sample was designed to reflect the continuum of ability that learning disability represents.

2. People without learning disabilities

Including:

- Social care professionals, including: Social Care Providers
- Family carers
- Medical professionals, including: GPs and Clinical Psychiatrists
- Vocational degree students, including: Student Journalists, Student Social Workers and Student Teachers
- Social Scientists
- Educational professionals including: Mainstream Teachers and Special School Teachers
- Local Authority Councillors

This sample was designed to represent key stakeholders within the field of learning disability in England, in order to represent how learning disability is understood in 'the real world'. The sample was deliberately composed of professionals working in learning disability practice (the social care professionals, family carers, medical practitioners and educational practitioners, student teachers and student social workers) and people who have the potential to influence the field of learning disability policy and/or public opinion (the local authority councillors, social scientists and student journalists).

The samples of both groups were opportunity samples, whereby; those included are representative of the professional and lay groups that could be accessed within the constraints of PhD research.

In the case of the participants with profound and multiple learning disabilities, their carers voices were also included in the research process and the findings analysed. The project's ontological position, whereby bodies are positioned as ultimately material, allowed this approach despite the fact that some researchers would cast this as speaking for people with learning disabilities (Blunt et al 2012). In positioning the body as material the body is argued to have an effect on how the body performs and what it can do. In acknowledging this as a material reality, the reality for people with profound and multiple learning disabilities is able to be accommodated in the research process. Moreover, people with profound and multiple learning disabilities generally cannot express nor cognitively process abstract concepts/questions for themselves. Nor can they perform everyday tasks in the same way that people without profound and multiple learning disabilities can. Indeed, as Klotz (2014 p.98) tells us 'the aspirations, concerns, behaviours and expressions of people with profound and severe intellectual disabilities are often very different, idiosyncratic, opaque and challenging to engage with'. Consequently, people with profound and multiple learning disabilities lead mediated lives: in many cases their life would not be possible without support. A mediated approach to involving people with a profound and multiple learning disability in research, therefore, should not be seen as a limitation or an encroachment on liberty but rather should be treated as a necessary condition of the research. The exclusion of people with profound and multiple learning disability from research has far greater consequences than replacing a traditional research method with an innovative one that can allow the needs of *all* people with learning disabilities to be embraced. There is both room and necessity for a plurality of voices.

Access

The sample was generated and accessed using my extensive professional network and the networks of my supervisors. All of the focus group participants work or study in Nottingham while some of the photovoice participants attended groups based in both Nottingham and Leicester. Initial contact with all groups was made in person, via email and by telephone. Where participants were recruited via an organisation i.e. people with learning disabilities attending pre-existing support groups, members of staff responsible for these groups were contacted first. This contact was followed by a visit by myself to the group to meet with the potential participants and to invite them to take part in the project.

All of the participants with learning disabilities were recruited through pre-existing groups. These groups included:

- Monday Mania. Based at Nottingham Mencap.
- Lakenders. Based at Nottingham Lakeside arts centre.
- Values photography group (Mondays). Based at Voluntary Action Leicester.
- Values photography group (Wednesdays). Based at Voluntary Action Leicester.

Ethics and consent

Before the fieldwork was carried out, ethical approval from the University of Nottingham School of Sociology and Social Policy was obtained for this project. Ethical considerations, however, do not cease to exist once official clearance has been given. The research process is not neutral (Mason 2002), instead it is littered with value judgements, power imbalances and moral baggage. Ethical questions occur at all stages of the research process, not only when methods are being planned (Edwards and Mauthner 2002). While this is true of all research projects, people with learning disabilities are often thought to be more vulnerable to manipulation and exploitation by researchers (Swain et al 1998). As Wolf (1996) tells us, the researcher role will always create a power imbalance. Further to this, Edwards and Mauthner (2002 p.15) tell us, the researcher is 'a central active ingredient of the research process rather than the technical operator that can be inferred by professional ethical codes'. Power imbalance between myself and the participants was something I considered throughout the project with all participants, I was particularly aware of the power imbalance between myself and my participants with learning disabilities. Just as feminist researchers exploring poor women from different cultures have found their own race and class divisive (Wolf 1996), my status as 'intellectually able' divided me from some of the participants. A number of ethical safeguards were implemented in acknowledgement of this. Such safeguards were provided according to individual need. These included: informed consent, accessible consent forms, on-going consent, letters to parents and carers, participant information including accessible versions, and parent and carer support ranging from reminding participants to take photos and checking understanding to taking the photographs and discussing them with the person they care for. Each of these safeguards are discussed below.

Participant information

All participants were given participant information sheets (see appendix A) prior to taking part in the research. This included information about: the project background and myself; the purpose of the focus groups or photovoice sessions; the date, time and location of the sessions; audio recording; confidentiality; consent and; contact details for myself. Accessible versions using plain English and simple pictures were used for participants with learning disabilities (see appendix B). In the case of people with learning disabilities, all participants were given a letter and participant information sheets for their parents/carers (see appendix C for examples). Although all participants with learning disabilities were adults, contact with parents/carers was considered necessary because the majority of participants lived with parents or carers. It was thought likely, moreover, that parents and carers would be involved in the project in some way, whether as the subjects of the photographs or more fully as the photographer on behalf of the participant.

Consent: focus groups

Standard University of Nottingham, School of Sociology consent forms were used for all focus group participants (see appendix D). All focus group participants were asked to sign the consent form at the beginning of the focus group session and were allowed time for questions and withdrawal. All participants were informed that they could withdraw their consent at any time during or after the focus group and their words would not be included in the analysis. None of the participants withdrew their consent.

Consent: photovoice

The majority of participants had the capacity to understand their involvement in the project. Some, however, did not. When involving people who lack capacity in research the Mental Capacity Act (HMSO 2005) requires the following questions to be asked: (1) is the research related to the 'impairing condition' that causes the lack of capacity, or to the treatment of those with that condition?, (2) could the research be undertaken as effectively with people who do have the capacity to consent to participate? In the case of this project, the research is related to the impairing condition that causes the lack of capacity and the research could not be undertaken as effectively with people who do have the capacity to consent. As previously stated, not to involve people with learning disabilities who cannot consent according to standards written with the cognitively able in mind marginalizes a significant minority of people with learning disabilities and would limit the research findings. In accordance with the Mental Capacity Act, answering yes to the first question and no to the second, justifies the involvement of people who lack capacity.

The Act further requires the researcher to demonstrate that the study will meet one or both of the following requirements (1) that it will be likely to be of benefit to the person lacking capacity, either directly (i.e. by improving her/his personal circumstances) or indirectly (by improving the quality of treatment or care more generally), and that this benefit is in proportion to any burden on that person caused by taking part and (2) that the research will serve to increase knowledge of the cause, treatment or care of people with the same or similar condition and that the risks to participants will be negligible, with no significant interference with their privacy or freedom of action. This research project addresses both requirements. The research benefits those lacking in capacity both directly and indirectly. Direct benefit includes the involvement in a new activity and the experience of participating in research. Indeed, a number of the participants expressed an interest in being involved in further research and one participant involved in the research had started his own photovoice project and showed me some photographs he had taken for this. In addition to this, the exhibition of the photographs taken will indirectly benefit participants. The exhibition will be opened to key stakeholders and will be open to the public for two weeks. It is hoped that the exhibition will both raise awareness regarding what learning disability is and impact on stakeholders approaches to learning disability service provision. The exhibition will also serve to increase knowledge of the cause, treatment or care of people with the same or similar condition as required by the Mental Capacity Act. These benefits are in proportion to any harm to the participants due to the potential for harm being negligible.

The Mental Capacity Act code of practice (DoCA 2007), recommends that each participant is treated as an individual case regarding consent. A person should not be deemed to lack capacity to consent simply because they have a particular diagnosis. Rather, capacity should be assumed unless there is proof against this. The guidance suggests researchers tailor their approach to gaining consent to the needs of individual participants. Accessible consent forms (see appendix E) were given to all participants before the photovoice sessions. This was to allow participants to familiarise themselves with the form with the support of parents/carers if necessary. Consent forms were then explained and signed in the first session. As with the focus groups, participants were informed that they could withdraw their consent at any time during or after the photovoice sessions and their photographs and words would not be included in the analysis. This was the case for one participant, who in the middle of the first session, decided that she did not want to take part. Her contribution has been omitted from the transcripts.

While all participants who were able to provide written consent did so, not all participants with learning disabilities were be able to do this. For those that could not, alternative methods of consent were implemented according to need, including: additional support, proxy/best interest decisions and participation as consent. Each of these options are discussed below.

Additional support

The Mental Capacity Act (2005) recommends additional support where necessary. The option of additional support was given to all participants with learning disabilities who used the accessible consent forms in order to ensure that these participants felt comfortable agreeing to take part in the project and that they understood what they were agreeing to. In their study addressing the lives of women with learning disabilities Welsby and Horsfall (2011) found that the majority of participants with mild to moderate learning disabilities engaging in their research project opted to have a support person (family member or friend) present to explain the form and the process they would be consenting to. This was also the case in this project. Where a participant expressed that they would like support with their consent form, I read out the consent form to the whole group and allowed time for questions and discussion.

Proxy consent/best interest decision

The Mental Capacity Act requires a best interest decision if a person is deemed not to have the capacity to consent. In such cases the Mental Capacity Act requires that this decision is made by a specified consultee, either a personal consultee such as a family member or close friend or a nominated consultee, who could be a professional from a relevant organization. Mencap's *Involve Me* (Mencap 2011) guide to including people with profound and multiple learning disabilities in decision making, also advocates proxy consent. When detailing their approach to gaining consent to use photographic images of people who lack capacity to consent they state, 'If people could not give consent, they were involved as far as possible and those close to them were consulted to ensure they believed that taking part in research would not be harmful. Decisions about taking part in activities such as sharing stories had to be made in their best interests' and 'Of course, we have to do everything possible to make sure people are happy for their photo or video clip to be used, but the reality is that we are asking people to agree to something very abstract. If you are sure someone is not able to give clear consent to the use of their images you can involve people who know them well in making the decision' (Mencap 2011 p.40). Following requirements in the Mental Capacity Act (2005) and Guidance in Mencap's *Involve Me* (2011) best interest decisions were made on behalf of participants who could not provide written or verbal consent. This was the case for all of the participants with profound and multiple learning disabilities. In these cases the participants' personal carers provided consent.

Participation as consent

In addition to the above, in line with other photovoice projects with people with learning disabilities (Povee et al 2014), I treated consent as a continuous process. Following, written consent or best interest decisions I was mindful throughout the photovoice process of nonverbal signals that might indicate the participant would like to stop. Cameron and Murphy (2006) suggest looking out for tiredness and expressions of discomfort. If such signals were made, where possible the participant, and where not the carer was asked if they wanted to continue. If the answer was no the participant was withdrawn from the project. As stated this happened on one occasion. In this case the participant was able to verbally articulate her request not to take part and was happy to use the internet while other group members took part in the photovoice sessions.

The practical application of each research method is discussed below.

Focus groups in practice

Twelve focus groups were held between February 2014 and January 2016. The length of time accounted for 6 months maternity leave taken by myself from April-October 2014. The focus groups were organised by their professional group in order to reveal any differences in talk about learning disability between the different groups. All but one of the focus group participants did not have learning disabilities. The one participant who did have a learning disability was a volunteer at the social care organisation.

Each focus group included between 2 and 6 participants (See appendix F for a demographic breakdown). On average the focus groups were completed within 1 hour. All focus groups were audio recorded using italk software on an itouch. All focus groups, with the exception of one, took place in a location known to the group, this was their usual place of work, study or support. The focus group for GPs was conducted in my living room. The GPs who participated were not part of the same practice and so did not have a shared space. The participants were known to me and my partner was present in another room in the house when I conducted the focus group as a personal safety precaution. In the two instances where the focus groups involved only 2 participants (the Local Authority Councillors and the Student Teachers) four people for each group had confirmed attendance. On the day, however, only two attended. Despite this, in each case, the participants interacted as the participants in the larger groups did and discussed the questions amongst themselves.

The focus groups began with a general introduction to the project, myself, how the focus group would proceed and consent forms were explained and completed. None of the participants had taken part in a focus group before and so the basic outline of what a focus group is, provided in the participant information, was reiterated. All participants were asked to discuss the questions as a group rather than directing their answers to me. It was explained that there were no right or wrong answers to the questions and that all talk, although being recorded, would remain anonymous and that they were free to leave or withdraw their consent at any time. Participants were then given the opportunity to ask any questions before starting.

Each focus group was asked to answer 3 pre-set questions designed to facilitate talk about learning disability. The three questions were as follows:

1. What does learning disability mean to you?
2. What sort of life do you think a person with learning disabilities might lead?
3. How might the life of a person with learning disabilities be similar or different to your own?

These questions were asked in the same order in each of the focus groups. Additional questions were also asked depending on the flow of conversation and the different discussions taking place within each group. These varied from group to group with two exceptions. All groups used other terms for learning disability in their talk, this prompted me to ask two additional questions:

1. What other terms would you use to refer to learning disability?
2. How do you feel about the term intellectual disability?

These additional questions were asked in every focus group. The focus groups ended with a chance to ask any further questions and a discussion of and invite to the exhibition. All of the focus group recordings were transcribed verbatim.

Photovoice in practice

Across the 4 photovoice groups 16 adults took part. Of the 16 participants: 7 were female and 9 were male; they were aged between 20-51years; 11 were White British, 3 were Asian British and, 2 were Black British; 6 had been categorised as having mild learning disabilities, 4 with moderate and 6 with profound and multiple (see appendix G for a full demographic breakdown). In the case of the participants with profound and multiple learning disabilities the voices of their carers were also included. All sessions were carried out between December 2013 and January 2014 and were audio recorded using an itouch and italk software.

During the first session each participant was given a digital camera to borrow for a week, together with a battery charger and accessible instructions (see appendix H). Two participants chose to use their own cameras. Digital cameras were chosen over analogue for two reasons. First, the option to delete photographs before anyone else sees them allows participants further control and autonomy over the aspects of their lives that they choose to share. While the spontaneity and uncertainty of analogue photographs (Pink 2006) is diminished, the added possibility of self censure is beneficial when working with groups considered to be vulnerable as this allows participants further time to consider what to show and what not to. All participants were asked if they were happy to share their photos before they were uploaded on to the laptop for group viewing and were given the opportunity to delete any images they didn't want to share. And second, as Povee et al (2014) tell us, digital photographs can be viewed on a screen, allowing the images to be viewed by more than one person at a time. This was particularly useful as it saved the time that would have been spent passing the photographs around. In addition to these advantages, digital cameras are now very cheap to purchase. I bought 6 second hand cameras via ebay, all for £25 or less.

In line with the photovoice method, the brief for participants was unrestricted; participants were asked to take photographs of anything that showed their everyday life. The aim of this was to convey the reality of learning disability. Initially some participants were concerned that their lives were too boring to photograph. These participants were reassured that nothing was too boring. Participants were given a week in which to take the photographs and were asked to return the cameras at the following session. All participants returned cameras with photographs on. Between 4 and 171 photos were taken. On average, participants took 29 photographs each. All equipment was returned on time and in working order with the exception of one lost battery and charger.

The photovoice sessions held with each group followed the same format. Two to three consecutive sessions were carried out depending on the time allocated to the project by individual group organisers. For two groups I was given an hour each week and for the other two I was given 2 hours each week. In the case of the groups where 1 hour was allocated I attended three times and in the case of the groups where 2 hours were allocated, I attended twice. It was decided that I would carry out the photovoice sessions at the same time as the pre-existing groups so as not to disrupt the participants' weekly routines. This was suggested by the group support workers but also follows suit with previous research involving people with learning disabilities. Gates and Waight (2014), for example found that people were much more likely to participate if research sessions were run within pre-exisiting college classes or support groups. In the case of this project, to arrange a specific time and place to deliver the photovoice sessions would have been logistically difficult. Many of the participants accessed the groups by means of a pre-booked taxi service, some participants attended other services before or after and others relied on buses or pre-arranged lifts.

The sessions ran as follows. The first session followed steps 3 to 7 of Wang's (1994) 9 steps: educating participants about the photovoice method, gaining informed consent, brainstorming the project focus, distributing cameras and allowing participants time to take photographs. In the first session for each group, I introduced myself as the researcher, introduced the project and how it would work, explained the consent forms, carried out a group getting to know you exercise, distributed the camera and allowed time to discuss the project and practice using the cameras. Consent forms were also explained and signed during this session. In addition to this, we discussed how the participants could negotiate the risks and ethics associated with taking photographs in public places and of other people. We discussed the importance of respecting other people's right to privacy. All of the participants agreed to ask the permission of others before taking their photograph and also to ask for permission before taking photographs in public places.

The getting to know you exercise involved all group members, including myself and any group support workers present. Individuals completed and shared a getting to know you form which asked all group members their name, age, what they like and dislike. Where participants weren't confident to or could not read and/or write, the forms were either completed with the help of myself or a group support worker or we completed the forms as a group, with me writing the answers down as individuals and/or their carers answered the questions. The getting to know you exercise served two purposes: it provided an icebreaker which allowed the participants to feel more comfortable to discuss things as a group with me present; and it provided useful context for me as a researcher new to the group and allowed me to feel closer to the content of the photographs once shared. The group sharing facilitated further discussion, much of which was jokey and amusing, indicating that the group members felt comfortable with me present. Participants were especially amused when their support workers shared their ages.

The second session differed depending on the number of sessions being run. In the case where this was the penultimate session, individuals returned their cameras and were asked to share their experience and the photographs taken. Photographs were uploaded on to a laptop and were shown to the group. Individual participants then talked the group through their photographs. Some participants scrolled through themselves and others asked me to do this. When talking through their photographs, Wang's (1994) SHOWeD framework of questioning was used as an aide for discussion. This includes questions such as: what do we see here? what is happening here? and how does this fit in to your life? Such questioning kept the discussion focused on the photos being shown while also allowing for wider discussion about the participants' everyday lives. In line with the focus group questioning, participants were also asked what learning disability means to them. In the case of the participants with profound and multiple learning disabilities the carers did the talking.

Where this was the final session participants were also asked to choose two favourite photographs to be shown in the exhibition. This task was completed in the third session for those groups that received three sessions. Two sets of hard copies of the photographs were printed. These were given to participants as a thank you; this was done in person where three sessions were delivered, and posted to the participants where two sessions were delivered. The third session for those groups whose sessions were an hour in length allowed for further discussion of the photographs and the exhibition; time did not allow this in the second session.

It should be noted here that often 'group' discussion took the form of me asking questions and the participants directing individual answers to me with little or no interaction from other group members. There were occasions where the participants interacted with each other, however, instances of this were rare. As Gates and Waight (2007) found in their use of focus groups with people with learning disabilities, discussed in the literature review, group discussion can often lapse in to individual interviews. While this is, methodologically, a problem for focus groups, the same is not true of the photovoice method, where discussion can take any form.

Where participants required additional support to take part in the project, carers provided this. As stated, this was the case for all of the participants with profound and multiple learning disabilities, however, support was also provided for members of the other groups and involved family members helping with the use of the camera, reminding participants to take photographs throughout the week, support with completing consent forms and the getting to know you exercise and further prompting when discussing the photographs taken. For the participants with profound and multiple learning disabilities, support workers involved the person they care for as much as possible in the taking of the photographs and the discussion.

The exhibition

The exhibition of the participants favourite photographs is currently being organised. I am in contact with the groups who participated and we are in the process of setting a date and organising an accessible venue for the photographs. So far, unfortunately, two community galleries in Nottingham (Lakeside and The New Art Exchange) have rejected our proposals for an exhibition (see appendix J). Other venues have been approached (Broadmarsh Shopping Centre in Nottingham and Embrace Arts in Leicester) and we are waiting for further communication from these organisations.

The analytic process carried out for each method is set out below.

The analytic process

Discourse analysis of the focus group talk

Steps 6 and 7 of Potter and Wetherell's (1987) flexible ten step approach to conducting their form of discourse analysis were followed when carrying out the analysis of the focus group talk. Potter and Wetherell (1987 p.167) describe the aim of step 6, coding, as 'not to find results but to squeeze an unwieldy body of discourse into manageable chunks'. The codes developed, although not analytical, should reflect the research questions and can be as broad as the findings necessitate. Unlike thematic analysis, owing to the range of linguistic resources available to speakers and the acceptance that speakers may shift between compatible and incompatible repertoires to construct meaning, anomalies and borderline issues can be coded. Writing in 1987, Potter and Wetherell suggest photocopying the coded transcripts and filing them for analysis. Advances in technology have thankfully provided labour saving computer programmes for data organisation. Here the focus group and photovoice transcripts were initially organised into broad codes using the analysis software, Nvivo for Mac. Nvivo for Mac is a platform for organising unstructured data and was chosen because it allows the initial coding of data, which can be a messy process, to be contained neatly in a computer file. The initial coding of the transcripts was an iterative process that involved reading and re-reading the transcripts to identify specific topics talked about in similar and different ways. With the research questions in mind, the transcripts were organised into 27 manageable chunks (see appendix I for details of these). Once this was complete stage 7, analysis, was carried out.

Potter and Wetherell (1987) state that stage 7 of their guide has two aims: to highlight patterns and to establish functions of the discourse. Potter and Wetherell (1987) do not provide a method for achieving these aims; rather they relate the process to the overall theoretical basis of discourse analysis. With this in mind, I read and reread the focus group transcripts many times in order to search for patterns across the talk. Specifically I was looking for instances of similarity and contradiction whereby the participants used similar patterns of words and phrases to make sense of what they were talking about, consistent with the characteristics of interpretive repertoires. When doing this I related the findings to the codes generated as part of step 6 and was able to finalise 3 specific repertoire pairs that could be found consistently throughout the participants' talk. These were:

- I know what learning disability is/learning disability is a confusing term.
- I don't like labels/labels are useful.
- People with learning disabilities are different to me/people with learning disabilities are the same as me.

Once I had identified these repertoires, I then read and reread the transcripts to confirm their use. In order to highlight instances of the use of particular repertoires I returned to the use of Nvivo. Here I cut and pasted sections of the participants' talk into what Nvivo terms 'node categories'. I created a node for each repertoire in order to show numerous examples of their use across the participants' talk. In organising the data in this way, I was then able to read through and refer to all of the examples contained within each repertoire or node category in order to think through the repertoires relatedness to the theory provided in the literature review and also the participants' shared social and cultural worlds. In doing this I was able to hypothesise the function of the repertoires used.

Interpretive engagement analysis of the photovoice findings

At stage 1 of the interpretive engagement process the participants' images and their verbal interpretation of them was recorded and relationships between the focus group participants' and the participants' with learning disabilities constructions of learning disability were noted. This stage complemented the SHOWeD framework of questioning asked as part of the photovoice method, in that such questions served to encourage the participants to provide detail about what their images show and what they mean to them.

Stage 2 of the interpretative engagement process involved the systematic detailing of the content of the photographs and the participants talk about them. To do this, I coded all of the photographs taken in relation to what they show (see p.239-241 of chapter 8) for the full breakdown). I then looked for relationships between the content of the images and the social context in which they were produced and also the participants talk about them. In doing this I did as Drew and Guilemin (2014) suggest and asked generative questions relevant to the photographs such as: what is being shown? What are the components of the image? What do the different components of an image signify? Is there more than one possible interpretation of the image? and how does the image reflect or depart from dominant cultural values? In addition to this, I also asked myself the question what is missing from the images? As Drew and Guilemin (2014) emphasise, is it is just as important to be cognisant of what the images do not show and why this might be. This was an iterative process that involved working between the three data sets: the photographs, the codes and the participants talk, until patterns and themes emerged. Following this process, the following four themes were finalised:

- The dominance of support settings.
- Distinct absences in content.
- The portrayal of multiple ways of being.
- Bodily difference.

At stage three of the analysis, I related the analytical findings from stages 1 and 2 to the theory presented in the literature review. In addition to this, I also looked for relationships between the focus group and photovoice analysis in order to answer research question (c) *what is the relationship between the constructions of learning disability produced by participants with and without learning disabilities and how can* this contribute to a re-evaluation of sociological perspectives of learning disability?

The findings of this process are detailed and discussed in the following four analysis chapters. Before the research findings are presented a reflexive discussion of the application of the research design is provided in order to acknowledge my own positionality within the research.

Reflexive commentary on the research process

I began this project with 7 years experience of working in public health practice within a local authority, and holding a Masters in Public Health qualification. Consequently, these prior experiences both equipped me with a number of skills that benefited this research project and also positioned me within the research process from the beginning in that I came to the project with my own pre-existing conceptions of what learning disability is. In acknowledging my positionality within the research process and how this changed throughout, I have been able to observe how my role as the researcher has shaped this process.

The organisation of the research project was very similar to the health improvement role I was previously employed in. Working with external partners in the public, third and private sector was something that I was very familiar with and confident in doing. Contacting and establishing relationships with the participants, therefore, was relatively unproblematic. Despite this, on two occasions participants who had confirmed attendance at a focus group did not turn up. I continued with the focus groups with a view to reorganising them if they proved problematic. The participants in each of these focus groups, however, engaged in lengthy discussions between themselves and it was decided not to try again. In addition to this I had previous experience of conducting focus groups as part of my previous role when consulting community members and so understood their use as a space where participants can have broad discussions (Barbour 2008). As will be seen in the analysis chapters, however, the focus group discussions here actually took place within specific and implicitly agreed upon boundaries. This was a feature of all of the focus groups and was something that I was surprised by. With hindsight, I wonder if I was naïve to think that the participants would engage in contradictory discussions that challenged the socially acceptable way of seeing learning disability.

In having previous professional experience of working with and developing relationships with people with learning disabilities, I came to the project with my own understanding of learning disability. Like the participants in the focus groups, as will be seen in the following chapters, my talk and understanding of learning disability was informed by the dominant models of disability. I did not, however, have any prior understanding or knowledge of these models and their use in academic literature. With hindsight, I can see how both my practice and my understanding were informed by the models. When planning projects for people with learning disabilities for example, as a Health Improvement Officer, I operated in a very top down way, in that I reacted to epidemiological health need in the area by implementing health improvement projects to address this need. Moreover, the projects I organised were generally *for* people with learning disabilities as opposed to *with* people with learning disabilities. This is something I recognised as a feature of the medical model of health, however, I was not aware of a medical model of disability. Like the focus group participants, as will be seen, I would rather not have been positioned as such, however, the organisation I was employed by necessitated this. Consequently, I tried to involve community members in the planning of projects as much as I could and I often framed grant bids in this way, a discursive action I can now see as a re-contextualisation of the discourse of the social model of disability. In addition to this my pre-existing concept of what learning disability is, was implicitly based on the medical model of disability, in that I generally thought about learning disability in terms of the material body and its effects on what learning disabled bodies can do. While I was aware of social barriers, I thought about them in terms of barriers to the people with learning disabilities attending my projects, such as transport issues, rather than barriers that affected their disability. In carrying out this project, as can be seen, this position has now changed. Nevertheless, this original position informed how I carried out the research project. I knew, for example that certain research methods would be hard to use with people with learning disabilities. For example, I worked with one participant on a walking project I organised for people with learning disabilities who had echolalia. In the twelve weeks of working with him, he only said the words 'Scooby Doo'. I knew from the outset, therefore, that interviews and focus groups would not be applicable for all people with learning disabilities.

In many ways I am the same as the focus group participants. I am a white, cognitively able, woman who works in the field of learning disability practice with a view to improving practice and reducing stigma. Likewise, for these reasons, I am not the same as the participants with learning disabilities. For this reason I was very aware of the potential for the participants with learning disabilities' generosity in sharing so much about their lives to go unrecognised. It is for this reason that the participants and I agreed to organise an exhibition to showcase their photographs. Indeed, the acknowledgement of my own positionality within the research process has allowed the benefits and challenges this presents to be taken in to account and accommodated.

The following four chapters discuss the analysis of the research findings produced as a result of the application of the research design outlined here.

Chapter 4: Introduction to the analysis

The following four chapters present and discuss the research findings. The first three chapters address the discourse analysis of the focus group talk and the final chapter addresses the interpretive engagement analysis of the photovoice work. Before the chapters addressing the focus group talk begin the repertoires identified within the participants' talk are introduced and commonalities across their talk are discussed in order to provide necessary context for the analysis that follows.

Using Potter and Wetherell's (1987) approach to discourse analysis three linked repertoires pairs were identified as being used extensively across the talk in all twelve focus groups. The these repertoires are as follows:

1. I know what learning disability is/learning disability is a confusing term
2. I don't like labels/ labels can be useful
3. People with learning disabilities are different to me/ people with learning disabilities the same as me.

All three repertoire pairs identify a change in perspective. Each pair contains two diametrically opposed repertoires. Indeed, the two repertoires within each pair exist in a dialectical relationship, whereby one is dependent upon the other for existence. When a switch is made from one to the other the preceding repertoire is not eradicated; rather it is preserved in a secondary position to be returned to later when needed again. Each half of the pair allowed the groups to achieve both different and similar objectives. In moving between the repertoires, the participants are engaging in Edley's (2001) metaphorical dance. One dance step allows them to demonstrate their knowledge while another allows them to undo this knowledge and reformulate another more ‘appropriate’ expression of knowledge. It was not the case that the focus groups’ talk made a direct switch from a commitment to one repertoire to another or from one pair to another, rather their talk moved back and forth between each of the repertoires. The participants used each repertoire as and when necessary to make sense of what was going on in their talk and to position themselves in relation to that talk.

Three distinct commonalities are apparent across the focus groups use of all three repertoire pairs: the largely ubiquitous use of the interpretive repertoires across all 12 focus groups; a general (mis)understanding of what learning disability is; and a shared desire to present a particular identity associated with popular moralistic values. Each of these commonalities have important consequences for the analysis and are discussed in turn below.

As stated in the methodology, the focus groups were organised by profession in order to allow any differences in talk about learning disability to become apparent. Rather than revealing differences in talk, however, all three repertoire pairs were used relatively universally across the focus groups to achieve the same two linked purposes – to construct a co-produced understanding of learning disability and to present a particular shared subject position. While the talk across the focus groups was largely similar there were, however, two identifiable differences. Two of the focus groups, the Parent Carers and the Clinical Psychologists performed the *learning disability is a confusing term* repertoire slightly differently to the majority of the focus groups. While the majority of the focus groups drew on this repertoire to question their own knowledge of learning disability, the Parent Carers and the Clinical Psychologists used it to question the knowledge of other people. The content of the repertoire, however, remained consistent as will be shown in chapter 5. In addition to this all but three of the focus groups, the Parent Carers, the clinical Psychologists and the Social Care Providers, included in their talk reference to conditions that are not 'officially' considered to be learning disabilities.

The inclusion of conditions outside of official definitions of learning disability is demonstrative of the second commonality to be addressed: the widespread (mis)understanding of learning disability throughout the focus groups' talk. Although accuracy is not the focus of the study, this commonality represents an interesting observation that has direct consequences for each of the repertoire sets and will be explored again within the discussion of the repertoires. With the exception of the three focus groups listed above, all of the remaining focus groups demonstrated a noticeable lack of 'official' knowledge. While the participants generally asserted that they knew what learning disability is (see chapter 5 for a discussion of this repertoire), their talk about their knowledge often did not reflect current or 'official' definitions of learning disability, such as the definitions found in Valuing People (DoH 2001) or DSM V (American Psychiatric Association 2013) identified in the introduction. Across the focus group's talk there was a tendency to include people who would not 'officially' be considered to have a learning disability.

The participants included a wide range of conditions that are not 'officially' considered to be learning disabilities in the UK. These conditions included: dyslexia [Mainstream Teachers, Student Teachers, Special School Teachers, Health Professionals, Student Journalists, Student Social Workers with and without experience and Social Scientists], dyspraxia [mainstream teachers and student teachers], ADHD [Social Scientists, mainstream teachers, student teachers], cerebral palsy [mainstream teachers], bilateral cataracts [mainstream teachers], blindness [social scientists], head injury [social workers with experience], stroke [social workers without experience], epilepsy [mainstream teachers], memory problems [mainstream teachers], motor neurone disease (Stephen Hawkins specifically), and high functioning Asperger's Syndrome [mainstream teachers, student teachers, student journalists].

The specific learning difficulty dyslexia was most commonly referred to. The participants talked about their sister with dyslexia [Student Journalist], an old school friend with dyslexia [Student Journalist], an old university friend with dyslexia [Social Scientist], themselves as people with dyslexia [Student Social Worker without experience], and their children with dyslexia [Local Authority Councillors]. Indeed, all of the focus groups that included 'unofficial' conditions talked about dyslexia as a learning disability. As outlined in the introduction, in the UK, learning disability is defined as something which presents itself before the age of 18 and has a lasting effect on development, including the ability to cope independently and the ability to understand new or complex information. Dyslexia, considered in the UK to be a specific learning difficulty (something which affects the way information is learned and processed, independent of intelligence (Holland 2011)), therefore, is not considered to be a learning disability. That dyslexia was so commonly included as a learning disability within the focus groups' talk is perhaps not surprising due to the common use of the term learning difficulty being used interchangeably with learning disability, as illustrated in the introduction.

Despite the (mis)understanding highlighted, all of the focus groups did also include 'official' conditions within their talk about learning disability, revealing confusion as opposed to absolute inaccuracy. Down syndrome was most frequently referenced and was included by all of the focus groups. In addition to Down syndrome some groups referred to rare conditions too, such as Angelman's syndrome [Student Journalists] and Fragile X syndrome [Student Social Workers with experience]. Other groups talked about the spectrum of ability, referring to mild, moderate, severe and profound and multiple learning disabilities [Health Professionals, Special School Teaching Staff, Student Social Workers with experience of people with learning disabilities, Clinical Psychologists, Parent Carers, and Social Care Providers], although people with severe or profound and multiple learning disabilities were conspicuous in their absence throughout the focus group discussions.

While the participants did not always explicitly state the level of ability they were talking about at any one time, that they talked in the main about people with mild and moderate learning disabilities and very often about people who do not have learning disabilities at all, was implicit within the examples they used and the content of their talk. Often the participants required prompting by myself to talk about the lives of people with severe and profound and multiple learning disabilities. When the participants did talk about this group, they were presented as a separate and more challenging group, with participants making statements such as 'unless we are talking about the extreme severe where you really are not aware of what's going on around you, which is a different category, I don't think there is any difference' [Mainstream Teacher 1], and 'if you are in a situation where you know if you are in a wheelchair and you can't particularly verbally communicate or whatever you know life for those people must be incredibly sad' [Local Authority Councillor 1].

The third commonality to be discussed is the participants' shared desire to present in a particular way. The participants' talk demonstrated that they were aware of what they perceived to be a morally 'right' and 'wrong' way of seeing learning disability. The 'right' way of seeing learning disability was framed in terms of popular moral values such as equality, freedom of choice and fairness; values that characterise the social model of disability. By contrast the 'wrong' way of seeing learning disability was framed in terms of problem bodies and tragic victims, typical of the medical model of disability. The 'right' way of seeing learning disability was explicitly agreed as an 'acceptable' way of seeing learning disability while the 'wrong' way was explicitly agreed to be an 'unacceptable' way of seeing learning disability. The participants worked hard both to associate themselves with the 'acceptable' way of seeing learning disability and to disassociate themselves with the 'unacceptable' way.

Across all of the focus groups, the participants' talk was organised so as to allow the participants to present as 'good people'; people who value equality and do not focus on difference. People who, ultimately, see learning disability in the 'right' or 'acceptable' way. The participants made use of all three repertoire pairs to construct and reconstruct this shared identity as necessary. Indeed, the participants performed both interactive and reflexive positioning work (Davies and Harre 1990) to align themselves with this subject position. The participants used caveats and disclaimers when addressing issues that might compromise this position (reflexive positioning), if a group member risked compromising this shared identity they were quickly brought back in to line by other group members (interactive positioning).

The participants' absolute desire to align with the 'good person' subject position and their hard work to achieve this could be explained as consequence of the research method. Focus groups conducted with professionals from the same discipline can sometimes result in a tendency for similar views to align (Clavering and McLaughlin 2007). In addition to this most of the participants in the focus groups did not know each other, which again could explain their desire to be seen not to get it 'wrong'. While these are valid explanations that no doubt might have affected how the participants performed and wished to be seen by others, the 'good person' status was co-constructed across all of the focus groups regardless of their area of expertise. Most importantly, this shared group subject position reflects the impact of the social model of disability and the transmission of its values into everyday professional talk. As demonstrated in the literature review, social model rhetoric has made has it clear that there are 'acceptable' and 'unacceptable' ways of seeing learning disability. Indeed, as will be seen, the participants' talk and the repertoires they used reflect the tension between the dominant models of disability. Their 'good person' subject position, therefore, is pivotal to the analysis as a whole and will be focused on heavily throughout the following chapters.

Although the participants moved between the repertoires and repertoire pairs as and when necessary to construct their understandings of learning disability and to position themselves as 'good people', each repertoire pair is discussed in its own chapter in order to provide clarity and structure for this thesis. The following three chapters discuss each repertoire pair in turn. Each chapter seeks to present the interpretive repertoires produced by the participants as they discussed learning disability within their focus groups and also to reveal how they attempted to negotiate the tensions they faced. In order to do this, the analysis focuses on how the focus groups drew on each repertoire pair and switched between repertoires to create and justify their construction of learning disability and desired 'good person' identity.

Each of the focus group analysis chapters follows the same structure. First, an overview of the repertoire pair is provided. Each repertoire is then examined in detail. Its characteristics, i.e. the particular terms and descriptors used, are identified and illustrated using pertinent examples from the data. In addition, movement between the two repertoires is then highlighted in action, again by using clear examples from the data. Finally, the functions and consequences of the repertoires and the tensions highlighted between them are discussed in relation to the literature review and the research questions.

Chapter 5: I know what learning disability is/Learning disability is a confusing term.

Context

The widespread (mis)understanding of learning disability found across the majority of the focus groups is an overriding feature of this repertoire pair. While the majority of the participants expressed confidence that they knew what learning disability is when utilising the *I know what learning disability is* repertoire, their talk shows that 'officially' they often do not. As stated in the previous chapter, all but two of the focus groups (Parent Carers and Clinical Psychologists) make reference to conditions that would not be 'officially' considered to be learning disabilities. It must be remembered, therefore, that when utilising this repertoire set those focus groups who demonstrate a (mis)understanding have constructed a different learning disability to that contained within 'official' definitions and that their expressed views are based on these constructions. This is not detrimental to the repertoire pair, but must simply be considered when making sense of the participants' talk. Whether, their knowledge is 'officially' correct or not, all of the focus groups use this repertoire pair in the same way, to co-produce a shared understanding of the term learning disability and to align themselves with the 'good person' subject position.

At face value, this repertoire pair appears to operate in direct conflict. Certainty and uncertainty are diametric opposites. On the one hand participants demonstrate their knowledge of learning disability and on the other they question their knowledge and the knowledge of others. The participants move back and forth fluidly between certainty and uncertainty. This contrasting relationship is common to interpretive repertoires as linguistic resources used to make sense of what is going on (Potter and Wetherell 1987). When the repertoires, identified here, are examined in more detail it is apparent that, although they represent conflicting points of view, they are in fact dependent upon each other for existence. Again this is consistent with the concept of interpretive repertoires outlined in the methodology. Interpretive repertoires are integral to a shared common sense and as such are informed by the social worlds in which they are used (Edley 2003). In directly contradicting themselves again and again, the focus group participants are illustrating their thought processes when trying to make sense of and construct their understandings of learning disability. Their certainty allows them to draw on examples from their experience while their uncertainty allows them to undo these examples and include further examples that better fit their growing construction of learning disability. This back and forth movement also allows the participants to develop and maintain their desired 'good person' subject position (Edley 2003). In order to show this each of the repertoires are illustrated and discussed below.

The I know what learning disability is repertoire

Features of the repertoire

The *I know what learning disability is* repertoire can be distinguished by the consistent presence of: medicalised language in which the participants referenced particular diagnoses by name and frequently used words such as diagnosis, cognitive, brain, biology, body, and chromosome; the location of learning disability within individual bodies; and the use of phrases denoting a commitment to equality in which the participants drew on phrases such as 'we all have needs', 'everyone needs support' and 'everyone can't do something'.

Use of the repertoire

The *I know what learning disability is* repertoire was used by all of the focus groups throughout their discussions. The participants drew on this repertoire to affirm their understanding of learning disability; they used the repertoire both explicitly, to clearly demonstrate their knowledge, and implicitly in the form of tacit knowledge by using examples in their talk or referring to particular conditions without need for explanation. The *I know what learning disability is* repertoire allowed the participants to disassociate themselves from what they considered to be the 'unacceptable' way of seeing learning disability, outlined in the introduction to this section. While this identity work is apparent within each of the repertoire pairs, as will be discussed in each analysis chapter, it is through the use of this repertoire that the participants' were first able to position themselves as 'good people'. The participants' work to do this is evident within three discursive acts: the co-production of an initial definition of learning disability; the provision of personal examples to add value to their understanding of learning disability; and framing learning disability to be a broad category. Each of these actions are discussed below.

Use of the *I know what learning disability is* repertoire to co-produce a definition of learning disability

All of the focus groups used the *I know what learning disability is* repertoire to co-produce their own definitions of learning disability. When responding to the first question – "what do you understand by the term learning disability?" all of the focus groups provided a definition of learning disability to demonstrate that they know what it is. The participants' talk when producing these definitions asserted their desire to present as ‘good people’ from the very beginning. Despite this desire, their definitions and their talk that followed are illustrative of a conflict between what the participants associated with the ‘unacceptable’ way of seeing learning disability and the ‘acceptable’ way of seeing learning disability, mirroring the tensions between the dominant models of disability highlighted in the literature review.

While the participants’ use of the medical model within their co-produced definitions was not explicit, its presence dominated their talk when constructing definitions to show their knowledge of learning disability. The definitions provided by each focus group, for example, were based on phrases that placed an emphasis on the individual with learning disabilities, such as: ‘*someone* has got something’ [Student Journalists], ‘*someone* with’ [clinical psychologists], ‘*Individuals* with conditions’ [Local Authority Councillors], ‘when *someone* has’ [Health Professionals], ‘*you* are born with it’ [Parent Carers], ‘an impairment that affects *one’s* ability to learn’ [Social Care Providers], ‘a *person* with a disability’ [Social Scientists], and ‘*somebody* who finds it more difficult’ [Student teachers].

Further to this, the majority of the focus groups specifically identified the brain as the site of learning disability. Extracts taken from the focus groups with the Parent Carers, Student Journalists, Student Social Workers and Student Teachers are presented below to illustrate this seemingly biological positioning. In each of the extracts the brain is positioned as an independent entity separate from the self.

Parent Carer 3: Well it’s [learning disability] about how your brain operates, how her brain operates, and how it has operated since birth.

Parent Carer 4: Can I just say something please? The thing with mentally handicapped, you knew that it was something to do with the brain.

Parent Carer 1: Yes.
Parent Carer 3: Yes.

Student Journalist 2: I remember one of the boys at this group I volunteered at, he had really severe autism erm and erm they had to pay 50p entry for this after school care erm and he, his mum always put the money in a purse in a pocket in his bag but he would always forget erm well, not forget but couldn't understand that to get the purse out of his bag he'd have to unzip it and this would be every day after school so you would always have to sort of reteach him how to do that. So I think obviously somewhere in the brain there is something that is kind of forgetting how to do everyday things and then that kind of really makes you think wow, something so simple as unzipping a bag is a struggle for someone every day.

Student Social Worker 1: I have a really positive attitude to dyslexia but I don't know much about the other types of learning disability and how they effect, I mean I have a friend who is so dyslexic that even if she writes to you on Facebook, its like the letters from that word are somewhere down in five words later and it, it, I can not understand how her mind works and I think its amazing that she does what she does but like, cos she is an artist, and you can see how like her brain does the same thing [as when she is mixing up letters] but in visual stuff its absolutely beautiful but in written stuff its like what is that brain doing why would that go there and how can you not see it but I understand that she can't, and not like being mean about her or anything but its really tough.

Student Social Worker 3: I think like you [SSW2 earlier on] said we are all very similar and very different in a multiple of ways. Like even with the triangle of autism, I feel like I am really closely on two of those impairments but not all three so I feel like, even though its only something that occurs in autistic people's lives I can like some of the things, like the way their brain works is very close to mine in several ways.

Student Teacher 1: So yea, I think er, and also as well probably specific, the idea of specific learning difficulties and er you know some people being perfectly cognitively able to understand erm the work for instance within a classroom but they might have something that er some part their brain or cognition that prevents them from kind of…

In these presentations, learning disability 'is something to do with the brain' [Parent Carers], it is located 'somewhere in the brain' [Student Journalists] and it is something the brain 'does' [Student Social Worker], that 'prevents them from kind of..' [Student Teachers]. The participants refer to the learning disabled brain as an 'it'. It 'operates', it forgets how to do things, it works in problematic ways and it 'prevents' people from doing things. In this way the brain itself is framed as being separate from the self. In framing the brain as an 'it', however, the participants' separation of the brain from the self differs to the separation Descartes discussed (presented in the literature review). For Descartes, thinking is not bodily; rather in thinking the body is known. Constructed in the terms seen in the extracts above, the brain is placed in a position of power over the self. The brain, moreover, is responsible for the self. The learning disabled brain 'operates' in such a way that 'prevents' the consequent learning disabled self from doing certain things and being a certain way. This framing of the brain as an independent and powerful entity causes Student Social Worker 1, to ask of her friend's brain, that causes her to jumble letters and create 'absolutely beautiful' artwork, 'what is that brain doing?' 'That' brain is thought to be devoid of her friend's self, but yet controls her behaviour. In this way, the self is constructed as relatively powerless. In the Cogito (Descartes 1640,1968) the reverse is true: the self has power over the body.

The participants' construction of the brain as powerful and the self as powerless is, perhaps, influenced by the intertextual hegemony of the medical model, discussed in the literature review, particularly the emphasis that is placed on ordinary looking and normally functioning bodies. As seen in the literature review, this construction of the body is complimentary to the prevailing political economy of neoliberalism, where similarity and the status quo is prioritised (Goodley 2014). Under this combined approach, the learning disabled citizen or self should take responsibility for their malfunctioning body by seeking remedial action. The focus groups' construction of the learning disabled brain, however, problematises this able-minded approach to being. As seen in the literature review, people with learning disabilities generally do not fit this ideal. The learning disabled brain, in terms of the focus groups' construction, will prevent the learning disabled self from achieving normality. In recognising the brain as a powerful entity, the participants recognise learning disability, by way of its location in the brain/body as a contributing factor in the lives of people with learning disabilities.

In addition to their emphasis on the individual body/brain the participants' definitions also focused on the deficits experienced by people with learning disabilities and the bodily impact of these. The participants used phrases such as 'an *inability* to process information in the same way or recall it in the same way as others' [Mainstream Teachers], '*reduced learning ability* which has an impact on their day to day functioning' [Health Professionals], 'probably it can be like *something wrong with* mentality or *something wrong with* health' [Social Scientists], 'global impairments that affect your day to day life' [Clinical Psychologists], 'It's something that makes doing things, learning things difficult' [Student Social Worker (b)), 'Something that prevents them learning as well' [Student Journalists], and 'they might have something, some part of their brain that prevents them from functioning' [Student teachers]. Such a focus on deficit is again reflective of a medical approach to disability.

Although the focus groups' definitions of learning disability were dominated by a medical understanding of learning disability, their talk shifted as their discussions progressed. As their talk continued, the participants' showed that they were keen to disassociate with such a way of seeing learning disability. In contrast to the participants' location of learning disability in the brain, the majority of the focus groups explicitly removed learning disability from the physical body as can be seen in the extracts presented below.

Parent Carer 6: Some say my daughter is disabled and that makes me annoyed because my daughter is not disabled, she is physically fine

Special School Teacher 2: A learning disability doesn't make you disabled, it makes it that you might not understand about certain things or understand why some things happen or why some people do certain things but that isn't disabling. If they have got a physical disability and some well quite a few of our students have, then they are disabled yes but the actual learning disability, well its not really a disability.
Special School Teacher 2: Yeah disability is a bit permanent isn't it it sort of implies that there will never be any improvement and our students do improve, even if its not at the pace or to the level that students without learning disabilities would.
Facilitator: So is it the term disability that you think is problematic?
Special School Teacher 3: Yes I think so because the learning disability, well it isn't a disability.

Student Teacher 1: I don't know but with learning disability its kind of like if you are physically disabled you actually can't move where as with a learning disability they can, well I don't know, in some cases.
Student Teacher 2: It's more complex.
Student Teacher1: Whereas if you say someone is physically disabled I don't think, it's not offensive because its just like factually true.
Student Teacher 2: If you spinal cord is cut?
Student Teacher 1: Yeah if your legs don't work, then you have got a physical disability haven't you, but I don't know, yeah.
Student Teacher 2: Yeah.
Facilitator: So are you saying that's different to learning disability?
Student Teacher 1: Erm well yea because its got different levels

Student Teacher 2: Some can do more than others and they might all be able to get there in the end. But like if your spinal cord is cut then you will never be able to walk.

Student Journalist 2: I think now, cos er people are a bit more politically correct and a bit more aware of these things, you would probably wouldn't be able to tell unless it is severe and they have got physical problems as well which is nice, I think that's a positive thing because at the end of the day they er it shouldn't matter.
Student Journalist 1: Everyone is equal.
Student Journalist 2: Yeah.
Student Journalist 1: Yeah, I agree I don't think that er sort of erm, maybe if someone tells you then but that's like a lot of things, if someone says something to you then you might start to notice it but erm I don't think that erm just on appearances that you would notice anything.

In these presentations, learning disability is presented as something that does not manifest physically. The participants' talk in these extracts remove learning disability from the body. It is acknowledged that some people with learning disabilities have physical disabilities but these are not constructed as part of the learning disability. People with learning disabilities are generally said to be 'physically fine'. Conversely, disability is constructed as a bodily phenomenon: it is something that manifests itself in physical locations that can be 'noticed' and physically seen, such as 'legs' that 'don't work'. People with disabilities are not 'physically fine' as when Student Teacher 1 states. 'if you are physically disabled you can't actually move'. Disability is constructed as a 'permanent' state from which 'there will never be any improvement'. In this way, the participants position the disabled body as a problem body and the learning disabled body as an unproblematic body. For this reason the etymological link between disability and learning disability is constructed as problematic and potentially 'offensive'. Indeed, Parent Carer 6 tells the group that when 'some say my daughter is disabled…that makes me annoyed because my daughter is not disabled, she is physically fine' and Special School Teacher 2 tells the group that 'a learning disability doesn't make you disabled'.

The participants' removal of learning disability from the body, here, indicates that the participants perhaps do not consider the brain to be part of the body. In the extracts presented to show the participants' location of learning disability in the brain, as seen, the brain is disassociated from the self. In further disassociating learning disability from the body, moreover, the brain, where learning disability is said to reside, is constructed as an ethereal and invisible entity and is afforded much power.

In addition to their removal of learning disability from the physical body and self the participants' definitions and further talk frequently contained phrases denoting their commitment to equality and their rejection of a deficit model. The participants often repeated phrases that functioned as caveats to their previous individually focused talk and reinforce their commitment to equality, such as: 'its not a problem' [Social Care Providers], 'we are all impaired in some way' [Social Care Providers], 'we all have things we can't do' [Social Care Providers], 'everyone has got needs' [Mainstream Teachers], 'people are people' [Social Scientists] and 'we are all human' [Special School Teachers].

The tension between their underlying medical understanding of learning disability and their desire to present as 'good people' who see learning disability in the 'right' way, is clearly exemplified in the two extracts below, taken from the focus groups with the Social Care Providers and the Student Social Workers with experience. Each extract is discussed individually in turn.

Facilitator: So the first question is for you as a group to chat amongst yourselves about is, what learning disability means to you, how you understand learning disability.
Social Care Manager 1: Ok.
Social Care Volunteer 1: Well I've got one so….
Social Care Manager 1: What would you say it was then?
Volunteer 1: Its just, you just live with it don't you, you don't, you haven't got a problem, you've got to live with it so you've got to get on with it.
Social Care Manager 1: Absolutely.
Social Care Volunteer 1: You just get on with it, its just part of you. Its part of who I am. It's not a problem.
Social Care Manager 1: It's kind of the same for me, only my son has learning disabilities so it's part of our lives as well. Just people are different, some people have learning disabilities, some people can't walk, some people aren't good at imagining how someone else might feel, you know and erm learning disabilities just mean that some things take you longer to learn basically.
Volunteer 2: We've all got it to some degree haven't we?
Social Care Manager 1: Yea we've all got some sort of thing that we can't do. Erm, I've got plenty of things I can't do erm.
Social Care Manager 2: Somebody that's impaired in some way shape or form, whether its physically, well mentally mostly and sometimes physically but it could be a combination of two things, a combination really. Its not necessarily, and it doesn't have to be severe either erm or noticeable. Its just something that, if somebody has a particular impairment whether it be co-ordination or speech or whatever then yea, that's what I understand by it. Like SCM1 said, I suppose we are all impaired in some way. It could be alsorts of ways.

Here, the Social Care Providers are keen to establish that learning disability is not a 'problem'. The Social Care providers use the difference that learning disability creates, 'some things take you longer to learn', to unite us as human beings, by claiming that 'we are all impaired in someway', 'we have all got things we can not do' and 'people are just different'. Difference is presented here as a normal characteristic of being human. This framing of difference as equalising is discussed further in the next chapter when the *I don't like labels/labels are useful* repertoire pair is presented. Despite the Social Care Providers' commitment to equality and their rejection of the deficit aspect of the medical model, however, their use of social model rhetoric does not break through the implicit certainty that learning disability is located within the individual. Their talk makes repeated reference to individual bodies; learning disability is something '*you* just live with', 'it's just *part of you*', it is '*somebody* that is impaired', it is something '*you* have got to get on with' and it is something 'that takes *you* longer to learn'.

This presentation demonstrates an awareness among the Social Care Providers that there are 'acceptable' and 'unacceptable' ways of seeing learning disability. The Social Care Providers want to associate themselves with what they view as an acceptable way of seeing learning disability that positions people with learning disabilities as equals. They also want to reject what they see as an unacceptable way of seeing learning disability, whereby learning disability is constructed as a 'problem' to be fixed. Their efforts to achieve this, although well intentioned, are unconsciously foiled by the hegemony of the medical model that implicitly makes itself dominant within their talk.

Similarly, the Student Social Workers with experience also work to disassociate themselves from what they perceive to be an unacceptable way of seeing learning disability, as demonstrated in the extract below.

Student Social Worker 1: Hmm I think if I had to define it it would be erm an impairment that that affects one's ability to learn.
Student Social Worker 2: Cognitive disability? But then you have also got to think of sort of the social model as well of is, if you can't read or whatever, is that society impairing you, not you being impaired by society [means disability]?
Student Social Worker 1: Hmm
Student Social Worker 3: Well for me, because I started working with people with learning disabilities like about 20 years ago I still have in my head kind of like lots of the definitions that were about around that time and so kind of like I know around that

> time it around people who erm kind of like had significant impairment before or by the age of 18 and it was very much linked to kind of like IQ troubles so I guess it was like quite a medical kind of like definition of learning disability and erm over time kind of like I guess, because I have continued to work with people with learning disabilities, and I have began to learn more and I guess kind of like quite a bit of the culture has kind of like changed and er the language has changed I know that people kind of like with learning disabilities themselves would rather it be defined as a learning difficulty rather than having a learning disability erm but I sort of in some ways I still struggle with that because I think it can be quite difficult to actually identify that group of people.

Here, the student social workers begin by locating learning disability in individual bodies by framing it in terms of ‘an impairment that affects one’s ability to learn’ and as a ‘cognitive disability’. Their talk then goes on to consider societal barriers that could create learning disability by asking ‘if you can’t read or whatever, is that society impairing you, not you being impaired by society [means by disability]?’ Student social worker 3 then follows this by considering how people with learning disabilities define themselves but finds their choice of learning difficulty problematic because ‘it can be quite difficult to identify that group’. Here, it can be seen that the social work students’ talk circles around the social model. They want to ‘think of it’ and they want to present as people who prioritise the preferences of people with learning disabilities but when they do this, the medical model influences their consideration. By expressing that it can be hard to identify people labelled as people with learning difficulties as opposed to disabilities, the Social Workers are implicitly locating responsibility for identification of such people with those who do not have a learning disability, in other words, those who have intellectual supremacy, a notion the social model rejects as disabling.

The contradiction presented above was common across all of the focus groups. Although the participants use the *I know what learning disability is* repertoire in their definitions of learning disability to establish their knowledge as the 'right' way of seeing learning disability in order to present as 'good people', their hard work is undermined by the underlying presence of the medical model throughout their talk. The participants want to show that they know what they are talking about which necessitates some use of the medical model due to its overriding dominance within the social, cultural and political worlds experienced by the participants, as seen in the literature review. Their knowledge that this is the case is sometimes explicit as will be seen when their confidence in objective medical diagnoses is discussed; however, the participants' also often used the language of the medical model less consciously, further demonstrating its hegemony. This unconscious individual emphasis is also evidenced in the participants' use of personal examples discussed below.

Use of the *I know what learning disability is* repertoire to provide personal examples to emphasise their 'good person' status

In constructing their co-produced definitions of learning disability, participants across all of the focus groups frequently drew on personal experiences to illustrate particular points throughout their discussions. The participants used the *I know what learning disability is* repertoire when providing personal examples to add value to their talk, in particular to bolster their 'good person' status.

The personal experiences provided were numerous and varied in scope. The participants talked as professionals in their own discipline, as lay people, as siblings, as parents, as migrants, as friends, as relations and as carers. Within their examples, the participants referred to people they know with particular learning disabilities or what they consider to be learning disabilities. Here, participants used medical diagnoses or categories to demonstrate their knowledge. The participants drew on the *I know what learning disability is* repertoire, when making reference to these conditions; within their groups it was tacitly agreed that everyone knew these conditions to be learning disabilities. None of the participants challenged either the speakers' or the groups' tacit assumptions. Extracts taken from the focus groups with the Mainstream Teachers and the Student Teachers demonstrate this use of the *I know what learning disability is* repertoire.

In the extract below the Mainstream Teachers had been discussing their experience of the 'inclusive schools' agenda, whereby pupils with disabilities are taught in mainstream schools. Mainstream Teacher 3 is listing the pupils with learning disabilities that she has taught in her classroom as part of this agenda.

Mainstream Teacher 3: I've had epilepsy, I've had bilateral cataracts erm yea cerebral palsy, two or three with cerebral palsy, a child with severe, who was in foster care, with severe learning delay in a wheelchair with no language no toilet training, that was very hard. He, it was total neglect, his first year he was left in a cot basically so it was total neglect he came, he couldn't walk at all but yea that was dreadful, he did go to a special school in the end. Oh and Down's syndrome, Holly years ago. Yea so a wide range. I think its brilliant. It's great from the children's point of view.

(teachers' discussion of the inclusive schools agenda omitted)

Mainstream Teacher 3: I'm quite passionate about special needs it's always been a passion and not seeing it as special needs in a way, just catering to needs. I've always had this thing that children

> can get out there and you can do what you want and you can these days.

In this presentation, Mainstream Teacher 3 uses the *I know what learning disability is* repertoire to list the types of learning disability she has experienced in the classroom. She has experienced the benefits of an inclusive approach to education first hand and she uses her wide-ranging experience to back up her 'good person' status. Based on her positive experience she frames the agenda as 'brilliant' and 'great from the children's point of view'. After the other Teachers have spoken about their experiences, she goes on to affirm her 'good person' status, telling the group that she doesn't see special needs as special needs but rather sees it as 'catering to needs'. She sets out her personal approach to learning disability which involves having 'this thing that children can get out there and you can do what you want'. She tells the group that she is 'passionate' about this way of seeing learning disability. She uses her personal experience of learning disability in the classroom to add value to her passion by showing that she not only thinks that children with learning disabilities 'can get out there and you can do what you want', but she knows this to be true.

Similarly, Student Teacher 1 draws on her personal experience volunteering with people with learning disabilities to bolster her use of the *I know what learning disability is* repertoire and the 'good person' subject position she wishes to convey.

Student Teacher 1: There was one man there, thinking about different kinds of learning disability, who er, it was an unusual one I think its something like Goldman Barr syndrome or something. But his was quite interesting because he had autism but he also had this kind of erm syndrome so he had kind of I think it affected like part of his brain or something and he was autistic but he was always talking about his family and he was also kind of emotional. I was, I quite naively, bought in to the idea that people with autism are less emotive so it was quite interesting for me talking to him about kind of how much he loved his family and getting emotional about stuff like that as well. I'm rambling on now but it was good for like challenging stereotypes, when you actually meet people with conditions that you talk about.

In this presentation, Student Teacher 1 is telling the group how her experience volunteering with people with learning disabilities changed her understanding of learning disability for the better. She tells the group that her first hand experience of working with people with learning disabilities allowed her to question her previous way of seeing learning disability that she describes as naïve and stereotypical. Where she had previously 'naively bought in to the idea that people with autism are less emotive' her experience of a man with autism who could express emotion caused her to re-evaluate her perspective. Here, she is using this experience and the knowledge it gave her to align herself with what she now views as an 'acceptable' way of seeing learning disability, an approach that challenges stereotypes and recognises that people with learning disabilities are not a homogenous group. Reference to the broad nature of learning disability was frequently made by participants across the focus groups to affirm their 'good person' status. Their initial construction of learning disability as a broad term to enable this identity work is discussed below.

Use of the *I know what learning disability is* repertoire to show that learning disability is a broad term

In this use of the repertoire the participants frequently used adjectives and phrases denoting scale to demonstrate learning disability's reach. Five of the focus groups (Mainstream Teachers, Local Authority Councillors, Health Professionals, Clinical Psychologists and Student Journalists) used the adjective 'broad' when constructing their definitions of learning disability. Other adjectives and phrases referring to breadth of coverage, included 'wide spread' [Mainstream Teachers], 'massive range' [Social Care Providers], 'big range' [Student Social Workers with experience], and 'wide scope' [Student Teachers]. Participants talked about 'lumping loads of different populations under one term' [Student Journalist], about learning disability including 'loads of stuff' [Student Teachers] and there being 'probably like hundreds of millions of diagnoses' [Student Social Workers without experience]. The word 'anything' also featured prominently in the focus groups' talk when constructing their definitions of learning disability. Learning disability was considered to be *anything* that can have an impact on learning. An example of this can be seen in the Social Scientists' discussion below. Here they use the word anything three times within a short extract to describe what learning disability might be.

Social Scientist 4: I was just gunna say if you look at kind of the two words of learning disability, its almost something that affects your ability to learn.
Social Scientist 1: Yea, I was going to say that.
Social Scientist 4: So that can cover anything.
Social Scientist 2: Umhmm.
Social Scientist 4: Anything that interrupts your learning, be it kind of an emotional state or a physical injury or whatever but that spectrum then is huge so.
Social Scientist 3: Yeah.
Social Scientist 5: Yeah.
Social Scientist 4: It could be anything I suppose.

Here, in addition to 'anything', the Social Scientists, also use a number of other vague and all encompassing verbs and adjectives to consider what learning disability includes. Learning disability is said to be 'something', that includes emotions, physical states and 'whatever'. It is thought to be a 'spectrum' that is 'huge'.

Constructing learning disability in this way further allowed the participants to maintain their good person status. The participants often used the broad nature of learning disability to demonstrate their commitment to equality. When asked to discuss the similarities and differences in the lives of people with learning disabilities in comparison to their own, the participants frequently drew on the *I know what learning disability is* repertoire to problematise this task, stating that the broad nature of learning disability rendered such a task impossible. The participants used their construction of learning disability as including 'anything', 'hundreds of millions of diagnoses' and 'loads of stuff' to show that people with learning disabilities cannot be talked about as a homogenous group. Once again the participants are demonstrating that there are certain ways of seeing learning disability that they do not want to be associated with. The participants do not want to be seen to talk about learning disability as one way of being, rather they want to show that they know that people with learning disabilities are all different just as people without learning disabilities are. Student Teacher 1 makes this clear when in response to the question what are the similarities and differences between the lives of people with learning disabilities and your own? she said 'I think I couldn't really comment on that any more than I could on any random person on the street'. This action is discussed in further detail in relation to the *people with learning disabilities are different to me/people with learning disabilities are the same as me* repertoire pair, where heterogeneity was commonly used as a reason for avoiding talking about difference.

In progressing their talk about their definitions of learning disability to address what/who is included within learning disability as a population category, as seen, the focus groups expanded their definitions to include literally 'anything'. It is here that the participants switch from certainty to uncertainty. In acknowledging that learning disability can include all sorts of different people with all sorts of different abilities and diagnoses, the participants became uncertain as to what learning disability might be. When considering who/what is included within learning disability, participants also employed the *learning disability is a confusing term* repertoire. This repertoire is illustrated and discussed below.

The *learning disability is a confusing term* repertoire

Features of the repertoire

The *learning disability is a confusing term* repertoire can be distinguished by the consistent use of the following speech acts: direct reference to their confusion and/or the confusion of others; the use of metaphors to convey confusion and the emotions it gives rise to; and the use of medicalised language such as, references to diagnoses, medical categories, biology and chromosomes. The focus groups were explicit in their use of this repertoire. When talking about their knowledge of learning disability, they often directly refered to their confusion and/or the confusion of others, claiming 'I got very confused' [Social Care Providers], 'this is where I am confused' [Health Professionals], 'I am very confused' [Social Scientists], 'I am confused' [Student Social Workers with no experience], 'I am getting a little bit confused' [Student Journalists], 'most people don't have a clue' [Parent Carers], and 'he is an artist, I really don't think that he would get it [learning disability]' [Clinical Psychologist].

Use of the *learning disability is a confusing term* repertoire

The *Learning disability is a confusing term* repertoire tended to be used when the focus groups' talk turned to one of two subject areas: the broad remit of the term, and the use and meaning of other terms. In addition to this, as seen in the discussion of the previous repertoire, the participants' used this repertoire at these times to disassociate themselves with what they perceived to be an unacceptable way of seeing learning disability. The focus groups switch rapidly back and forth between the two repertoires, using them in conjunction with the two other repertoire pairs, discussed in the following chapters, to achieve a co-produced understanding of learning disability that maintains their desired 'good person' status.

The majority of the focus groups drew on the *learning disability is a confusing term* repertoire in order to question their previous use of the *I know what learning disability* *is* repertoire. At face value this might appear nonsensical, however, as stated, the back and forth interchange of these repertoires allowed the participants to make changes to their co-produced understanding of learning disability in order to strengthen their much desired 'good person' status. As stated, not all of the focus groups performed this repertoire in the same way. While the vast majority of the focus groups questioned their own knowledge, two of the focus groups, the Parent Carers and Clinical Psychologists used the repertoire to doubt other people's knowledge rather than their own. Despite this the *learning disability is a confusing term* repertoire was drawn upon as a consequence of two situations regardless of performance: the construction of learning disability as a broad term and the presence of alternative terms. Each of these situations are discussed below.

Use of the *learning disability is a confusing term* repertoire as a consequence of the construction of learning disability as a broad term.

The Health Professionals' and the Student Teachers' talk, presented below, provides two examples of the use of the *Learning disability is a confusing term* repertoire when used as a consequence of their knowledge that learning disability is a broad term. Despite their rejection of an individualist approach to learning disability, the use of medicalised language and a reliance on its objective status provides both groups with comfort and certainty; its absence, however, has the opposite effect, making them feel uncomfortable and confused.

Health Professional 1: It's kind of broad
Health Professional 3: It's very broad erm in description and I feel uncomfortable using it on its own without an additional *diagnosis* or before a *diagnosis* has been given. It's where I get confused.
And later on

Facilitator: So how do you feel about the term learning disability overall?

Health Professional 3: Well I think it can be confusing. I definitely don't feel comfortable using it unless it has been diagnosed already by someone else. But then erm like I said I don't know when a learning difficulty, because that's the term I would use if there isn't a diagnosis, then becomes a learning disability. So yea I'm a bit uncomfortable using it really, overall.
Health professional 1: Yeah, I think it is very broad

Here, it can be seen that the Health Professionals find certainty in medical diagnoses made by someone else. While the Health Professionals use the *I know what learning disability is* repertoire to identify that learning disability is 'very broad in description', they then switch to the *learning disability is a confusing term* repertoire, outlining their discomfort 'unless it has been diagnosed by someone else'. The Health Professionals do not consider themselves to have this expertise, stating 'I don't know when a learning difficulty, because that is the term I would use if there isn't a diagnosis, becomes a learning disability'. Only when 'someone else' has made the diagnosis, do the Health Professionals feel safe to use the term learning disability.

The extract below, taken from the focus group with Student Teachers, demonstrates a similar trend.

Facilitator: So what other conditions would you lump into learning disability, you have said dyslexia, dyspraxia, are there any other conditions you would include?
Student Teacher 1: Erm, oh what do they call it? kind of like gross erm, hmm like a general kind of delay. I can't remember what they actually call it, where they just generally kind of take longer to get to places in their learning and kind of what possibly in the old days would be labelled as slow, not that I think we should say that, but yea erm so something like that erm.
Student Teacher 2: Down's syndrome, I suppose is often like associated with learning disability on some level.
Student Teacher 1: Yeah, oh there is lots isn't there? But I am just trying to think.
Student Teacher 2: I know!

Student Teacher 1: Erm er erm.

Student Teacher 2: All I know is the biological things so you know like all the people who have got an extra gene somewhere or like an extra chromosome.

Faciliator: So like Down's syndrome?

Student Teacher 2: Yea but there is other ones like where there is an extra one in a different place, like loads of stuff. So! I think I am coming to the conclusion that I don't know very much at all about learning disability!

Student Teacher 1: Yeah I know its scary sometimes isn't it when you think you know quite a bit and then you start talking about it and you think 'well I'm not sure about that, and I'm not sure about that either' ha ha so yeah.

Here, the Student Teachers try to provide examples of other conditions that they would consider to be a learning disability, having previously used the *I know what learning disability is* repertoire to construct a definition of learning disability and to give personal examples. Indeed, the Student Teachers use the *I know what a learning disability is* repertoire throughout this extract to demonstrate that they do know what a learning disability is, using medicalised language to provide status to their descriptions. Student Teacher 1, however, re-orientates herself with the 'good person' subject position by stating 'not that I think we should say that' after she has used the label 'slow' to refer to people who 'take longer to get to places in their learning'. When Student Teacher 2 is unable to remember 'what they actually call it', she resorts to scientific knowledge to add value to her knowledge stating: 'all I know is the biological things' and referring to 'an extra gene somewhere' and 'like an extra chromosome'. It is here that their talk reverts back to a reliance on medical knowledge. After searching for additional conditions that they would associate with learning disability beyond the dyslexia and dyspraxia that they have provided in examples of their personal experience of learning disability, the Student Teachers lose confidence in their medical knowledge and switch to the *learning disability is a confusing term* repertoire. Student

Teacher 1 declares 'I am coming to the conclusion that I don't really know a lot about learning disability!' To which Student Teacher 2 adds that uncertainty is 'scary sometimes'. Apparent within in this presentation, therefore, is the Student Teachers' realisation that their medical knowledge is lacking which causes them to doubt their knowledge of learning disability in which they were previously certain.

Implicit within their talk is the perception that learning disability is something that requires expert, objective knowledge to understand; something they come to realise they do not have, resulting in their doubt. Indeed, the Health Professionals outlined that they would use an alternative term, learning difficulty, in the face of uncertainty. The availability of alternative terms was also used as a reason for confusion among the focus groups, as is discussed below.

Use of the *learning disability is a confusing term* repertoire as a consequence of alternative terms.

All of the focus groups listed additional terms that could be and have been used to refer to people with learning disabilities, including; learning difficulty [Local Authority Councillors, Clinical Psychologists, Health Professionals, Teachers, Social Workers with and without experience, Parent Carers, Student Journalists, Sociologists], people with impairments [Social Care Providers], aspies [Parent Carers], slow [Student Teachers], mentally handicapped [Parent Carers and Clinical Psychologists], retarded [Parent Carers], special educational needs [Student Teachers, Mainstream Teachers, Local Authority Councillors], thick [Local Authority Councillors], special [Mainstream Teachers], service users [Student Social Workers with experience], clients [Student

Social Workers with experience and Parent Carers], citizens [Parent Carers], additional needs [Special School Staff] and intellectual disability [Clinical Psychologists].

Across the focus groups, terminology to refer to learning disability was considered to be in a constant state of change, with new terms rendering old terms incorrect, out of date and sometimes offensive. This perceived ever changing list of terms resulted in the participants expressing uncertainty as to which term should be used, drawing on the *learning disability is a confusing term* repertoire to show this. Statements such as Special School Teacher 5's, 'well it's like with black or gay or whatever, the terms are always changing and sometimes you don't know what is best', were common throughout the focus groups. The participants did not want to get it 'wrong' and expressed concern that in getting it wrong they could both cause offence and appear ignorant. This concern will be explored further in the next chapter when the *I don't like labels/labels are useful* repertoire is discussed.

Within their expressions of terminological variety, the *learning disability is a confusing term* repertoire was particularly evident when participants talked about the term 'learning difficulty'. Across the focus groups that used this repertoire to question their own knowledge, the participants were generally uncertain if learning disability and learning difficulty both referred to the same conditions and if the two concepts could be used synonymously. The (mis)understanding discussed in the previous chapter, is directly relevant here. In considering dyslexia (a specific learning difficulty) to be a learning disability, the participants become confused as to what the difference between a learning disability and a learning difficulty might be. Two examples, taken from the focus groups with the Local Authority Councillors and the Student Social Workers without experience of learning disability, demonstrate the use of this repertoire when considering the meaning of the term learning disability.

When talking about the different terms available to describe learning disability, the Local Authority Councillors said:

Local Authority Councillor1: I would suspect that I would probably use them all interchangeably but I couldn't tell you whether that is right because if you logically analysed it learning difficulty could be for someone who on an intelligence level isn't different as a person, they find learning more difficult. Whereas disability has the tag that there is something that inhibits their ability to learn but yeah it's just, you start to disappear down the rabbit hole after a while don't you?

Local Authority Councillor 2: Yeah. And I think I would use them all interchangeably as well. Erm, I don't know whether I sometimes find that I wouldn't possibly use disability hh because hh I might not be sure that the type of issue that I'm talking about would be labelled as a disability. So as I say, the one I am most used to is dyslexia. Is dyslexia a disability? I don't know if it is? It's an issue, it's sort of still, it's something people are still learning about and analysing. Is it a disability? I'm not sure.

Local Authority Councillor 1: And once you get to the similar sort of boundaries on mental and physical health, erm again, you are just not sure which one, where where it would fall into

In this presentation, the Councillors are confused by the word disability and what it might include. Their talk about the use of different terms and specifically their talk about the term learning difficulty is comprised mainly of questions that they attempt to answer, only to generate more questions. The Local Authority Councillors ask themselves if their interchangeable use of the two terms, learning disability and difficulty is correct, they ask themselves if dyslexia is a disability twice, and they seek confirmation from one another that learning disability is semantically confusing, asking, ‘you start to disappear down the rabbit hole after a while don’t you?’ Their uncertainty is directly linked to the specific word, disability. Here, the councillors set up disability as being different to a difficulty because it ‘has the tag that there is something that inhibits their ability to learn’, implying that disability is associated with someone who is different as a person, whereas difficulty ‘could be for someone who isn’t different as a person, they find learning more difficult’. Councillor 2 considers the possibility that dyslexia might not be enough of an issue to be labelled as a disability. The word disability and its perception by the Councillors as something that would be associated with someone who is different as a person, someone who has significant enough issues, causes the councillors, who have previously used the *I know what learning disability is* repertoire, to question their knowledge.

Similarly, when talking about their confusion between the two labels, learning disability and learning difficulty, the Student Social Workers without experience said:

Social Work Student 2: I am confused between learning difficulties and learning disabilities and I feel like there might be a line somewhere that I don’t know what it is that erm.
Student Social Worker 3: I agree with that because I am dyslexic but
Student Social Worker 1: Me too, I consider myself disabled though.
Student Social Worker 3: I don’t. I wouldn’t put myself erm in the same bracket as someone with autism because
Student Social Worker 1: No I wouldn’t
Student Social Worker 3: I don’t feel like I would need as much support and it would be like a waste of resources for me to classify myself like that if that makes sense
Student Social Worker1: Erm, I don’t think of it in terms of that. I don’t think of it in terms of the financial side of it at all. I understand where you are coming from though because like you know being at this uni, I have draw down funding for mine but I feel like its just stuff that I need to help me do my best and that’s why I think of myself as disabled person because people who have disabilities are just you know, people but they need help to do their best if that’s what they want and erm, your [Facilitator] what do we think

learning disability is, and I do think that its people who need more support than the average person to be able to erm get on board with the same level of information and materials and stuff like that.

Student Social Worker 3: I find it difficult to classify myself because even within dyslexia there is different levels, like my Mum is dyslexic and hers is a lot more severe than mine erm and I find it difficult for people to be understanding so when I say ‘oh I’m having a computer for my exam’ they will say ‘why?’ and because I do quite well on my assignments they don’t, even though I am dyslexic, they don’t see me as almost justified, deserving of that support because I do sometimes do better than people that aren’t dyslexic

Student Social Worker 1: Have you known that you are disabled for a long time?

Student Social Worker 3: About two or three years.

In this presentation, the Student Social Workers are unsure what differentiates learning disability from learning difficulty and consider the possibility that there might be a difference. The presence of an additional term creates uncertainty in their talk. Student Social Workers 1 and 3 draw on their personal experiences as dyslexic students and how this affects their knowledge of learning disability. As a person with dyslexia, known by those with specific knowledge to be a learning difficulty, Student Social Worker 1 identifies herself as having a learning disability, stating ‘I consider myself disabled though’. Social Work Student 3, who is also dyslexic, at first tells the group that she does not consider herself to be disabled, stating that ‘I don’t feel like I would need as much support and it would be like a waste of resources to classify myself like that’. Here Social Work Student 3 is implicitly using the *I know what learning disability is* repertoire to show that she knows that learning disability implies a certain level of support. Social Work Student 1 agrees with this but believes that as a dyslexic student she needs the additional support that people with learning disabilities do, stating ‘I do think that it's [learning disability] people that need more support than the average person to get on board with the same level of information and materials and stuff like that', again employing the *I know what a learning disability is* repertoire. Despite their use of this repertoire, the *learning disability is a confusing term* repertoire is present throughout this extract. Student Social Worker 2 thinks there might be a difference, Student Social Worker 1 identifies herself as disabled as a consequence of her dyslexia and Student Social Work Student 3 begins by asserting that her dyslexia isn't a learning disability; by the end of the extract, however, she identifies as disabled.

Both the Local Authority Councillors and the Student Social Workers without experience consider the possibility that learning disability and learning difficulty mean different things and use dyslexia as an example. Although they consider this as a possibility, they are both unsure and so use the terms synonymously.

In questioning their own knowledge of learning disability the focus groups that did so attempted to rewrite their definitions of learning disability to better fit what the participants perceived to be an 'acceptable' way of seeing learning disability, whereby learning disability is presented as a heterogonous way of being. In working to do this, however, their reliance on what they saw as 'objective' medical knowledge was made further apparent. This was also the case for the remaining two focus groups who did not attempt to rewrite their constructions of learning disability as seen below.

Use of the *learning disability is a confusing term* repertoire to question other people's knowledge.

As stated, the performance of *learning disability is a confusing term* repertoire, differed slightly between the focus groups. While all of the groups acknowledged that the term is confusing due to its broad nature and the variety of terms available, as illustrated above, the Clinical Psychologists and Parent Carers used the repertoire to question the knowledge of others while maintaining their own knowledge of learning disability as correct. These groups particularly relied on their expert knowledge and used expert language to demonstrate this. Examples from the Clinical Psychologists' and the Parent Carers' discussion are provided below, to show this performance of the repertoire.

As with all of the focus groups, the Parent Carers established their knowledge of learning disability at the beginning of the focus group. The Parent Carers, however, did not waver in their certainty.

Facilitator:	What do you understand by the term learning disability?
Parent Carer 2:	Its very difficult to understand actually because there is such a vast number of people who are really different. They are all different and so I have already asked people about learning disability and erm people have, I've said to them 'what do you think learning disability means?' and they have said to me, 'oh well perhaps they have difficulty in writing or reading'
Parent Carer 3:	Ah well that's learning difficulties isn't it.
Parent Carer 2:	Well whatever, you know they don't know the difference do they?

Here, the Parent Carers explicitly refer to how learning disability can be confusing for people who do not know about it. When Parent Carer 2, says that 'it's [learning disability] is very difficult to understand actually', she is not saying that she finds learning disability very difficult to understand but is making reference to the difficulty experienced by others. Consequently, she has taken it upon herself to survey 'non-experts' and has found that they do not understand, thinking it is as simple as 'difficulty in writing or reading'. Parent Carer 3 interjects with his own knowledge that, 'that's learning difficulties isn't it'. To which Parent Carer 2 dismisses the ignorance of 'non experts', stating 'they don't know the difference do they?', using the *learning disability is a confusing term* repertoire to do so.

The Parent Carers later go on to use objective expert knowledge to further show how learning disability can be a confusing term for people without their level of understanding.

Parent Carer 1: Well if you have Asperger's for instance or something like that, that can in some cases be high functioning but that is err, within the autistic spectrum what people will say is that you can be at the extremely able end, 2% of folks on the autistic spectrum are er significantly superbly bright, with doctorates but only 1% of the average population, so therefore, erm someone with Asperger's in that sense wouldn't have a learning disability they but they would have a disability, you you can argue that. So what the NAS [National Autistic Society] says is they say that if you have got a spectrum of people with autism 2% are exceptionally bright, but more than average have a learning disability. So NAS actually separate out learning disability with autism and autism as a higher end, able end of the spectrum so they, they actually separate that out and they say you, you are all on the spectrum, but some people are very able and some people have a learning disability and some people have associated problems like epilepsy. But that is quite complicated knowledge and most people don't have a clue about that so they wouldn't, they would get very confused then.

Here, Parent Carer 1 demonstrates her specific expert knowledge, using statistics and reference to national bodies. Parent Carer 1 uses the NAS acronym without feeling the need for explanation because she knows what it means and assumes the other Parent Carers will share this knowledge. Parent Carer 1 frames her knowledge as 'complicated knowledge', that 'most people don't have a clue about'. Without such 'complicated knowledge' she tells the group that those people that 'do not have a clue about' it, 'would get very confused'.

In a similar use of the *learning disability is a confusing term* repertoire, the Clinical Psychologists also use their expert knowledge of learning disability to question the knowledge of non experts. When talking about the term intellectual disability Clinical Psychologist 2 further identifies the confusion others experience because they do not have the expert knowledge that Psychologists do.

Clinical Psychologist 2:	Well because I am not sure [partner's name] would understand the term intellectual disability, I don't think he would because he is not, you know, bless him, he is not a psychologist by any stretch of the imagination, he is an artist, that's, he wouldn't, I really don't think he would get it.

In this presentation, Clinical Psychologist 2 does not blame other people for not being able to understand such terminology. Without a knowledge of psychology, the ability to understand the term intellectual disability is considered to be beyond lay people. Clinical Psychologist 2 uses the idiom 'bless him' when referring to her partner to intimate that she does not blame him for his ignorance, he is simply, 'not a psychologist by any stretch of the imagination' and so would not be able to understand learning disability.

Later, the Clinical Psychologists use their own knowledge, to identify that even other experts can get it wrong.

Clinical Psychologist 1: I have had other psychologists that perhaps are not so au fait with learning disability as a sort of population group and so they might say learning difficulties and there is a bit of me that always wants to go, ‘ooo, that’s the wrong phrase’

Clincal Psychologist 3: And actually talking about kind of labelling, the bit I now struggle with is where do you fit the developmental stuff like Autism or Asperger’s or you know because its kind of, its been incorporated into LD services but it doesn’t really, there is kind of a level of functionality in that as well that doesn’t

Clinical Psychologist 2: Yea it doesn’t necessarily fit does it?

Clinical Psychologist3: Well depending on kind of where you are on that spectrum

Clinical Psychologist 1: People often have a dual diagnosis of learning disability and autism, it’s the ones that are classed as high functioning that would be different, where as I think when working with people with a learning disability, you often see autistic traits in them and because of their impairments and their cognitive profile, it shows up differently but there are elements of autism and there is such a huge overlap, that I think it is really difficult to separate out the two diagnoses as it were, so I think often

In this presentation, the Clinical Psychologists both highlight the lack of knowledge of other experts and use their own expert knowledge to resolve the issue of where ‘development stuff like Autism or Asperger’s’ fits. Here the Clinical Psychologists cast themselves as ‘expert experts’. Clinical Psychologist 3 uses her expert knowledge to identify that the inclusion of people with Autism and Asperger’s in learning disability provision, ‘doesn’t necessarily fit’. Clinical Psychologist 1 adds to this, employing her expert knowledge of the area by referring to ‘dual diagnosis’, ‘autistic traits’ and ‘cognitive profile’. Without this knowledge ‘other Psychologists’ are shown to be capable of getting the terminology wrong, referring to learning difficulty when they are actually talking about learning disability. In their role as ‘expert experts’, the Clinical Psychologists find this frustrating, they want correct the ‘non-expert experts’ who have got it wrong as a consequence of their limited knowledge.

The performance of the repertoire is slightly different here to how the majority of the focus groups performed it, in that the repertoire is used to question the knowledge of others as opposed to their own knowledge, as seen the emphasis on the need for objective, medicalised knowledge about learning disability in order to understand it. This standpoint, however, was not unique to the Parent Carers and the Clinical Psychologists. Across all of the focus groups objective expert knowledge was framed as essential to the understanding of learning disability. Without expert knowledge such as statistics, knowledge of biology and the experience of diagnosis, learning disability is constructed as an elusive term that cannot be fully understood.

Conclusion

The conclusion that follows summarises the research findings in terms of the functions and consequences of the participants' use of the *I know what learning disability is/learning disability is a confusing term* repertoire pair and discusses the key findings in relation to the contribution they make to the sociological theorisation of learning disability.

Function and consequences of repertoires

To summarise the analysis above, the participants use both the *I know what learning disability is* and *the learning disability is a confusing term* repertoire primarily to construct a particular identity, that of the 'good person' who values equality and rejects individualist approaches. In doing so, however, their talk reveals a direct conflict between the identities they want and do not want to be associated with. This conflict mirrors the tension between the social model and the medical model of disability discussed in the literature review. Despite the participants' hard work to present as 'good people' their talk is reflective of the language of the medical model, whereby disability is positioned as an individual issue. It is for this reason that the *learning disability is a confusing term* repertoire is useful for those focus groups who used it to question their own knowledge that is based on an individualist/deficit focused perspective. As seen, this repertoire allows them to undo their certainty expressed in the *I know what learning disability is* repertoire. In this way, the *learning disability is a confusing term* repertoire acts as a disclaimer to the previous reliance on a perspective they do not wish to be associated with. In reframing their knowledge as uncertain, the participants are able to reinforce their 'good person' status.

The participants are torn between their ultimate desire to present as 'good people' and their difficulty in escaping the dominance of objective knowledge and the comfort that this provides them. The tension this presents within the participants', talk and the participants' oscillation between the two repertoires to manage this, is illustrative of an ideological dilemma (Bilig et al 1988): to appear like they know what they are talking about within the framework available to them, but also to align themselves with the 'acceptable' way of seeing learning disability that critiques the epistemological basis of their knowledge. Consequently, both repertoires function to allow the participants to manage and negotiate this dilemma.

As Edley and Wetherell (1999) tell us, interpretive repertoires are socially and culturally produced resources that allow individuals to engage in, share and comprehend common understandings of the world. Indeed, Edley (2003) uses the metaphor of a library to show what he refers to as the encultured nature of interpretive repertoires. In this metaphor interpretive repertoires are available to speakers to use or borrow; he tells us that ‘when people talk about things, they invariably do so in terms already provided for them by history’ (Edley 2003 p.198). Here it can be seen that both repertoires and the ideological dilemma they are used to manage are products of learning disability’s social and cultural past and present and the dominant shared discourses that preside at the time. As Edley (2003 p.202) tells us ‘people are encultured into particular, even partial ways of understanding the world’. As seen in the literature review, social model discourse suggests that there is a ‘right’ and a ‘wrong’ way to see disability and this is reflected rhetorically in academic and policy literature. The medical model, closely linked with learning disability’s negative past, is framed as an ‘unacceptable’ way of seeing learning disability. The participants draw on the repertoire pairs to demonstrate that they know this and consequently do not want to be associated with a medicalised way of seeing learning disability. Their discursive work to avoid this and the tensions they encounter when their ideal is faced with the hegemony of the medical model is further highlighted in the following two chapters.

Key findings

The participants’ use of this repertoire pair to manage the ideological dilemma above, points towards two key findings that have direct consequences for the future study of learning disability and its sociological theorisation. First, the participants’ constructions of learning disability show that learning disability is not universally understood to mean the same thing and that ‘real world’ constructions of learning disability are often (mis)understandings. Second, in attempting to reflect current ‘acceptable’ theories of learning disability, ‘real world’ constructions of learning disability obscure the body.

While the participants' constructions of learning disability were relatively consistent across the focus groups, in that all of the focus groups used this repertoire pair to achieve the same aims, the specifics of their talk revealed widespread inconsistency as regards to the types of conditions and diagnoses thought to be learning disabilities. As seen in the analysis presented above, in using this repertoire pair some participants included dyslexia in their talk, some included cerebral palsy, some talked about stroke in terms of a learning disability, some about bilateral cataracts, some about ADHD, some about memory problems and others about head injury. This is a surprising finding considering the majority of the participants' close proximity to people with learning disabilities in their professional practice, and the skills and knowledge this requires. The inclusion of conditions such as epilepsy and cerebral palsy as learning disabilities is likely a reflection of their historical categorisation as such (Rix 2006). That professionals working in current learning disability practice, however, still talk about such conditions as learning disabilities is unexpected. The (mis)understanding demonstrated is deepened as a consequence of the presence of the use of alternative terms to refer to the term learning disability, as seen in the participants' talk and also in the literature review. The general consensus that dyslexia is a learning disability is illustrative of this, in that this 'specific learning difficulty' presents an additional term causing the participants confusion as to whether or not a learning difficulty is the same as a learning disability.

At this point in the analysis when asking 'what does learning disability mean in the real world?', moreover, it would be fair to quote Student Social Worker 2 and answer that learning disability means 'hundreds of milllions' of different things. Although the participants' talk reflected the dominant theoretical approaches to learning disability, it should not be assumed that everyone knows what is being talked about when the term learning disability is used, even those who work in learning disability practice. Nor should it be assumed that people universally understand what is being referred to when alternative terms are used. This is of direct consequence for academic research and its dissemination into practice.

The (mis)understanding demonstrated is perhaps explicable if the second finding is considered more fully. As seen in the participants' use of the two repertoires to manage their ideological dilemma, the participants' desire to present as 'good people' limits what they can actually say about learning disability. The basis of their much desired 'good person' status reflects the rhetoric of the social model whereby the medicalisation of disability as a deficient way of being is rejected in favour of a focus on sociocultural barriers. This 'acceptable' way of seeing learning disability, thereby, does not allow for the learning disabled body to feature in their constructions of learning disability. While the body was present implicitly within their talk (for example in references made to the location of learning disability, what bodies can do and specific conditions of the body) explicitly, the participants' talk demonstrated a desire to avoid talking about the body. Indeed, when talking about the location of learning disability, while individual bodies featured in their talk, the participants actively separated the brain from both the body and the self, constructing it as an ethereal and independent entity. If the participants were to explicitly acknowledge the body in their desired constructions, their understandings of learning disability might not have included the range of (mis)understandings presented.

The notable absence of (mis)understanding within the Clinical psychologists' and the Parent Carers talk is interesting here. As with many of the other groups, both the Clinical Psychologists and the Parent Carers encounter learning disabled bodies on a very regular basis. While this did not have a bearing for some of the other focus groups who did demonstrate (mis)understanding, the combination of this and the presence of explicit and unapologetic medical discourse perhaps explains why these groups' constructions of learning disability typically mirrored 'official' definitions. Within Clinical Psychology, for example, both research and practice are heavily medicalised: research is largely based on what is seen to be objective knowledge and practice is typically undertaken within medical settings. For the Parent Carers, much of their relationship with learning disability is medical: their children have been diagnosed by medical professionals and the care for their children is typically overseen by psychologists or psychiatrists. Thus the body, while materially present, is also theoretically present. For the other professional groups such as the Special School Teachers, the Mainstream Teachers and the Social Care Providers, while the material learning disabled body is regularly present, it is more often than not theoretically absent because the discourse that informs their practice is more likely to be based on social model principles and/or these principles as reflected in the neoliberal rhetoric of choice and control, as seen in current social care policy, demonstrated in the literature review.

In summary, while the medical model is highly problematic, the theoretical and the material presence of the learning disabled body can be seen to be a useful combination that allows the material reality of learning disability to be acknowledged. The absence of the body, conversely, can result in the (mis)understanding and consequent misrepresentation of learning disability which is more than likely to result in furthering the marginalisation of people with learning disabilities as what their bodies can and cannot do are glossed over. This relationship is supported further as the analysis progresses. The following chapter discusses the participants' use of the *labels are damaging/labels are useful* repertoire pair and follows the same structure outlined in the introduction to this section.

Chapter 6: Labels are damaging/Labels are useful

Context

The *labels are damaging /labels are useful* repertoire pair was used consistently and similarly across the focus groups. As seen in the previous chapter, the focus group participants constructed learning disability as a term that is applied to particular individuals based on broad definitional criteria. The focus groups drew on this repertoire pair to further their construction of learning disability, expanding it to be a label with both positive and negative consequences. The participants' use of this repertoire pair, however, is not as evenly balanced as their use of the previous pair. The participants drew much more frequently on the *labels are damaging* repertoire than they did on the *labels are useful* repertoire. As Wetherell et al (1987) tell us, repertoires do not have to be evenly used, one can dominate over another. In this case the participants used the *labels are useful* repertoire with caution, almost always switching back to the *labels are damaging* repertoire as a caveat to their recognition of the practical use of the label learning disability. Hewitt and Stokes (1975) call this rhetorical work credentialing. Credentialing involves the provision of disclaimers to avoid 'an undesired typicifcation' (Hewitt and Stokes 1975 p.4). Billig et al (1988 p.112) use the example of the statement 'I'm not prejudiced' to credentialise what could be perceived as prejudiced statements.

The participants' talk, when drawing on this repertoire pair, was illustrative of a re-contextualisation of the general argument presented within labelling theory, into everyday discourse. Generally speaking labelling theory articulates that deviant behaviour or stigmatised identities are a consequence of interactions between the person so labelled and the reaction of others rather than being a consequence of individual characteristics (Becker 1963). Societal rules and the social groups that make such rules, moreover, are said to create deviance by applying the rules to particular individuals and labelling them as deviant (Becker 1963). In other words, labels are social constructs that can instil particular identities in individuals so labelled. It is the negative connotations that this theory attached to the term label and the act of labelling that particularly featured in the focus group participants' talk. Indeed, caution featured throughout the use of this repertoire pair. Across all of the focus groups reference to the words 'label' and 'labelling' were made with caution.

The term learning disability was generally thought to be a negative label with stigmatising and life changing consequences. For instance, Social Scientist 1 said 'the problem that I have with names and labels and things like that is because I think most of them imply a more er a moral judgement'. All of the focus groups were keen to show their commitment to the 'good person' subject position constructed initially in their use of the *I know what learning disability is/learning disability is a confusing term* repertoire pair, seen in the previous chapter, and used their rejection of the act of labelling and dislike for labels to show this. For example, the participants frequently made statements such as 'I would rather we didn't have to have a label really because they are human beings like all of us' [Special School Teaching Staff Member 3].

In contrast to this standpoint, all of the focus groups discussed the practical uses of labels and considered their use acceptable in certain contexts. When doing this, the participants moved rapidly back and forth between the repertoires, returning to the *labels are damaging* repertoire to disassociate themselves from the negative act of labelling despite its practical uses. The contrasting use of this repertoire pair suggests the presence of a theory/practice disjuncture that will be discussed as the analysis progresses. Each repertoire is discussed, in turn, below.

The *labels are damaging* repertoire

Features of the repertoire

The *labels are damaging* repertoire can be distinguished by the consistent use of the following speech acts: direct reference to the objectionable nature of labels via the use of extreme case formulations (Pomerantz 1996) such as ‘I hate labels’ [Mainstream Teachers] and ‘I don’t like any labels’ [Social Scientists]; the use of language associated with labelling theory such as, ‘self-fulfilling prophecy’, ‘stereotype’ and ‘stigma’; the use of personal examples to show the damaging effects of labels; and an explicit commitment to equality. In addition, the participants frequently drew on words and phrases denoting restriction and negativity, such as: ‘stigma’, ‘boxed in’, ‘put in a zone’, ‘abnormal’, ‘broken’, ‘problem’, ‘different’, ‘handicapping’ and ‘moral judgement’ to convey the adverse impact of labels.

Uses of the repertoire

The *labels are damaging* repertoire was used across the focus groups to do two things: to highlight the negative effects of labels both to those being labelled and those doing the labelling; and to demonstrate their commitment to the ‘good person’ subject position established in their use of the previous repertoire pair. Each of these uses are illustrated and discussed below.

The use of the *labels are damaging* repertoire to show the negative effects of the label learning disability

Across the focus groups learning disability was generally perceived to be a negative, stigma-laden label. Although, this was stated explicitly by many of the participants, as when Mainstream Teacher 1 said 'well it definitely has a stigma attached to it', reference to stigma was also implicit throughout the focus group discussions, as when Mainstream Teacher 1 also said 'you wouldn't say learning disability to someone that doesn't think there is anything wrong with their child'. This implicit undertone suggests that the stigma the participants associated with learning disability was something they all tacitly knew.

When talking about the negative consequences the term learning disability can have as a result of the stigma associated with it, all of the focus groups drew on the *labels are damaging* repertoire to highlight the negative effects of the term upon both those being labelled and those doing the labelling. Each of these acts are illustrated below.

Use of the *labels can be damaging* repertoire to show the negative effects on those being labelled.

When using the repertoire to discuss the negative effects on those being labelled the participants framed this in two different ways. Learning disability was seen as having the potential to impose stigma from the outside via the imposition of an unfair, stigmatised identity and also from the inside via what the participants referred to as a 'self-fulfilling prophecy' or 'learned helplessness'.

The imposition of stigma from the outside

To demonstrate the widespread acceptance that learning disability is a negative label that has adverse consequences for those labelled, participants across the focus groups used the *labels are damaging* repertoire to exemplify other people's reactions to people with learning disabilities and to disassociate themselves from this. Extracts taken from the focus groups with Mainstream Teachers, Student Teachers and Health Professionals are provided to illustrate this use of the repertoire.

Mainstream Teacher 3: People can judge, they make assumptions that you will be a certain way if you have got a learning disability and its well its not positive. Its assumed you are stupid or maybe like a child and of course the person might not be but its because the label gives these assumptions and pictures of how someone will be.

Student Teacher 1: Yeah, yeah. I think there is a tendency within teaching sometimes with some teachers to think 'oh learning disability they will need to be in bottom set'.

Health Professional 1: And whether or not people still see, still attach it to a stigma if you say learning disability and maybe not as much as if you say difficulty.
Health Professional 3: That's why I feel uncomfortable using learning disability if the diagnosis is yet to be given because disability sounds so much more permanent than difficulty and maybe even more frightening for parents.
Health Professional 2: Yea disability definitely has that aspect to it. You know it's permanent; it could make people think that there is no hope. Like those I have seen that have the label but seem to be able to get by with a normal day to day life but don't work and receive support because of the label learning disability. It's seen like they can't take part in normal life activities when if it's mild they really can.

In these presentations, the participants make reference to other people's negative perceptions of learning disability. Other people: 'judge', have a 'tendency' assume and 'attach a stigma' to people with learning disabilities. The participants present these judgements as negative and unhelpful to people with learning disabilities. They are not comfortable with other people's perceptions of learning disability and the widespread acceptance of this. In associating learning disability with being 'stupid', 'like a child', being in 'the bottom set' and not being able to 'take part in normal life activities', other people's reactions are thought to be 'not positive' and serve to impose an unwarranted label on the individuals so labelled that renders 'normal life activities' inaccessible to them. Health Professional 3 makes her discomfort explicit, stating 'that's why I feel uncomfortable using learning disability'. She does not want to use the term learning disability without the certainty that an existing diagnosis offers due to its stigmatised connotation that could frighten parents.

Extracts taken from the focus group with Mainstream Teachers and the focus group with the Clinical Psychologists further demonstrate the participants' discussion of the negative effects of the label learning disability when imposed by other people.

Mainstream Teacher 1: Well it definitely has a stigma attached to it. I mean if you are told you are not doing as well as others well that doesn't sound good does it?
Mainstream Teacher 2: I think its all about being aware of what is normal and erm the pressure to be the same as everyone else. I've seen it when children have been bullied for being SEN and well I definitely think it's because that label singles them out as not normal.
Mainstream Teacher 1: Yeah. And also there are a lot of derogative names that go with it.
Mainstream Teacher 3: Thick, slow.
Mainstream Teacher 1: Spaz.
Mainstream Teacher 3: Children can be cruel.

Clinical Psychologist 3: Well it's also that conversation about secondary gains, so access to services, access to specialist support without considering the impact of carrying a diagnosis for the rest of your life, which effectively is what happens….People who have to carry a diagnosis of an intellectual issue or a developmental problem that, well its going to be with them forever.

Clinical Psychologist 2: Yeah and that's the conversation I have had when I was working in children's services and that's the conversation you have to have with parents isn't it, about actually what is the diagnosis going to offer, how is that going to benefit the person and how is it actually going to handicap the person as well.

Clinical Psychologist 3: Hmm.

Clinical Psychologist 2: Because it can do, the stigmas attached to the labels, they can be handicapping for people.

In both of these extracts the participants draw on *the labels can be damaging* repertoire to construct learning disability as a label imposed by others that can have negative consequences for the person so labelled. The other people that can do the labelling are implicitly positioned as people without learning disabilities: children who 'can be cruel', teachers who can tell you that 'you are not doing as well as others' and clinical psychologists who 'diagnose'. People with learning disabilities are positioned in a subordinate role, they are 'told' about their learning disability and they 'carry' their diagnosis given to them by someone in a position of relative power. The doing of this 'telling' and 'diagnosis' is constructed as a powerful act carried out by those with intellectual supremacy; including the participants themselves. Despite this, the imposition of a label is said to 'single out' people with learning disabilities and is said to be 'with them forever'. The impact of the act of labelling is constructed, here, as a negative act that the psychologists frame as 'handicapping' and the Mainstream Teachers frame as having the capacity to result in adverse consequences, such as bullying.

The participants' construction of the term learning disability as something that is given to people with learning disabilities by people without learning disabilities is reflective of the dominance of the current system of diagnosis and the emphasis placed upon a hierarchy of intellectual ability within a neoliberal society (Goodley 2014). The participants, however, challenge this system by framing their roles in diagnosing and telling as potentially damaging. This tension between their ideal and their practice is illustrative of the same ideological dilemma presented in the discussion of the previous repertoire pair. Wetherell et al (1987) experienced a similar theory/practice disjuncture when talking to final year male undergraduates about their attitudes to careers. In their study, the men's talk showed an initial commitment to equal opportunities. When talking about the practicalities of this commitment, however, the men's talk often contradicted their ideal and restored inequality. As Wetherell et al (1987 p.69) state 'the practical talk ensures that the ideal remains an ideal'. This dilemma or theory/practice disjuncture becomes further evident as the analysis progresses.

Some of the participants drew on their own personal experiences to highlight the negative effects of labelling. Extracts taken from the focus group with Local Authority Councillors and the focus group with Mainstream Teachers demonstrate this.

Local Authority Councillor 2: The one I always used to hate which was short hand for SEN was 'well they've got a statement'.
Local Authority Councillor C1: Hmmm.
Local Authority Councillor 2: Err and, and from a professional point of view, so statemented special educational needs, always sort of sounded such a stigma erm that said, whether its SEN or learning disability you know none of it is nice to hear erm and I know that you know, I've found myself as a parent with kids with dyslexia which is

> quite mild and you say 'well they are only dyslexic you know!' and you kind of get drawn in to sort of defending your own kids erm and going to the lowest common denominator and saying well 'there's nothing really *wrong* with them', and you shouldn't say it, and you shouldn't put yourself in that situation that has made it be a difference between your child or one type of disability, but you do, you get drawn in to it er, you try to advocate for your child and then you get into labels.

Here, Local Authority Councillor 2 draws on his experience 'from a professional point of view' and 'as a parent with kids with dyslexia' to show the negative effects of the term learning disability. As a professional he tells the group that learning disability is 'not nice to hear' and as a parent, he tells the group how the label learning disability 'draws him' into its stigmatised connotation. As an 'advocate' for his children, he finds himself 'defending' their label as children with a learning disability, telling others 'there is nothing really wrong with them'. Here, it can be seen that Local Authority Councillor 2 tacitly knows that learning disability implies a stigmatised way of being. In telling the group that learning disability is 'not nice to hear' and talking about his attempts to defend his children's status he implies that he knows that learning disability is not something to be valued. Local Authority Councillor 2 does not want to perpetuate the stigma insinuated by the label, stating 'you shouldn't say it, you shouldn't put yourself in that situation that has made it be a difference between your child or one type of disability' but feels unable to remove himself from the widespread association that learning disability implies that something is 'wrong' with the person/child so labelled. Here, again, it can be seen that learning disability is constructed as a powerful term that has the capacity to impose an unwanted identity upon individuals.

Mainstream Teacher 3 found herself in a similar position, stating:

Mainstream Teacher 3: Well ___ my son in theory has got a learning disability. He was diagnosed, but again it was on a very need to know basis, I mean he was diagnose, he was, he, he was Asperger's. I don't know how I survived his childhood, but I'm here I'm here. He was a bit of a nightmare. I had high expectations for him though, it was a need to know basis, teachers who needed to know, knew, I never used the term unless I had to, I never wrapped him in cotton wool.

While Mainstream Teacher 3 does not explicitly acknowledge, here, that learning disability is a stigmatised label, this association is implicit in her talk. Mainstream Teacher 3 tells the group about her actions to disassociate her son from his label as a person with a learning disability, how she shared his diagnosis with people 'on a very need to know basis', how she had 'high expectations for him though' and how she 'never wrapped him in cotton wool'. In the same way that Local Authority Councillor 2 explicitly told other people that there was nothing 'wrong' with his children, Mainstream Teacher 3 sought to demonstrate to others that there was nothing wrong with her son. What both participants are doing in these extracts is demonstrating their instinct to protect their children from their label as children with learning disabilities because of their knowledge that learning disability implies a certain way of being that they do not want other people to associate with their children. Their behaviour is motivated by the perceived reaction of other people. In believing that other people will make negative judgements about their children, the parents respond in a way that mirrors and upholds the perceived and unwanted reaction of others.

The widespread acceptance that learning disability is a pejorative term that implies a stigmatised way of being, was further discussed across the focus groups in terms of its deeper consequences for those so labelled. It is here that the participants used the *labels are damaging* repertoire to discuss the internalisation of learning disability by those so labelled.

Learning disability's capacity to impose an internalisation of stigma

When talking about an individual's capacity to internalise the stigmas associated with learning disability, the participants' talked about a 'self-fulfilling prophecy' and 'learned helplessness'. Examples of this can be seen in the three extracts below taken from the focus groups with Health Professionals, Student Teachers and Mainstream Teachers.

Health Professional 2: I see lots of people that have you know, that are classified on their records as having a learning disability and it's actually very mild and they live a normal day-to-day life.
Health Professional 1: Yeah.
Health Professional 2: They don't really need any care but they have been labelled as having that learning disability.
Health Professional1: Yeah.
Health Professional 2: So their out look, their work, often they have erm you know, they have employment support allowance and things like that, because their outlook is that they don't need to work and things like that. So I suppose labelling can be helpful for us to identify them but whether it is helpful for the patient in terms of their life is er.

Student Teacher 2: Erm like imagining myself being labelled with a learning disability, I think I would have a high degree of helplessness. Learned helplessness.
Student Teacher 1: Oh ok, yeah.
Student Teacher 2: So if you give people like erm different erm different, oh what are they called? Durrr……Anagrams! If you give half the class one set of anagrams and the other half another set and one is really hard and one is really easy and then the last one is the same for both sheets, by the end of it the hard ones have given up whereas the easy ones work the whole way through the sheet, so like they both can do it, you know like in a way, so that was like to illustrate learned helplessness. So I think I would feel pretty hopeless if I was labelled with a learning disability, like there is no hope in trying because my ability level is like caught at a certain point and I can't get it any higher

Mainstream Teacher 3: I hate labels, talking from personal experience I think it's the worst thing you can do. I think it's good to have some answers but to give a label you can get the self fulfilling prophecy.
Mainstream Teacher 2: Hmm, yeah…..Yeah, I think they get boxed a bit as well so and they put themselves in a box as well.
Mainstream Teacher 3: Yeah!
Mainstream Teacher 2: And that says loads, they get put in a zone. One of the kids yesterday I could see he had great potential but because he didn't see himself like that, he was never going to fulfil it
Mainstream Teacher 3: You get, 'I can't do that because I've got ….' Or 'I can't help doing that because I've got…' so the, and as they get older they can abuse it as well.

Here the participants talk about the power of the widespread negative perception of the term learning disability to affect how people with learning disabilities see themselves. In these extracts people and children with learning disabilities are seen to have internalised the identity associated with their label. In the participants' talk, those so labelled are seen to take on the role of their label by adopting a certain 'outlook' [Health Professionals] and 'put[ting] themselves in a box' [Mainstream Tecahers]. Consequently, people with learning disabilities may display behaviours that conform to their restrictive label, such as feeling like; 'they don't need to work and things like that' [Health Professionals], or that 'there is no hope in trying' [Student Teachers]; and not seeing themselves as people with 'great potential' [Mainstream Teachers] instead feeling 'hopeless' [Student Teachers]. The participants draw on examples from their professional practice to demonstrate this, referring to children in the classroom saying 'I can't do that because I've got.. or I can't help doing that because I've got' [Mainstream Teachers] and to patients who think 'they don't need to work' [Health Professionals].

Common to all the extracts provided to illustrate the use of the *labels are damaging* repertoire is the participants' desire to disassociate themselves with the stigma and damaging effects that they all associate with the term learning disability despite often working in roles that impose this stigma. The participants talk in terms of other people's reactions and interpretations, which they explicitly recognise as undesirable. Participants across all of the focus groups work hard to position themselves as 'good people' who reject the act of labelling.

The use of the *labels are damaging* repertoire to maintain their 'good person' subject position

As seen the participants construct learning disability as a term that evokes a particular negative image; that of someone who is 'stupid' [Mainstream Teachers], who is 'helpless' [Student Teachers], who cannot achieve anything [Special School Teachers], who 'cannot work' [Health Professionals] and who cannot 'achieve independence' [Student Social Workers with experience]. The participants expressed their dislike for this stereotyped identity by drawing on the *labels are damaging* repertoire to assert themselves as 'good people', using phrases such as 'people are people' [Social Scientists, Parent Carers and Special School Teachers], 'they are all human beings like the rest of us' [Special School Teaching Staff], 'we all have stuff we can't do' [Social Care Providers] and 'we all have needs' [Student Social Workers with experience, Social Care Providers, Mainstream Teachers]. This use of the *labels are damaging* repertoire is illustrated in the three extracts below, taken from the focus groups with Social Scientists, Special School Teachers and Student Social Workers with experience, each extract is discussed individually in turn.

Social Scientist 4: Maybe we acknowledge, maybe we are more comfortable, I certainly am, when someone else maybe with a learning disability, acknowledges themselves as different. I would never want to make that judgement or that decision but if someone else is comfortable then maybe that makes me feel more comfortable, like, yeah, it's just a rough area, you know certainly for me, I just wouldn't want to cross any lines or barriers or make anyone feel bad so you just kind of put yourself a bit back and just kind of don't make any judgement.

Social Scientist 1: Just wait for them to come up with it and kind of tell you.

Social Scientist 4: Yeah.

Social Scientist 1: Or I dun know, I kind of feel like before they make this acknowledgement 'ok I have a learning disability' or 'I don't' or 'I don't want you to recognise this' like, I feel like I am walking on egg shells, because I don't know, like I don't wanna, you know, show different treatment because for me people are people, regardless of you know whether they have a learning disability or not, whether they are like gay, from England, from Colombia you know I don't care about these things but you know it's kind of like, I dun know, before you know whether people are ok with, you know I think you need to get to know somebody first, you know I feel like I am walking on egg shells. I don't wanna come across as judgemental because I certainly wouldn't want anyone to do that to me .

In this presentation, the Social Scientists are discussing how they feel about knowing that some of their students have been labelled as having a learning disability. They are speaking as both professionals and as lay people, indeed, they switch between these identities to do certain things.

Social Scientist 4 talks for the group as a collective, by using the plural pronoun 'we' to refer to Social Scientists as a group, stating 'maybe *we* acknowledge, maybe *we* are more comfortable'. Social Scientist 1, reiterates this perspective by agreeing, stating 'wait for them to come up with it and kind of like tell you'. When using 'you', here, Social Scientist 1 is also referring to Social Scientists as a whole, in the position of teaching students with learning disabilities. The Social Scientists are demonstrating their tacit knowledge that the label learning disability implies difference and that this difference has a stigma attached to it. The Social Scientists' intimate that to associate the label learning disability with an individual student is to make a stigmatising moral judgement about that student. The Social Scientists present this judgement and the stigma it holds as damaging to both the student and the professional. The student could be judged and the professional could 'come across as being judgemental' [Social Scientist 1].

The Social Scientists present learning disability as such a negative label that they are only 'comfortable' using it as Social Scientists once a student who has a learning disability identifies as so. When Social Scientist 4 says, 'I would never want to make that judgement or decision' she not only recognises the dangers associated with labelling, she is also constructing learning disability as a moral classification that she does not want to be associated with unless the person so labelled gives her permission to do so. The Social Scientists construct learning disability as something that has 'lines or barriers' that can be crossed, making them feel like they could take a step in the wrong direction, causing them to feel 'uncomfortable', like they are 'walking on eggshells'. They do not want to upset their students and they do not want to appear to be associated with a judgemental subject position.

In order to disassociate themselves with the negative connotations that they implicitly associate with learning disability, the Social Scientists use the *labels are damaging* repertoire to assert their personal commitment to equality. When disassociating themselves from the stigma of learning disability, the Social Scientists switch to talking as lay people, asserting their own personal feelings about equality. First, Social Scientist 4 tells the group that she 'would not want to make anyone feel bad' by applying the label learning disability before the student she is thinking of identifies as being a student with a learning disability or before she gets to know them. Social Scientist 1 furthers this disassociation with the negative implications of labelling by telling the group that she does not want to treat anyone differently, that 'people are people' and that she doesn't 'care about' whether someone 'has a learning disability or not, whether they are like gay from England, from Colombia'. She uses empathy to add further emphasis, saying that she 'wouldn't want anyone to do that [label] to me'.

The Social Scientists, therefore, recognise that learning disability is part of their professional vocabulary but are keen to disassociate themselves as individuals from the stigma that they attach to learning disability and the potential damage that they perceive could result to both them and the student. Association with this particular subject position is also demonstrated in the extract taken from the focus group with Special School Teaching Staff.

Special School Teacher 3: I would rather we didn't have to have a label really because they are human beings like all of us.

Special School Teacher 7: Well it's like with black or gay or whatever, the terms are always changing and sometimes you don't know what is best.

Special School Teacher 5: I have never seen a difference, so really why do we need it, like you say. I mean of course there are different conditions, downs, autism, fragile x and whatever but its just like I don't know diabetes, MS or any other condition that people live with. Like you say [SST7], people are people. I have always, I started out not seeing a difference and I never have.

In this presentation, the Special School Teaching Staff are disassociating themselves with the label learning disability by drawing on the *labels can be damaging* repertoire to construct themselves as 'good' people committed to equality. Prior to this extract the Special School Teachers had talked about their use of the term learning disability as part of their role as Special School Teachers. After having said that they all use the term learning disability in their work, they quickly move to the use of the *labels are damaging* repertoire to show their personal dislike for learning disability as a label. Here, like the Social Scientists, the Special School Teaching Staff talk in the first person to assert their individual commitment to equality outside of their collective role as teachers who have to use the term learning disability. The Special School Teachers begin most of their statements with 'I', often following this with extreme case formulations (Pomerantz 1986), stating: 'I would rather', 'I have never', 'I mean', 'I have always' and 'I started'. Implicit within Special School Teacher 5's statement, 'I have never seen a difference', is her knowledge that negative difference is associated with learning disability. She uses the extreme case formulation, 'I have never' to ensure that she personally is not considered to be someone who upholds this knowledge.

Like the Social Scientists, the Special School Teachers draw on the phrase 'people are people' to assert their commitment to equality. In addition to this Special School Teacher 3 states, 'they are all human beings like all of us'. The use of these phrases allows the speakers to dismiss any difference among people that learning disability might denote, because, essentially, we all belong to the same species. Such phrases also allow them to identify as professionals who use the term learning disability, but who do so with a critical awareness and a personal commitment to equality. This action is also seen in the extract below, taken from the focus group with Student Social Workers with experience of working with people with learning disabilities.

Student Social Worker 2: I think as well, working with erm working with people with learning disabilities or difficulties erm you just sort of accept them as people.
Student Social Worker 1: You don't question the tag learning disability do you?
Student Social Worker 2: You don't see the differences. You don't question the tag, yeah, you just sort of see them as people.
Student Social Worker 1: Yeah with, I find that with volunteering at Mencap. I don't even think like when I first started my volunteering with them we ever really spoke about it, it was just when you were introduced to people, it was 'this
Student Social Worker 2: They are just people
Student Social Worker 1: This is
Student Social Worker 2: Fred, yea this is whoever
Student Social Worker 1: This, this is Bob' erm and you just get on you don't actually talk about
Student Social Worker 2: Yeah you very rarely say 'so what's wrong with him then?'
Student Social Worker 1: Yeah!
Student Social Worker 2: You just sort of get on with it
Student Social Worker 1: Yea, you get to know people as you would do anybody else.

In this presentation the Student Social Workers are talking about their approach to working with people with learning disabilities. Like the Social Scientists and the Special School Teachers, the Student Social Workers demonstrate that they know that learning disability is associated with a different, stigmatised way of being. When Student Social Worker 2 tells the group, 'you don't see the differences. You don't question the tag, yeah, you just sort of see them as people' she is disassociating herself from this knowledge. Although she knows that learning disability implies difference, she 'just sort of see[s] them as people'. Although she later tells the group again that 'they are just people', she furthers this by telling the group that really there is something 'wrong' with people with learning disabilities, stating 'you very rarely say 'so what's wrong with him them?'' Because she is a 'good person', however, she 'just sort of get[s] on with it'.

Common to all three of these presentations is the tacit knowledge that learning disability is associated with a different, stigmatised way of being that the participants play a role in upholding. In each of the extracts, the speakers work hard to disassociate themselves from this association and present themselves as 'good people' who do not see difference and who are committed to equality. As seen in the examples provided, despite their dislike for the term, learning disability is presented as a term that the speakers use in their everyday vocabularies within their particular specialisms and also within their personal lives if they have children, friends and relatives with learning disabilities. Further to this all of this, as contained within some of the extracts, the focus groups all drew on the *labels are useful* repertoire to justify their use of the term learning disability in practice. The use of this repertoire is discussed further below.

The labels are useful repertoire

Features of the repertoire

The *labels are useful* repertoire can be distinguished by the following speech acts: the use of words and phrases such as 'useful', 'helpful' and 'practical' to denote the benefits of the term learning disability; the expression of a paradoxical feeling of regretful practicality when talking about their use of the term learning disability in practice; and the provision of credentialing statements to enable them to maintain their commitment to their 'good person' subject position. Consequently, this repertoire is also characterised by the presence of the *labels are damaging* repertoire.

Uses of the repertoire

The participants used the *labels are useful* repertoire to do two things: to highlight the practical use of labels and to establish acceptable contexts in which labels can be used. These functions tended to overlap. When talking about the practical benefits of labels, the focus groups often discussed acceptable contexts and vice versa. The extracts provided as illustration, more often than not provide examples of each use. Each use, however, is discussed separately to provide clarity.

Use of the *labels are useful* repertoire to highlight the practical use of labels

When talking about the use of the term learning disability, the participants talked in terms of its practical benefits. Across the focus groups, the participants constructed learning disability as a practical category that is useful for both professionals when identifying people with particular needs and for the people so labelled in order to access services. Once participants had acknowledged this and in some cases, while acknowledging this, however, they would then draw on the *labels are damaging* repertoire, in order to show that although they use the label and can see practical benefits, ultimately, they are personally uncomfortable with the label and do not want to be thought of as someone who uses it without a critical awareness. Extracts taken from the focus groups with the Student Social Workers with experience of working with people with learning disabilities, the Mainstream Teachers and the Parent Carers illustrate this trend.

Local Authority Councillor 2: Personally as a parent, I can't see how certain schools get round things without having some sort of database er which indicates how many children they have got that need extra help erm but I think that sometimes there is all sorts of perverse incentives both for schools, colleges and for parents because you know sometimes, schools get extra money, if they have got a number of children on the SEN register. For kids if they have got a statement or er they are seen to have a particular disability, they get extra time in exams. Erm and as a parent advocating for a child, you kind of think 'oh well you know, I

> know that my kids are quite bright kids but they take their time processing and writing stuff down and so therefore the idea of them getting 20% extra time or whatever, it does it makes you sort of get into that mind-set that that's the thing that you have got to get. But equally I've seen parents who are very offended when labels are put on children but I still think generally, provision and progress on this area is light years ahead of when I was at school, because when I was at school in the 70s, kids were just called slow or thick and so you know it was only if they were profoundly deaf or something that any sort of special provision was made, from my memory of being at school. If a child who, what would now be seen as having some sort of learning difficulties, they were just the kid in the corner of the class that they called thick or whatever.

Here, Local Authority Councillor 2 is talking about the benefits of the label learning disability for four distinct groups: for schools, for the children so labelled, for the parents of children with learning disabilities and for society as a whole. Local Authority Councillor 2 tells the group that the term learning disability is useful for schools in that it 'indicates how many children they have got that need extra help' and that in some cases it allows the school to access additional funding. The parents can use the label to advocate for their child's needs, allowing them access to additional support such as extra time in exams. Speaking generally, Local Authority Councillor 2 states, 'provision and progress on this area are light years ahead of when I was at school'. This indicates that while learning disability still implies a stigmatised identity, this stigma is relative to todays social world that is more accepting than the social world in which he grew up where children with learning disabilities 'were just the kid in the corner of the class that they called thick or whatever'. For Local Authority Councillor 2, therefore, the label learning disability can be used as a currency to again access to support that is needed.

The Clinical Psychologists also refer to such practical benefits. In the extract below, however, they quickly turn this benefit in to a potential negative, drawing on the *labels are damaging* repertoire to do so.

Clinical Psychologist 3: And, if you do get a service while the person is a child, what you are not going to get is a service when the person is an adult because once I had a young woman with executive functioning difficulties which possibly resulted in alcohol, erm you know kind of erm alcohol use but she got plenty of services until she was 18 and then of course after 18, we couldn't then offer her a service, you know she got referred to us, but she just did not fit the criteria. So what we had actually done is create someone who has actually got a label and then we can't do anything for her. So you know these labels can be useful in terms of getting a service but if you don't have a label that fits the criteria we can't do anything

In this presentation, the Clinical Psychologists have been discussing how support services can only be accessed with a formal diagnosis. This is constructed as both a benefit 'in terms of getting a service' and as a possible negative, 'if you don't have a label that fits the criteria'. Clinical Psychologist 3 talks to the group with regret about the power of their roles as Clinical Psychologists who can 'create someone who has actually got a label' and not be able to offer them anything in return. Here, Clinical Psychologist 3 draws on the *labels are damaging* repertoire. In carrying out her role as a Clinical Psychologist, she is imposing labels on people by giving them a diagnosis and thereby 'creat[ing] someone' with a particular identity. Implicit in Clinical Psychologist 3's regret is her knowledge that in diagnosing an individual as someone with a learning disability, she is imposing a stigmatised identity. She recognises the potential benefit of such a label in practice but personally is uncomfortable carrying out the act of labelling. Common across the extracts presented, and particularly seen here in Clinical Psychologist 3's talk, is the presence of the theory/practice disjuncture alluded to earlier. The participants demonstrate a strong personal dislike for the act of labelling and the consequences it can have. Their personal ideal, however, is limited by their professional acknowledgement that labels are useful.

The Mainstream Teachers also refer to this this theory/practice disjuncture, stating:

Mainstream Teacher 3: You kind of use it in school because it means they are not where they should be, it gives you an indication straight away.
Mainstream Teacher 2: Yeah its useful for that so you know as a teacher what their needs might be but there is no need to talk about it for other reasons.

Here, the Mainstream Teachers reflect that learning disability is a necessary term in practice as, ‘it gives you an indication straight away’. As seen in the previous extracts, learning disability is constructed here as a currency that can be used to access the support needed. The Mainstream Teachers, however, credentialise their recognition of the practical benefits of the term by switching to the *labels are damaging* repertoire. Whatever it is that learning disability ‘gives you an indication’ of is not to be talked about ‘for other reasons’. Here the Mainstream Teachers demonstrate their tacit knowledge that the thing that learning disability indicates is damaging and should only be referred to for reasons of practicality. The extract taken from the focus group with Student Social Workers with experience of working with people with learning disabilities demonstrates a similar oscillation between the two repertoires.

Student Social Worker 3: Increasingly, because like, like all those terms like service user and things like client. I really, really struggle with and I do, I kind of try and avoid using kind of like any terminology like that because I just think, kind of like you [SWS2] say, you kind of like would see the person like first rather than using that label.
Student Social Worker 1: Yeah, I don't
Student Social Worker 3: But sometimes you do have to write, client or service user, because in practice you have to identify the groups you are working with.
Student Social Worker 1: Yeah, I think in certain situations, that's its, depending on what you are doing, who you are working with you know you it's the same as for anything. There has to be a label on something to a certain extent, even if it is just something as straight forward as just, just as gender.
Student Social Worker 2: Yeah, you perhaps avoid using it with the person but sort of in an office I would.
Student Social Worker 1: It's just, it's just a descriptive word erm, everything has to have a descriptive word so that you can communicate to others what it is or who they are or certain characteristics

Prior to this presentation, the Student Social Workers established that they are not comfortable with the term learning disability and so are considering other labels. While asserting she 'really, really struggle[s]' with using the terms available to her and 'tr[ies] to avoid using' them, Student Social Worker 3 regretfully accepts that 'in practice you have to identify the groups you are working with'. Student Social Workers 1 and 2 support Student Social Worker 3 in her switch from the *labels are damaging* to the *labels are useful* repertoire by providing reasons why this is necessary. Student Social Worker 1 states that 'there has to be a label on something to a certain extent', later adding that, 'it's just a descriptive word' to aid communication. Similarly, Student Social Worker 2 tells the group that while she wouldn't use a label with the person she is labelling she would use it in 'an office'. Here we can see that none of the social workers want to be seen as people who use labels without a critical awareness of the negative consequences of doing so. The Social Workers work to defend their use of labels by constructing them as unavoidable words that they have to use to convey meaning and ‘certain characteristics’. This message is also conveyed by the Parent Carers in the extract below.

Parent Carer 1: And what we need is a uniform language that everyone understands, that we can advertise under, that we can write bills under for parliament.
Parent Carer 5: You see that’s a good idea, you see, you know the, the labels, they are alright in their place, if you are talking about funding streams and that type of thing but professionals take these labels and they put them outside this arena and that’s wrong. Cos, let me wind it back to the beginning, what was your question Victoria?
Facilitator: About the type of terminology you would prefer?
Parent Carer 5: Well I ask you that question, how would you like to be called? Apart from Victoria?
Facilitator: Erm, a woman?
Parent Carer 5: Well you have got a name, it’s Victoria and you are proud of that name and it’s the same, they have all got bloody names and you know thinking of other terms outside of certain settings its just stupid, they are dancing around the obvious, just treat them like you would like to be treated.

In this presentation, the Parent Carers begin with the idea that labels are necessary to ensure a common understanding and a uniform language to be used across settings, to ‘advertise under’ and when ‘writing bills under parliament’. Once this has been established and agreed upon by Parent Carer 5 who states ‘that’s a good idea’, Parent Carer 5 then makes the switch to the *labels are damaging* repertoire. The group follow this with a long discussion about the dehumanising effects of labels, comparing the term learning disability with the identification numbers given to criminals in prisons. While Parent Carers 1 and 5 agree that a common label that ‘everyone understands’ is required, Parent Carer 5 goes on to assert his personal stance that labels are ‘stupid’ and that ‘they are dancing around the obvious’, which is that ‘they have all got bloody names’ and so people should ‘just treat them like you would like to be treated’. Here, the parent carers are showing a paradoxical approach to the label learning disability: it is both 'stupid' and a 'good idea'.

Their oscillation between the *labels are useful* and the *labels are damaging* repertoires further illustrates the theory/practice disjuncture seen in the previous extracts. In theory, the Parent Carers dislike the term learning disability because it distinguishes those so labelled from those who are not. Learning disability's capacity to differentiate is constructed as problematic in theory because as Parent Carer 5 states, people with learning disabilities should be treated 'how you [someone without learning disabilities] like to be treated', however, in practice this differentiation is constructed as useful because it allows 'everyone to understand'. Although the participants want to associate themselves with the 'good person' subject position whereby labels are rejected as othering, their use of the *labels are useful* repertoire renders this ideal impractical. This theory/practice disjuncture is also evidenced when the participants talk about the contexts in which they use the term learning disability.

Use of the *labels are useful* repertoire to establish acceptable contexts in which labels can be used

In discussing the practicality of the term learning disability, all of the focus groups used the *labels are useful* repertoire when considering the acceptable contexts in which to use the term learning disability. When discussing when and where they would use the term learning disability the participants also tended to discuss when and where they would not use the term, switching to the *labels are damaging* repertoire to do so.

Extracts taken from the focus groups with Special School Teachers, Parent Carers and Mainstream Teachers illustrate this use of the repertoire.

Facilitator: So is learning disability a term that you all use?

Collective: Yes.
Special School Teacher1: We use it when filling out forms or when in meetings with other people don't we? But I don't think we use it any other time.
Special School Teacher 4: Yeah we use it formally I suppose but not day to day with staff members or pupils.
Special School Teacher 6: No, no. The students are Tom or Emily or Joe.
Special School Teacher 3: Yeah always. I only really use the label learning disability if I'm doing paper work. Its useful for that, like as a general category but
Special School Teacher 1: I also use syndrome names in paper work too.
Special School Teacher 3: Yeah, yeah but we wouldn't use them you know when talking to someone unless it was an organised meeting or something.

In this presentation, the Special School Teachers identify the contexts in which they do and do not use the term learning disability. Here, the Special School Teachers construct learning disability as a term that is appropriate in certain contexts that are part of their specialist profession, such as 'in meetings with other people' and 'when doing paperwork' but is inappropriate in others, such as talking to students or other people outside of a meeting. The teachers frame these contexts as 'formal' and 'day-to-day', with formal contexts representing an appropriate context in which to use the term learning disability and 'day-to-day' contexts representing inappropriate contexts. In recognising that there are certain contexts in which it is ok to use learning disability and other contexts in which it is not, the Special School Teaching Staff are implicitly inferring that learning disability represents a contentious subject. This construction is also alluded to by Social Care Provider 1 in the extract provided below.

Social Care Provider 1: We tend to call most people ‘visitors’ or we use their name, we don’t use terms. The only time we use terms is when erm you are describing the service to other people. So when describing it to professionals or someone ringing up asking if they can come to it, we’ll say people with learning disabilities come and people on the autistic spectrum because then, it gives, people know what you are talking about, but when people actually come we will normally say, visitors or we will use peoples names, we learn people’s names. So we just use people’s names because they are people like we are so it depends on the context. But if I was going and talking to the university, I would use the term learning disability and autistic spectrum, because then everyone understands what the service is about and that’s what we use on websites because people will know what we are talking about. But when people come here we will just use names.

Here, the Social Care Providers set up the same distinction between when it is and isn’t appropriate to use the term learning disability illustrated by the Special School Teachers. The Social Care Providers use the term learning disability when communicating formally with ‘professionals’, ‘people ringing up’ to enquire about the service and ‘the university’ in order to ensure that all parties understand what is being talked about. Indeed, Social Care Provider 1 states ‘the only time we use terms is when erm you are describing the service to other people’. When referring to ‘other people’, Social Care Provider 1 is referring to people without learning disabilities. Talking to people with learning disabilities is implicitly framed as an inappropriate context in which to use the term learning disability because ‘they are people like we are’. Using people’s names allows the Social Care Providers to demonstrate this belief. Indeed, Social Care Provider 1 tells the group three times in the same sentence that they use people’s names. When stating ‘we just use people’s names because they are people like we are’, Social Care Provider 1 is implicitly inferring her knowledge that the term learning disability identifies people as being different to ‘people like we are’. She is also presenting herself as someone that treats all people equally regardless of what their formal label might imply. It is this knowledge and her concern to be seen as a 'good person', which motivates her to differentiate between when and where the term learning disability can and cannot be used. The extract presented below, taken from the focus group with Mainstream Teachers demonstrates a similar trend.

Mainstream Teacher 1: You don't beat around the bush that much with teachers. Not when its teachers talking with teachers you kind of get straight to the point, you don't have time to really get detailed. If you were discussing with parents you would be a bit more careful with the term you use.

Mainstream Teacher 3: Yes definitely.

Mainstream Teacher 1: You wouldn't say learning disability to someone that doesn't think there is anything wrong with their child.

Mainstream Teacher 3: You would use their name, you wouldn't say well they've got cerebral palsy or they've got dyspraxia, you wouldn't use it would you? You kind of use it in school because it means they are not where they should be, it gives you an indication straight away.

Mainstream Teacher 2: Yeah it's useful for that so you know as a teacher what their needs might be but there is no need to talk about it for other reasons.

In this presentation, the Mainstream Teachers' discussion is loaded with tacit knowledge that learning disability represents an undesirable, stigmatised identity. The only acceptable context presented to use terms referring to learning disability, is with other teachers and only then for the pragmatic reason of time constraints. Learning disability allows the Mainstream Teachers to avoid 'beat[ing] around the bush' to identify students with learning disabilities 'straight away', however, it is considered damaging enough that 'there is no need to talk about it for other reasons'. The Teachers imply that learning disability distinguishes the children so labelled as having something 'wrong', stating 'you wouldn't say learning disability to someone that doesn't think there is anything wrong with their child'. When Mainstream Teacher 2 states 'there is no need to talk about it for other reasons' she is intimating that the children she works with require protection from their label.

In all three of these presentations, learning disability is constructed as a label that implies an undesirable identity that people need protection from. Common to all of the acceptable contexts is the absence of people with learning disabilities. Although people with learning disabilities are the very people who live with the label, interaction with people with learning disabilities is considered in all three of the extracts as an unacceptable context in which to use the term learning disability. People with learning disabilities are, moreover, constructed as people with a label that they require protection from. In addition to this, the participants' discussion of the context further highlights the theory/practice disjuncture discussed above. Here the participants use context to maintain their ideal, that learning disability is a negative term, however, in using the term regularly and without concern in certain contexts their ideal remains an ideal.

Conclusion

The conclusion that follows summarises the research findings in terms of the functions and consequences of the participants' use of the *labels are damaging/labels are useful* repertoire pair and discusses the key findings in relation to the contribution they make to the sociological theorisation of learning disability.

Function and consequences of the repertoire pair

To summarise the analysis above, as with the *I know what learning disability is/learning disability is a confusing term* repertoire pair, the participants primarily use the *labels are damaging/labels are useful* repertoires to present themselves as 'good people'. Whether the participants are constructing labels as damaging or as useful, their talk is consciously presented in terms of this identity. Across the focus groups the participants demonstrated a shared knowledge that labelling is an act that can have negative consequences for both the person so labelled and the person doing the labelling. The participants also demonstrated a shared belief that learning disability, as a label, implies an undesirable way of being that they do not want to implicate themselves in. The participants work hard to disassociate themselves from the stigma they know to be associated with learning disability by repeatedly using phrases that denote equality and by setting out conditions for the terms of use. Despite this, the participants struggle not to entangle themselves in the stigma they seek to reject. Indeed, their talk often reflects the stigma they work to avoid. The participants acknowledge their role in the act of labelling people with learning disabilities by discussing their use of the label. This use is premised on their shared knowledge that learning disability implies an undesirable way of being. Consequently, they justify their role in the act of labelling by specifying that their use of the label learning disability is limited to interactions with those without a learning disability. Further to this their expressed ideal allows them to maintain their personal, moral commitment to the 'good person' identity. While the participants set up their ideal as the obvious and 'right' position, their talk of the practical, however, ensures that their ideal will only ever remain ideal no matter how committed they are to it. The participants' talk of the ideal and the practical is a product of the participants' social worlds and the rhetoric that dominates within these worlds. As seen in the previous chapter, the dominance of medical model and neoliberal rhetoric is very difficult to escape.

As with the *I know what learning disability is/learning disability is a confusing term* repertoire pair, the participants experience a tension between their personal commitment to equality and their everyday language when using this repertoire pair. The participants want to show that they are 'good people' who disagree with the act of and consequences of labeling but they are also individuals whose linguistic practices and professional knowledge uphold the system they disagree with. It is these contrasting aims, seen in the analysis as a theory/practice disjuncture, that lead the participants into a similar ideological dilemma experienced in their use of the *I know what learning disability is/learning disability is a confusing term* repertoire pair. The participants ideally want to reject the act of labeling but they cannot escape the need for categorisation and the dominant medical discourse this is premised upon. Both the *labels are damaging* and *the labels are useful* repertoires function to allow the participants to negotiate and manage this ideological dilemma in order to maintain their desired subject position.

Key findings

The function and consequences of the *labels are damaging/labels are useful* repertoire pair discussed above make an important contribution to the sociological theorisation of learning disability. As seen in the analysis presented, the participants' talk is reflective of a re-contextualisation of the general argument presented in labelling theory; that stigmatised ways of being are the consequence of interaction between the person so labelled and the reaction of others (Becker 1963). Indeed, the participants' talk about labels is characterised by the language of labelling theory; words such as 'stereotype', 'stigma' and 'self-fulfilling prophecy' featured throughout the participants' use of this repertoire pair. The participants' talk alludes to their knowledge that labelling is a negative act and that learning disability is a negative label that can influence both how the person so labelled behaves and identifies and also how others perceive such individuals. In addition to this, the participants recognise themselves as implicated in this identity work, as individuals who defend their own children with learning disabilities and as professionals and lay people who operate within the societal rules that construct labels.

The participants' buy-in to the general discourse of labelling theory, however, encounters a number of challenges that also reflect some of the criticisms of labelling theory itself. In the main labelling theory has been critiqued for its focus on the stigmatised identity as opposed to the actions that might generate the need for such an identity (Farrell 2014). Whether or not this is a valid critique of labelling theory itself, it serves to highlight a consistent pattern in the participants' talk seen in each of repertoires pairs discussed: the avoidance of difference. In focusing on sharing their knowledge and their dislike of the negative implications of the act of labelling and of the label itself in order to maintain their 'good person' identity, the participants manage to avoid talking about the fundamental differences that play a part in the application of the term learning disability. As Farrell (2014 p.73) states 'drawing attention to labelling may signal a dislike of it, but evades the differences associated with disorders'.

Goffman (1963) explored how the stigmatised manage their label and found that in order to construct a front of normalcy the stigmatised engage in 'passing' behaviour. Here the participants' talk shows how those implicated in upholding stigma manage this role. As seen, the participants' use of and recognition of the need for labels is made in terms of a regretful practicality that the participants feel the need to credentialise heavily. As with the participants in Goffman's (1963) ethnography, the professionals here can also be seen to perform a kind of 'passing' behaviour. Instead of acting to conceal their imposed and lived stigma in order to appear 'normal', as Goffman (1963) found his participants did, the focus group participants acted to conceal the stigma they create by 'passing off' their behaviour as based on accepted moral ideals of equality and fairness. The participants' reliance on phrases such as 'people are people' and 'we all have needs' allows them to normalise people with learning disabilities as people just like and equal to themselves despite the label that sets them apart as different. The limitation of their talk to people with mild learning disabilities in general also allows the participants to construct a guise of equality. The focus group participants, moreover, demonstrated a strong desire to be seen as or to pass for people who do not uphold stigma and who 'hate labels'. Their 'passing off' behaviour allows them to maintain their ideal in the face of the practical reality that labels are often both necessary in practice and based on bodily difference (Farrell 2014). It is suggested that such 'passing off' behaviour is also found in the social policy and inclusive research discussed in the literature review.

The tensions seen in the participants' approach to labelling is reflective of a wider trend within the current sociocultural world inhabited by the participants: the fear of getting it wrong and causing offence. Such fear is seen almost daily in media exposés of ‘politically incorrect’ celebrities and politicians. Labels are used all the time in everyday talk to categorise and make sense of what is being talked about. For example, when referring to the people they teach, the Social Scientists use the label ‘students’ and when referring to the people they see in their surgeries, the Health Professionals use the label ‘patient’. Some labels, however, are considered to be and are constructed as more damaging than others. It is these labels that the participants refer to when making statements such as ‘I hate labels’ and ‘I don’t like any labels’. The labels with less potential to damage a persons’ self identity are not thought of as ‘labels’. As Goffman (1963 p.7) observed, the notion of what he refers to as the ‘normal human being’ serves to provide ‘the basic imagery through which laymen currently conceive themselves’. It is the stigma that has the potential to set people apart as not normal that is associated with labels such as learning disability, that problematises its use for the participants and instils discomfort. As seen in the literature review, learning disability does not hold up well in a society that prioritises cognitive ability as a mode of progression (Goodley 2014). This focus on sameness is discussed further in the next chapter where the *people with learning disabilities are different to me/the people with learning disabilities are the same as me* repertoires are discussed.

Chapter 7: People with learning disabilities are different to me/ people with learning disabilities are the same as me.

Context

The *people with learning disabilities are different to me/people with learning disabilities are the same as me* repertoire pair was used by the participants throughout the focus group discussions. It was most heavily drawn upon, however, when discussing the questions: what sort of life do you think someone with learning disabilities might lead and what are the similarities and differences between your life and the life of someone with learning disabilities? The participants' reactions to these questions were similar across all of the focus groups. Initially, the participants demonstrated a general reluctance to discuss the questions, presenting the broad nature of learning disability, its variety of specific diagnoses, and its lack of specificity, as reasons why answering such questions would be difficult for them, making statements such as: 'I don't know how to deal with that without a specific diagnosis' [Student Social Worker without experience 1] and 'I think it's really hard to answer because you go back to that thing that if the defining factor is IQ, that IQ can be made up in any which way' [Clinical Psychologist 1].

As outlined in the methodology, the reason for asking such general questions was to encourage the participants to talk broadly about learning disability. While the broad nature of learning disability was included in all of the focus groups' definitions of learning disability, the participants were not comfortable talking broadly about learning disability and preferred to talk about individual examples and specific diagnoses. In some cases when the group felt they could not talk about learning disability without being given a specific example, I asked the group to give an example and this helped to initiate discussion that eventually broadened to cover learning disability in general. The Social Scientists needed the most prompting, as illustrated in the extract below.

Facilitator: Maybe if you think about one of the labels and then if you think about the type of life you think that person might live.
Social Scientist 1: Hmmm.
Facilitator: So can you think of one?
Silence.
Facilitator: Do you want me to throw one out and then you talk about it?
Social Scientist 1: Yeah.
Social Scientist 2: Yeah please.
Facilitator: Ok then so how about we say Down syndrome?
Social Scientist 5: I knew you were going to say that.
Facilitator: Well I'm just thinking you will all know of Down syndrome.
Social Scientist1: Yeah.

Before this extract the Social Scientists had been procrastinating on how difficult it is to talk about the lives of people with learning disabilities listing a multitude of reasons for this including: the variety of diagnoses and labels, the organisations a person with learning disability is involved in and their everyday social environment. Following the prompting illustrated in the extract, three of the focus group participants went on to discuss their personal experiences of the lives of family members and friends' family members with Down syndrome. This was the case across the focus groups; despite their initial reluctance to talk about their understanding of the lives of people with learning disabilities and the similarities and differences they might entail, all of the focus groups went on to do so and had long, in-depth discussions, often providing personal experiences to exemplify their points as will be seen in the discussion that follows.

When discussing the lives of people with learning disabilities there was a marked difference in how the participants talked about people with severe or profound and multiple learning disabilities. As discussed in the introduction to the analysis, the participants' talk focused almost exclusively on people with mild and moderate learning disabilities. Their use of this repertoire pair, therefore, was generally only used with this group in mind. When the participants did use this repertoire pair to talk about the lives of people with more severe learning disabilities, the participants used particularly negative words and phrases such as: 'suffering' [Student Social Workers (a)], 'struggle' [Student Social Workers (a)], 'pain' [Student Social Workers (a)], 'sad' [Local Authority Councillors], 'not toilet trained', [Mainstream Teachers], 'not able to communicate' [Mainstream Teachers], and 'more detached' [Student Journalists]. This is in direct contrast to the words and phrases used to describe the lives of people with learning disabilities in general, such as 'lots of hobbies' [Student Teachers], 'happy' [Special School Teachers], 'full' [Student Social Workers (a)], 'fruitful' [Health Professionals] 'rich' [Student Social Workers (a)], and 'a better life than mine' [Parent Carer].

At face value, it appeared that the participants acknowledged a variety of differences between themselves and people with learning disabilities. In this context their use of the *people with learning disabilities are the same as me* repertoire appeared to be contrary to their use of the *people with learning disabilities are different to me* repertoire. On closer analysis, however, it became clear that the two repertoires are linked and that the repertoire pair functions in a closely knit dialectical relationship (Billig et al 1988), whereby use of one necessitated the use of the other and vice versa. A clear example of this dialectical relationship can be seen in Social Care Provider 1's statement: 'I would say we are all very similar and we are all very different and erm that applies whether you have a learning disability or not so erm just like V2 said, some people can draw and some can't, that's those two different groups, some people have learning disabilities and some people don't but we are all the same because we all have things we can and can't do'. Here it can be seen that in acknowledging difference, Social Care Provider 1 does so in order to show similarity. In reverse, she frames similarity as the presence of differences between people. The dialectical use of this repertoire pair will now be explored further as each of the repertoires are discussed in detail.

The People with learning disabilities are different to me repertoire

Although the participants did not want to talk about difference and expressed an initial discomfort about being asked to do so, the participants' talk across all of the focus groups addressed a wide variety of differences including: difficulty finding a partner [Parent Carers], possible lack of sexual relationships [Student Social Workers with experience], increased likelihood of not having children [Parent Carers], loneliness [Student Teachers], social isolation [Local Authority Councillors], not being able to read [Local Authority Councillors], not being able to make a snap decision to take a holiday to France [Local Authority Councillors], unemployment [Health Professionals and Special School Teachers], needing extra support in the class room [Student Teachers, Mainstream Teachers, Local Authority Councillors and Student Journalists], needing extra support at university [Social Scientists and Student Journalists], attending day services [Parent Carers, Student Teachers, Student Journalists], receiving disability benefits [Mainstream Teachers], relying on care givers [Mainstream Teachers, Local Authority Councillors, Student Social Workers with and without experiences, Clinical Psychologists, Health Professionals, Student Journalists, Student Teachers], experiencing carer loss [Student Social Workers without experience], doing things and learning things slowly [Local Authority Carers, Social Care Providers and Student Journalists], having a teaching assistant at school [Student Journalists and Student Teachers], being in bed at school [Student Journalists], attending a special school [Student Teachers, Health Professionals, Student Journalists], increased propensity to psychological and physical health problems [Health Professionals], increased risk of alcoholism [Clinical Psychologists], increased risk of dementia [Student Social Workers with experience], increased risk of physical, mental and financial abuse [Student Social Workers with and without experience and Health Professionals] and subjection to increased surveillance [Student Social Workers with experience].

Features of the repertoire

The *people with learning disabilities are different to me* repertoire can be distinguished by the consistent use of the following speech acts: self comparison; the provision of credentialing statements (Billig et al 1998) that followed their discussions about differences, such as ‘people are people’, ‘we are all human’, ‘we all have equal value’, ‘they are really nice people’, and ‘sometimes I feel like I have got more of a connection with you [person with a learning disability] than I have with my friends!’; the use of personal examples; and the use of words and phrases denoting difference, such as: ‘limited’, ‘prejudice’, ‘restriction’, ‘vulnerability’, ‘constrained’, ‘dependent’, ‘retracted’, ‘barriers’, and ‘hurdles’.

Uses of the repertoire

The *people with learning disabilities are different to me* repertoire was used to achieve two linked functions: to frame difference in such a way that its acknowledgement became acceptable to the participants, and to maintain their 'good person' status. As when talking about labels, the participants demonstrated a tacit knowledge that talking about difference could compromise their desire to present as 'good people'. When talking about difference, the participants worked hard to frame it positively so as not to appear superior. The participants used three contradictory strategies to do this, including: talking about difference in terms of something that is imposed upon the person with learning disabilities by external forces that can be removed; talking about difference as a consequence of individual conditions; and the deployment of credentialing statements in order to frame difference as equalising. Each of these strategies allowed the participants to talk about the unavoidable reality of the differences experienced by people with learning disabilities without mitigating their 'good person' status. Each strategy is discussed below.

Use of the *people with learning disabilities are different to me* repertoire to frame difference as something that is imposed upon people with learning disabilities by external forces.

Across the focus groups the participants drew on the *people with learning disabilities are different to me* repertoire to discuss a range of external barriers responsible for creating difference in the lives of people with learning disabilities. The barriers discussed included: structural barriers such as the prevailing political economy; social barriers such as the presence or absence of family and support networks; and cultural barriers such as the widespread misunderstanding of the needs of people with learning disabilities. When talking about difference in this way the participants talk is reflective of the argument made within the social model of disability, highlighted in the literature review, whereby disability is framed as a consequence of limiting barriers that are external to the individual.

Structural barriers

Extracts taken from the Clinical Psychologists and the Special School Teachers talk demonstrate the participants' construction of difference as a consequence of the prevailing political economy.

Clinical Psychologist 1:	Even those with mild learning disabilities, the shift in society, I work with lots of kind of adults sort of late 40s early 50s that might have had a job previously, stacking shelves, and the change in the way society runs its businesses all of that, there is now no space for those people because they don't fit in to a company profile.
Later on....	
Clinical Psychologist 3:	We don't have those roles any more, we are very much less labour intensive, even in the means of production we are much less labour intensive and I can think of some people who I was at school with who actually got, would have had, would have been able to achieve a diagnosis at some point, I think the thing is now we have not got systems that say can we encourage employers to employ people with learning disabilities. Once upon a time there would just have been roles for people who would have been considered to be a bit daft.
Special School Teacher 1:	And with the economy as it is, a lot of our students would have been finding jobs but now hardly any of them are. I mean some places do have their quotas, Marks and Spencer are good for that aren't they? But otherwise there are kids with GCSEs, A levels, and so they get the jobs, not the kid with learning disabilities.

Here, the participants' discussions link the differences in employment status experienced by people with learning disabilities, to the prevailing neoliberal political economy which they set out to be at odds with supporting people with learning disabilities and treating them as equals. As discussed in the literature review, a neoliberal political economy is characterised by a rhetorical commitment to a small state and the dominance of market forces (Goodley 2014). In addition to this, in the UK there is a focus on individual success obtained via educational achievement and employment status (Goodley 2014). The participants talk about this in terms of 'the shift in society', 'the change in the way society runs its businesses and all that' and 'the way the economy is as it is'. The focus on academic success as a route to employment is particularly highlighted in these extracts as a barrier for people with learning disabilities. For the participants, the movement of the means of production away from a 'labour intensive' focus has resulted in a reduction of jobs for people with learning disabilities. Jobs like 'stacking shelves', and working in 'Marks and Spencer's', once available to people with learning disabilities and people who would once have been 'considered a bit daft', are now given to 'kids with GCSEs and A Levels' due to the surplus of mainstream educated workers meaning that people with learning disabilities no longer 'fit into a company profile'.

In framing difference in terms of the strong social model's argument that disability is ultimately a structural issue, the participants' standpoint, here, encounters the same problems, highlighted in the literature review, that the strong social model does. The removal of such barriers reveals the complexity of learning disability that ultimately negates their argument. As quoted in the literature review, Shakespeare (2006 p.49) tells us that 'short of a global catastrophe which returned western society to medieval levels of economic and social organisation, it would be impossible to recreate a world in which literacy and numeracy were not important attributes for economic independence and advancement'.

This is not to say, however, that the political economy is not a negative factor in the lives of people with learning disabilities that contributes to their generally inequitable experiences. Rather this framing strategy is convenient for the participants in that it allows them to pass over any more complicated reasons for difference in employment, such as cognitive ability, that might challenge their 'good person' status. Moreover, talking about the differences in employment opportunities faced by people with learning disabilities in this way allows the participants to distance themselves from such differences. Difficulty in achieving employment becomes a consequence of an unfair political economy, something that is largely out of the participants' control. To acknowledge that some people with learning disabilities might not find employment because employment is not appropriate for them, because for example they have a profound cognitive disability, would go against their perception of equal opportunities. The participants employ a similar strategy when talking about social barriers.

Social barriers

Across the focus groups the participants also talked about barriers in terms of support provided by families and carers. The participants talked about this in two contrasting ways, establishing the family as both a site of restriction and of freedom. Extracts taken from the focus groups with the Student Teachers, Student Social Workers with experience (a) and Student Social Workers without experience (b) exemplify how the participants used the *people with learning disabilities are different to me* repertoire to present difference as a consequence of oppressive families/carers.

Student Teacher 2: I feel like often they might have to spend time with people like service providers and or their family who might not be the same age as them. Because I don't know, whenever I was doing voluntary work with people with learning disabilities erm it was really funny because they were trying to do like a nativity play, it was really good but the main, the Joseph, like the main male character, couldn't make the woman link with him because he had only ever been linked with somebody because he was only ever being led around. So they were just like 'will you link Mary?' and he didn't really know how to do it, because he had only ever, he had always been in a dependent role in his life.

Student Social Worker 3 (a): I think I think like my point earlier I think that families and parents have got really kind of like low expectations of their children who have kind of like got learning disabilities. And I worked on a project kind of like on personal budgets so people could really use kind of like their funding really creatively and there were no barriers because it was kind of like a pilot and you were encouraged to think creatively about what support could look like and that could be and for some people that would have been relevant perhaps supporting somebody to get a Saturday job or supporting someone to do some volunteering and sort of starting to have conversations with parents and kind of like saying, actually like the overwhelming responses were like 'oh well they would never be able to do that' and then when you talked to them about the possibility of actually going in to town on their own for lots of parents it would be like 'oh well there is no way they would actually be able to cross a road, there is no way that they would be able to catch a bus'.

Student Social Worker 1 (b): You are impaired in developing your independence by the caring situation. A good example is teenagers, if you have Down's syndrome you are still going to have, well at some age, you are going to go through adolescence psychologically not just physically and you are going to want to take risks and explore your life but er it may not be possible because you are constrained by your carer who thinks they are doing the best for you.

In these presentations, the participants cast parents and carers as a restrictive and constraining force in the lives of people with learning disabilities. People with learning disabilities' lives are presented as different due to the presence of overbearing family members who 'think they are doing the best for you' but actually have the effect of placing the person in a 'dependent role'. Implicit within the participant's examples of the effects of dependency, is the idea that people with learning disabilities have the potential to be independent, risk takers and creative choice makers if only it were not for their overbearing carers. When Student Teacher 2 provides the example from her voluntary experience she tells the group that Joesph was unable to initiate linking arms with Mary 'because he had only ever been in a dependent role in his life', inferring that the absence of imposed dependency would have allowed him to take the lead. This is also implied when Student Social Worker 3 provides her example of parents who are sure their child cannot cross a road, catch a bus or go into town on their own. Without the parent's 'low expectations', Student Social Worker 3 intimates that the people she worked with would have been able to get a 'Saturday job' or a position doing 'some volunteering' just as other children their age would be able to. Student Social Worker without experience 1 also infers the chance for independence in the absence of carer restraint, when she tells the group 'it [risk taking and exploring who you are] might not be possible because you are constrained by your carer'. Here, she is inferring that without this constraint, such activities could be possible.

When talking about adolescence, however, Student Social Worker 1's talk demonstrates a trend found throughout the participants' use of this repertoire pair: the limitation of being to able-minded being. Student Social Worker 1 assumes that adolescence is something initiated by the individual's mind and body only, rather than something that is strongly dictated by social norms and expectations. 'Taking risks' and 'exploring your life' are conditions that reflect a relatively recent, typically western and fundamentally cognitively able stereotype applied to teenagers. Student Social Worker 1 frames such rebellion as ordinary. While this might be the case for cognitively able teenagers and indeed some teenagers with learning disabilities, particularly the type of learning disabilities mainly considered by the focus group participants, this is not the case for all people with learning disabilities. In limiting her understanding of adolescence, thereby, Student Social Worker 1 demonstrates her ignorance of other ways of being. This ignorance, however, is useful in that it allows her to apply the same way of being to everyone regardless of cognitive ability. In doing so she can ignore the potentially very different ways of being a teenager which people with learning disabilities might experience, such as not being able to comprehend Social Worker 1's perception of rebellion, and maintain her 'good person' status that is dependent upon her commitment to all people being the same.

Paradoxically, across the focus groups the participants also talked explicitly about the presence of family members and carers in the lives of people with learning disabilities as a positive force that can open doors and enable people with learning disabilities to access this single way of being. When talking about the positive role that families can play, the participants generally did so by talking about the absence of supportive families and carers and the differences that this can create. Extracts taken from the focus groups with the Special School Teachers, Mainstream Teachers and Student Journalists demonstrate this way of talking.

Special School Teacher 6: Also, it depends on your family and how supportive they are. Like you [SST3] you are great, you get ___ and ___ out and about all the time. I mean ___ is going to the theatre twice this week isn't she? But,
Special School Teacher 3: Yes.
Special School Teacher 6: But, if you haven't got support from your family it, it can be hard. If you can't get out.

Mainstream Teacher 3: And that can be abused too can't it because if you are relying on a carer to make decisions for you then you have to hope they've got your best interests at heart because that happened with Holly's auntie the carers do things like 'you would like to go to the theatre to see x y and z because then they go, because they are paid to go with her, you would like to go. And my cousin in Scotland with Down's syndrome, she has carers, two carers, but she is in a flat and they say 'Oh you would like to go to Blackpool for a week wouldn't you?', so yeah I say it can be abused very easily.
Mainstream Teacher 2: Yeah I think that it's better now but still and I've seen it in children with that label, things can be hard, especially if you can't get the support in the classroom. Like also maybe if family support isn't good either.
Mainstream Teacher 1: That's true.

Student Journalist 2: I think they might struggle with sort of the social aspect of being an adult so like relationships, going out, erm because its, it's normally in Autism that it's the kind of like social side of things that they have the problem with isn't it? So erm but I think you would just sort of adjust and adapt which people probably do. I think because like my mum is a nurse so I think, and like obviously very supportive, so I think that would be, if I had a learning disability, family life would be absolutely fine because I would know that I would have that support

Where previously the participants had talked about supportive families as having the potential to constrain people with learning disabilities, here a supportive family is cast as essential to the lives of people with learning disabilities, allowing them to 'go out to the theatre twice a week', to navigate 'relationships' and to avoid being exploited by carers making the wrong decisions. In order to show this, the participants draw on personal examples: Special School Teacher 6 uses another focus group member as an example of a parent of children with learning disabilities (the children are young adults) and how her support allows them to live well; Mainstream Teacher 3 talks about her daughter's friend's auntie and her cousin who both have exploitative carers rather than supportive families; and Student Journalist 2 compares her own life to show the need for a supportive family. Without a supportive family/carers to enable people with learning disabilities to live as they want to, the participants tell their groups that 'it can be hard' and 'things can be hard'. In contrast, life for people with learning disabilities who do have a supportive family is said to be 'absolutely fine'. With a supportive family, moreover, people with learning disabilities can be just like everyone else.

While the presentation of a supportive family in the lives of people with learning disabilities as both a positive and a negative force that can impose and reduce difference might seem contradictory, in whichever way the participants present the family, the purpose remains the same. In locating the presence of a supportive family as either a source of restriction or independence the participants can frame the differences they are talking about as being imposed by something/someone that is not them. In doing so the participants can implicitly distance themselves from such differences.

Cultural barriers

Lack of understanding about learning disability and the negative implication of this on the lives of people with learning disabilities also featured prominently in the participants' construction of difference as something that is imposed on people. This is ironic considering the focus groups' own (mis)understandings demonstrated throughout their talk. Nevertheless, lack of understanding was used to justify a number of differences in the lives of people with learning disabilities. Extracts taken from the focus groups with the Student Social Workers with (a) and without experience (b) demonstrate how the participants drew on the *people with learning disabilities are different to me* repertoire to do this by using personal examples.

Student Social Worker1 (b): There was a service user that I didn't work with but erm on my first placement at a Surestart Children's Centre, I went to one of the erm Webster Straton parenting classes, the first one er and basically this woman was there and her children were under well they were at risk of being taken away form her and it was a very sad story they were actually, she parented those children with her step dad when she was 36 and erm, so obviously what I am saying is that she had some learning difficulties that had never been diagnosed and erm part of the problem with her being on a parenting course was that it's gunna take her much more intense work than a community you know in a big room with another 20 people like it's not gunna be right for her, she is very likely to have those kids taken away from her.

In this presentation Student Social Worker 1 uses a personal example from her training to illustrate how a lack of understanding of the needs of people with learning disabilities can create difference in their lives. In the example she provides, Social Service's lack of understanding of the woman's learning disability, 'that had never been diagnosed', is framed as the reason why she could be at risk of having 'those kids taken away from her'. In failing to diagnose her learning disability she has been placed on a parenting course that is inappropriate for her needs. Here, student Social Worker 1 casts herself in the role of expert observer. In this role she is able to diagnose the woman she sat next to as 'having some learning difficulties' despite this not being picked up by social services or any one else. In casting herself as someone who understands people with learning disabilities and their needs, she is able to locate the differences she is highlighting as a consequence of the misunderstanding of others.

Similarly, the Student Social Workers with experience also present their knowledge of lack of understanding as a reason for difference.

Student Social Worker 3 (a): I think the assumption that the really vulnerable can just be able to just, it can be just as oppressive as well. Like there was a women who I worked with and she had a car accident when she was nine and she sustained brain damage and she was in a relationship and had a child with a bloke who doesn't have any mental problems and social services were trying to split them up and remove the child and they thought she was vulnerable to him but it was just a case of that even though she had speech impairments from her accident and things like that it wasn't vulnerability it was just love.
Student Social Worker 2 (a): Yeah people can be really suspicious.
Student Social Worker 1 (a): It can be the basis of prejudice like if you think there is a normal guy and an abnormal woman or vice versa then there is clearly something suspicious going on whereas actually it's not necessarily that at

> all. I hate using the word abnormal, I was just using it from the perspective of the prejudiced person.

In this presentation the Student Social Workers with experience present a general lack of understanding of learning disability as a reason for the increased surveillance that people with learning disabilities are said, in this extract, to experience. Student Social Worker 3 uses a personal example from her professional practice to demonstrate the negative effects of misunderstanding. Ironically, her example demonstrates a clear (mis)understanding of learning disability by the Student Social Workers; that learning disability is the same as 'mental problems'. In this example, the family of three being discussed is presented as receiving heightened surveillance from social services due to them believing the mother 'to be vulnerable to him [the father]'. As with the example discussed above, Student Social Worker 3 casts herself in an expert role that allows her to make judgements on the situation she was involved in. Student Social Worker 3 begins her example by stating 'like there was this woman who I worked with'. By stating this, Student Social Worker 3 asserts herself as being able to have a valid opinion on the case she is about to use as illustration of that the perception of vulnerability can be oppressive. Student Social Worker 3 disagreed with social services' perception of vulnerability, telling the group 'it wasn't vulnerability, it was just love'. The family, in her example, are shown to be experiencing unjust treatment based on a lack of understanding of their situation. Student Social Worker 1 follows up this example by widening the presence of misunderstanding by talking from the perspective of a 'prejudiced person'. Here, misunderstanding is seen as the basis of prejudice and the negative effects that this can have on the lives of people with learning disabilities. Prejudiced people are presented as viewing learning disability in terms of the normative categories 'normal' and 'abnormal,' and 'vulnerable' and 'exploitative'.

People without learning disabilities are afforded the category of 'normal' and 'potentially exploitative' if in a relationship with an 'abnormal' person, and vice versa, people with learning disabilities are seen as 'abnormal' and 'vulnerable to abuse' by 'normal' people. A relationship between 'a normal guy and an abnormal woman or vice versa', as in the example given by Student Social Worker 3, is presented as a source of suspicion that would result in added surveillance in their lives. Student Social Worker 1 is keen to present herself in disagreement and so uses the extreme case formulation 'I hate using the word abnormal' to credentialise her talk, just in case her focus group peers had misunderstood her phrasing, and telling the group that such relationships are 'actually not necessarily that [suspicious] at all'.

In both of these examples the presence of a general lack of understanding of learning disability by others allows the participants to talk about differences by way of framing such differences as a result of widespread ignorance. The participants are again able to remove themselves from the creation of these differences by casting themselves as people who do understand learning disability. Implicit within both extracts is the inference that if everyone understood learning disability as well as the participants do, then the differences illustrated could be avoided.

In all of the extracts presented to show how the participants used different strategies to frame difference as a consequence of external factors, the participants are able to both distance and tie themselves to difference according to the content of their discussion. They are able to eliminate their role in the differences that people with learning disabilities experience, differences that the participants present themselves as uncomfortable with. At the same time they are able to tie themselves to such differences by presenting themselves in roles that can work towards eliminating differences, either as supportive parents, knowledgeable future social workers or teachers equipping students with life skills. In this way the participants' eliminate their own agency from the imposition of difference but at the same time, claim agency in the removal of difference. The participants can employ either strategy in order to maintain their 'good person' subject position, discussed in the previous chapter. By distancing themselves from difference, they can show that they do not have a role in the imposition of differences and by tying themselves to difference, by way of both their humanity and their profession, they can show that they are working towards the elimination of difference.

Fundamental to the participants' framing strategies is their construction of difference as a social construct that imposes disability in much the same way as the social model. While the participants acknowledge learning disability as an individual condition that has certain characteristics, this again is framed in a similar way to the social model's construction of impairment, whereby impairment is the bodily aspect of disability. Consequently, as stated, their talk is also reflective of the inherent problem experienced by the social model when applied to learning disability. In presenting the removal of barriers as the solution to disability, as in Finklestein's imagined village (1975), discussed in the literature review, and the participants' discussions of structural, social and cultural issues, being is limited to able minded being. In their examples, people with learning disabilities are made to conform to this normative way of being in order for the participants to maintain their 'good person' status. To recognise alternative ways of being would make this position in its particular form difficult to continue with as it would require the consideration of material difference and the extension of equality to something more than sameness.

Locating difference in individuals

Contrary to the above framing strategy that located difference outside of the person, the participants' use of *the people with learning disabilities are different to me* repertoire also revealed a distinct tension in their construction of difference. In finding difference difficult to talk about, the participants often reverted to talking about individuals and the differences that conditions located in individuals can create. As seen across the previous two chapters, the participants work hard to reject the medical model of disability, indeed, as stated it is the desire not to be associated with this model of disability that makes it difficult for them to talk about difference. Despite this, from the very outset, the medical model is present within their talk about differences, similarities and the lives people with learning disabilities lead.

In an attempt to present as people who understand learning disability and accept people with learning disabilities as equals, the participants, as shown above, reason that they cannot talk about these issues due to the broad nature of learning disability, specifically the range of diagnoses, and ability levels that these diagnoses infer. The examples below, demonstrate the participants' initial reaction to the question, what sort of a life do you think someone with learning disabilities might lead?

Mainstream Teachers 3: Hmm well that's when you would say its too broad to say really.
Mainstream Teacher1: Yea it depends what they've got really because it could be the same socially as us but then.

Health Professional 3: I guess it would depend on the level of learning disability, erm.
Health Professional 1: Yea, depends I suppose if it's just, if its kind, if, if they have got any kind of physical problems as well as a learning disability and psychological difficulties as well erm because a lot of the time they all kind of become interlinked erm.

Social Scientist 1: And also it depends on their learning disability because I think, you know, there are different kinds and they affect your daily life in different ways so it depends on the context on the type of learning disability.

Here it can be seen that in trying to present as someone that understands learning disability in the 'acceptable' way, the participants try to avoid talking about difference. The reasons they give, however, are imbued in the way of understanding learning disability that they seek to avoid, whereby learning disability is seen as an individual problem that divides 'them' from 'us'. Such responses were common across all of the focus groups. In all three of these extracts, the participants use of the words, 'they've', 'they' and 'their', to locate learning disability within the individual. For example, Mainstream Teacher 1 tells the group, 'it depends what *they've* got', Health Professional 1 states, 'if *they* have got any physical problems' and Social Scientist 1 says 'it depends on *their* learning disability'.

While the participants' desire to convey their support for social model principles is reflective of the social model's influence, the presence of the medical model within the participants' talk, despite their efforts to reject it, serves to highlight the ongoing dominance of the medical model within both professional and lay conceptions of learning disability. This tension between wanting to present as someone who does not perpetuate the medical model and the implicit hegemony of the medical model within their talk is demonstrated further in the extracts below, taken from the focus groups with the Local Authority Councillors and the Social Scientists.

Local Authority Councillor 2: Your condition potentially is a barrier, if you can't read, then like I say how do you know you are taking the right tablets or whatever, but then if you haven't had support to know then that's a barrier too, if the sort of services and things aren't in place to make life easier for you then that's a barrier. Certainly I think things are improving, you know, with the services for support that are available but obviously it can still be very difficult because of your condition and how that makes you different from the rest of us.

Here, Local Authority Councillor 2 demonstrates that he is aware of the discourse addressing social barriers. Under the social model, however, disability is removed when barriers causing it are overcome. Here, Local Authority Councillor 2 demonstrates that while social barriers are being overcome, 'with the services and support that are available', the presence of an individual 'condition' ultimately overrides the effect of barrier removal, because of 'how that makes you different from the rest of us'. Here, Local Authority Councillor 2 explicitly locates disability with the individual. His use of the words 'you' and 'your' when he states 'if you can't read' and 'it can still be very difficult because of your condition', clearly demonstrates this.

Similarly Social Scientist 1 said:

Social Scientist 1: I think that's really difficult to say because there is such a huge spectrum of learning disabilities. So I don't know, a kind of person with erm kind of Down's syndrome, well depending on the level, because I know there are different levels of Down's syndrome that you can have, but depending on the level they might need kind of support to live their life and a lot of erm kind of outside input from other people. I think if they live in a care home then obviously that's gunna have a huge impact on their life if they need kind of constant care or support from someone else to kind of get through the day.

In this presentation, Social Scientist 1 talks about Down's syndrome in terms of a cause of the differences an individual with Down syndrome might experience. Needing 'support to live their life', 'liv[ing] in a care home' and needing 'constant care or support from someone else to kind of get through the day' are all framed as a consequence of Down syndrome. Social Scientist 1 uses her knowledge of Down syndrome, 'I know there are different levels of Down's syndrome', to do this, going on to tell the group that the level of Down syndrome will dictate the differences someone with Down syndrome will encounter, stating 'depending on the level, they might kind of need'.

In all of these examples it can be seen that the participants' talk is imbued with the medical/individual model of disability, something they work hard to distance themselves from. As outlined in the literature review, the medical model is often referred to as the deficit model of disability because of its focus on bodies that are lacking in some way. Although the participants talk of difference as something that is caused by individual conditions/bodily deficit appears contradictory and, theoretically it is, it does not seem from the talk that the participants intended for this to be the case. In highlighting difference as a consequence of individual conditions, the participants hoped to show their 'good person' subject position by presenting individual conditions as something that individuals cannot help. Individual medical conditions were not put forward as the fault of the individual but rather were intended to be presented in terms of something that is out of the individual's control that they cannot be blamed for. Common to the participants' discussions about the differences that they acknowledged and their framing strategies that allowed this was their explicit presentation of such differences as being imposed upon the person with learning disabilities by something or someone external to them, whether this be a medical condition that is out of their control or a cultural, social or environmental barrier.

Use of the *people with learning disabilities are different to me* repertoire to frame difference as equalising

Across the focus groups the participants also drew on the *people with learning disabilities are different to me* repertoire to frame difference as equalising. In recognising and talking about differences, the participants often framed this in terms of evidence that people with learning disabilities are actually no different to themselves, rapidly switching to the *people with learning disabilities are the same as me* repertoire to allow them to make such contradictory statements. In doing this, both repertoires are switched between so rapidly that they cannot be talked about separately; each repertoire depends on the other for existence. Billig et al (1988) found a similar pattern when looking at the talk of National Front Supporters who often followed their prejudiced statements with references to sympathy and tolerance in order to frame their views as reasonable and justified. When talking about the lives of people with learning disabilities, in order to be able to talk about difference without moral accountability, the participants can be seen to perform similar credentialing acts.

Extracts taken from the focus groups with the Social Care Providers, the Mainstream Teachers and the Student Social Workers without experience demonstrate this credentialing work.

Student Social Worker 1:	Yeah and that's kind of liberating really, in an idealistic society if everyone could identify their problems as a disability of some sort then maybe they would be a bit more emphatic but clearly scale and the society that we are in at the moment, they are not fully integrated at the moment so
Student Social Worker 3:	I think it comes back down to othering, like you hear a word like learning disability or autism and you just have one thought that everyone with a learning disability they are all the same, they all think the same way and its only when you break it down and look at yourself and you look at that triangle and what what's entailed and you can start relating it to yourself and then maybe expanding your mind a bit and not being as narrow minded when it comes to assumptions about people anyway.

Prior to this presentation and also following this presentation the Student Social Workers without experience draw on the *people with learning disabilities are different to me* repertoire to talk about a variety of differences including, academic achievement, carer loss, sex and relationships and living arrangements. Here, the Student Social Workers can be seen to be performing credentialing work to justify their talk about these differences in order to present their views as reasonable. The Student Social Workers' draw on the *people with learning disabilities are different to me* to repertoire to talk about how people with learning disabilities are seen as different to people without learning disabilities as a consequence of their disability, as when Student Social Worker 1 told the group 'if everyone could identify their problems as a disability'. The participants make it clear, however, that this not how they view learning disability and make direct appeals to 'everyone' to 'expand your mind' in order to remove 'narrow minded' 'assumptions' that result in 'othering' people with learning disabilities. The

Student Social Workers' use of the *people with learning disabilities are the same as me* repertoire, although not explicit, is implicit within their appeals. The Student Social Workers present their understanding of learning disability as 'liberating' and 'idealistic' and urge others to go against 'the society that we are in at the moment' and 'look at yourself and that triangle [triangle of Autism]' and 'start relating it'. For 'everyone' to see their 'problems' as a disability is presented as the ideal situation, in order to ensure that the differences ordinarily associated with people with learning disabilities are overcome and that people with learning disabilities are positioned as equals. This solution is reflective of a number of disability studies theorists' call to acknowledge the universality of impairment throughout a life course (Shakespeare 2006).

In the extracts below, Social Care Provider 1 and Mainstream Teacher 3 do as the Student Social Workers encourage. Indeed, such egalitarian talk was common throughout the focus groups.

Social Care Provider 1: I would say we are all very similar and we are all very different and erm that applies whether you have a learning disability or not so erm just like V2 said, some people can draw and some can't, that's those two different groups, some people have learning disabilities and some people don't but we are all the same because we all have things we can and can't do.

And later

Social Care Provider 2: Well I suppose similar, you would say that you know emotionally, we all carry emotions and they are always going to be there.

Mainstream Teacher 3: Who are we to judge their lives. If they seem the same or different to ours who has the right to judge. Everybody has needs. Like me and my memory.

All three of these statements followed the participants' discussion of differences in the lives of people with learning disabilities compared to the lives of people without learning disabilities, further demonstrating the participants' credentialing work. Reflective of the discursive dominance of the medical model, the differences discussed both prior to these presentations and contained within them, focus on deficits such as not being able to do something and requiring support. In both of these presentations, the speakers present the differences they have spoken about as an equalising characteristic. The participants do this by making generalised statements such as 'we all have things that we cannot do', 'we all have needs' and 'we all carry emotions'. Social Care Provider 1 and Mainstream Teacher 3 refer to people without learning disabilities to add emphasis to these statements, Mainstream Teacher 3 using herself and her memory problems and Social Care Provider 1 using Volunteer 2's example that not everyone can draw. In doing this, the participants simplify difference, which allows them to talk about it in acceptable terms that do not compromise their moral standpoint. The differences the participants have talked about, no matter how significant, are rendered trivial by their subsequent use of the *people with learning disabilities are the same as me* repertoire. This acts to credentialise their acknowledgement of difference and ensure they maintain their good person subject position. As Billig et al (1998) found with the terms health, and also prejudice, their use is reliant upon the presence of a dialectic or opposite; health and illness, prejudice and equality. Here it can be seen that the participants' talk about difference necessarily includes its opposite, equality.

The participants' talk about difference, given their perception of 'appropriate' and 'inappropriate' ways of seeing learning disability, illuminates yet another ideological dilemma based upon their ‘good person’ status and the tension this presents when faced with the reality of learning disability. Talk about the experiences of people with learning disabilities compared to the experiences of people without learning disabilities is very difficult to do without talking about difference due to the fact that multiple ways of being are being compared. Despite this, the participants are keen to present as people who do not see difference. All three of the framing strategies illustrated above allow the participants to rhetorically negotiate the dilemma that talking about difference presents. The participants use all of the strategies to frame difference positively. Difference becomes something that either is out of the individual’s control, in the form of social barriers or bodily conditions, or is actually equalising. Consequently, the participants’ use of the *people with learning disabilities are different to me* repertoire did not undermine their ‘good person’ subject position, discussed in the previous chapter. Rather, their construction of difference as something that is imposed upon people with learning disabilities, allowed the participants to, contrastingly, both distance themselves from and tie themselves to the presence of any differences they discussed, as was necessary to maintain their ‘good person’ subject position. In framing difference as something that is imposed on others as a consequence of structural, social, and cultural barriers, the participants can distance themselves from the differences they discussed because difference has become something they both do not condone/impose and something they can work to remove. In framing difference as something that is a feature of all human beings, the participants can include people with learning disabilities as people like themselves, thus maintaining their commitment to equality.

In attempting to manage their ideological dilemma, the participants also apply the strategy of glossing over fundamental differences such as cognitive capacity and its influence over an individual's way of being such as being able to conform to social norms such as work, marriage and procreation. In doing so they are able to maintain their ultimate commitment to the *people with learning disabilities are the same as me* repertoire to ensure their 'good person' status. This repertoire is discussed in detail below.

The *people with learning disabilities are the same as me* repertoire

Features of the repertoire

The *people with learning disabilities are the same as me* repertoire can be distinguished by the consistent use of the following speech acts: the use of humour and laughter to emphasise their belief that people with learning disabilities are the same, such as when Social Care Provider 1 said, 'Yeah some of us are weirder than others ha ha ha ha'; the reduction of people to species; and the use of positive words and phrases when talking about people with learning disabilities and the lives they lead, such as 'happiness', 'laughter', 'friends' and 'full of hobbies'

Uses of the repertoire

The participants used the *people with learning disabilities are the same as me* repertoire to perform one overriding action, to credentialise their use of the *people with learning disabilities are different to me* repertoire in order to present themselves as 'good people'. While the *people with learning disabilities are the same as me* repertoire was directed in the main towards people with mild and moderate learning disabilities, the participants also used this repertoire to talk about people with severe and profound and multiple learning disabilities.

The use of the *people with learning disabilities are the same as me* repertoire as a caveat to maintain their 'good person' subject position

The participants' credentialing work has been highlighted when the *people with learning disabilities are different to me* repertoire was discussed in relation to the participants' framing of difference as equalising. Here, it can be seen that the *people with learning disabilities are the same as me repertoire* often followed the participants' use of the *people with learning disabilities are different to me* repertoire in order to present themselves as 'good people'. Examples of this work are provided in the extracts below taken from the focus groups with the Parent Carers and the Student Social Workers without experience.

Parent Carer 1: I think we come back to the same thing, that people are people
Parent Carer 7: well yes, I mean _____ [daughter] enjoys shopping, going to the football, she likes going to the cinema, she likes going out to the pub and going for meals and things like that, she enjoys social activities
Parent Carer 5: better life than me!
Collective: Laughter.

Following the parenting class example provided by Social Worker 1, seen on p.211 the Student Social Workers said:

Student Social Worker 3: I think that story is just as likely to occur with somebody that didn't have learning difficulties.
Student Social Worker 1: Yea that's true that could happen.

Mainstream Teacher 3: But could you argue that they are having an equally fulfilling life for them as who is to say what is a good life. Is going out everyday and socialising all the time a good life or is being at home and watching the tv because that's what you want to do, a good life? So I think people unless we are talking about the extreme severe where you really are not aware of what's going on around you, which is a different category, I don't think there is any difference I think its what you make of it and who are we to judge in a way.
Mainstream Teacher 1: Good point.

In each of these presentations the groups are working to reorient back to their shared 'good person' status as a consequence of acknowledging difference. The extract taken from the focus group with the Parent Carers followed a long and candid discussion about the differences that people with learning disabilities experience, including living in a care home, living the life of a child, not being able to understand why things happen, needing regular support, carer loss, and attending day services. Parent Carer 7 had previously compared her life when she was 33 to her daughter's life as a current 33 year old, stating, 'when I was 33 I had been to work, I was married I had 3 children, I had a house, all these things and they are all things that my daughter doesn't do. She lives at home. I mean my grandchildren now are 3 and 5 and really in lots of ways you know her ability is only like theirs. She needs help to make decisions, she can't go out by herself'. Parent Carer 1 makes the first move to credentialise their talk about differences by reminding the group that although they can list differences, ultimately, 'people are people'. Having been reminded of this, Parent Carer 7 begins to list all of the things that make her and her daughter the same. 'Social activities', including going 'shopping', 'to the football', 'to the cinema', 'to the pub' and 'out for meals' are all listed as things her daughter enjoys. Parent Carer 7 implies that these are all things that people without learning disabilities also enjoy when she says 'well yes, I mean ___ enjoys' and follows this up with the list of activities. In response to this Parent Carer 5 uses humour to demonstrate his agreement that people with learning disabilities are just like everyone else, going as far to suggest that people with learning disabilities are better off, by joking that Parent Carer 7's daughter has a 'better life than me!'

Similarly the extract taken from the Student Social Workers talk immediately followed Student Social Worker 1's example of the woman attending a parenting class (seen on p.211). In her example, Student Social Worker 1 sets the woman with learning disabilities apart from the other participants on the course who do not have learning disabilities, who can understand and take part in the course and so might not risk losing their children. Student Social Worker 3 credentialises Student Social Worker 1's example by drawing on the *people with learning disabilities are the same as me* repertoire and stating 'that story is just as likely to occur with somebody that didn't have learning difficulties'. Having been reminded of this, Student Social Worker 1 switches to the *people with learning disabilities are the same as me* repertoire in order to agree. In switching to the *people with learning disabilities are the same as me* repertoire, the participants maintain their 'good person' subject position.

Likewise prior to the extract taken from the Mainstream Teachers talk, they had been talking about the life a person with learning disabilities might lead and Mainstream Teacher 2 had said 'I think, well, the world would be a lot smaller in terms of where they put themselves because their worlds tend to be a lot smaller'. In order to credentialise Mainstream Teacher 1's acknowledgement that people with learning disabilities experience the world differently to people without learning disabilities, Mainstream Teacher 3 turns Mainstream Teacher 1's statement around to make sure that the group know that she would not 'judge' people with learning disabilities' lives and that in the context of mild and moderate learning disabilities, there isn't 'any difference'. Mainstream Teacher 3's explicit appeal to equality reminds the group that talking about difference could undermine their 'good person' status.

In contrast to the previous two examples, however, Mainstream Teacher 3 makes a point of distinguishing between people with mild and moderate learning disabilities, for whom she tells the group that life isn't any different, and those with 'extreme severe' learning disabilities 'who are really not aware of what is going on around' them. In the case of these people, Mainstream Teacher 3 intimates that the use of the *people with learning disabilities are different to me* repertoire is valid. Interestingly, this was not routinely the case across the focus groups. If the participants talked about people with severe learning disabilities, and as stated this was rare, they still drew on the *people with learning disabilities are the same as me* repertoire as can be seen in the example taken from the focus group with the Student Social Workers with experience.

Student Social Worker 3: I remember kind of like working with somebody, probably one of the people who I have worked with who have had the most profound disabilities, so he had cerebral palsy and kind of like was completely paralysed and he ended up having to have like PEG food and very very disabled kind of like man but I worked with him kind of like for like four years and the thing that was by the end of those four years, like so apparent is that absolutely regardless of that man's disability kind of like there was something about that man's, his character and his spirit kind of like just the things that he would choose to laugh at or find funny or kind of you know that he would get upset by, kind of like really impacted upon me because I thought 'oh my god, you know this is someone who can't talk, he can't eat, he is completely dependent and completely different to me in that respect' but actually in terms of what makes somebody a person it was there and kind of like really powerfully there.

Here, Student Social Worker 3 uses the *people with learning disabilities are the same as me* repertoire to show that even people with 'profound disabilities' are the same as someone without a learning disability. She uses the *people with learning disabilities are different to me* repertoire to create an image of the man in her example who 'can't talk, can't eat and is completely dependent' to show that he is 'completely different to me' but then switches to *the people with learning disabilities are the same as me* repertoire in order to credentialise her acknowledgement of difference, by reducing people to species, stating 'actually in terms of what makes somebody a person it was there kind of like really powerfully there'.

As seen in the examples above, and as has been a continuous theme throughout the data corpus, the pressure to be seen as a 'good person' was a dominant force within the participants' talk. This pressure is clearly demonstrated in another extract taken from the focus group with Student Social Workers with experience.

Facilitator: ok, so going back to what you were saying about a retracted life for people with more profound learning disabilities

Student Social Worker 3: can it still be rich?

Student Social Worker 1: I struggle with that a lot. I I don't know, with, with some people I have met with a learning disability I think 'your life is certainly rich, there is no shadow of a doubt' I worked with a girl that had got erm a part time job at the ice stadium and you know she she had a good rich life but then having been to a centre for children with complex autism, and, and you know actually seeing pain on their faces, seeing struggle and I have to question, how, how, to what extent is that a rich life does the suffering, that the child is clearly experiencing, is it outweighed by…

Student Social Worker 2: I think you can always make arrangements for their life so that at some points it is as rich and it's the same sort of happiness, whether its through sort of sensory means or you know day trips or something like that. You know at some point in their lives they could have that kind of like experience, even if it is not continuously rich throughout their whole life

Student Social Worker 1: well that's just life, life isn't rich all the time for any of us
Student Social Worker 2: no, no. I think they have sort of aspects of their life that are sort of as rich as other peoples, if not their whole life, at least sort of an aspect is you know?

In this presentation, Student Social Worker 1 tries to go against the group's credentialing work and Student Social Worker 2 works hard to bring her back in line. Here, when thinking about the lives of people with more severe learning disabilities, Student Social Worker 1 goes against the group's shared self presentation as 'good people'. Where she had previously adhered to this self presentation, she subsequently admits to the group that she 'struggles' to employ the same values when it comes to people with complex learning disabilities and uses a personal example to demonstrate when she has encountered this struggle. In detailing this example, Student Social Worker 2 interjects, stopping Student Social Worker 1 from going into further detail about the 'pain on their faces' and the 'struggle' and 'suffering' that she has witnessed. This is the first and only instance of the Student Social Workers talking in this way. That this instance is stopped so abruptly by Student Social Worker 2 is significant. Student Social Worker 2 draws on the *people with learning disabilities are the same as me* repertoire, in order to demonstrate that she does not experience such a struggle. She uses the first person to tell the group straight away that, 'I think you can always make arrangements for their lives', telling the group that such arrangements can bring 'the same sort of happiness' as experienced by people without learning disabilities. In making her statement Student Social Worker 2 returns the group conversation to its desired subject position, returning the group conversation to the use of the *people with learning disabilities are the same as me* repertoire. Following this work, Student Social Worker 1 reorients to the group perspective. Her attempt at questioning the group's consensus is easily foiled by Student Social Worker 2 and she acquiesces to the group position, returning to the *people with learning disabilities are the same as me* repertoire stating ‘well that’s just life, life isn’t rich all the time for any of us’. The participants’ reorientation, here, could also be seen as a reflection of the potential for focus groups to generate consensual talk (Clavering and McLaughlin 2007) as discussed in the methodology.

Across all of these examples, the participants are able to credentialise their talk of difference due to their presentation of learning disability in terms of normative ways of being. Across all of the focus groups’ talk, people with severe or profound and multiple learning disabilities were largely not considered. In addition to this, when using the *people with learning disabilities are the same as me* repertoire, the similarities discussed were limited to likes and dislikes and social activities such as hobbies, enjoying going to the cinema, watching football and eating out. Large scale issues such as relationships, sex, having children, owning a house etc while mentioned as differences were later reframed as equalising and were ultimately ignored when presenting people with learning disabilities as the same as people without learning disabilities. Such work, allowed the participants to manage the ideological dilemma presented by the materiality of learning disability buttressed against their ‘good person’ subject position.

Conclusion

The conclusion that follows summarises the research findings in terms of the functions and consequences of the participants’ use of the *people with learning disabilities are different to me/people with learning disabilities are the same as me* repertoire pair and discusses the key findings in relation to the contribution they make to the sociological theorisation of learning disability.

Function and consequences of the repertoire pair

To summarise the analysis above, the focus groups' talk about similarities, differences and the lives that people with learning disabilities lead encounters yet another ideological dilemma based on the participants' shared construction of the 'good person' subject position. The participants want to present as 'good people'; however, talk about the lives of people with learning disabilities in general necessitates talk about difference due to the support needs that people with learning disabilities have and that people without do not. Talk about difference, as demonstrated throughout all three analysis chapters, is something the participants were particularly keen to avoid. Difference does not fit their shared desire to present as 'good people'; moreover, difference presents a fundamental challenge to this identity. In seeking to avoid the difficult task of avoiding talk about difference the participants once again encounter an ideological dilemma based on their construction of the 'good person' status: their idealisation of the 'acceptable' way of seeing learning disability is challenged when the material reality of learning disability is present.

The participants use the *people with learning disabilities are the same as me/people with learning disabilities are different to me* repertoire pair to manage this dilemma, oscillating between the two to ensure their desired 'good person' identity remains intact while still discussing the inevitable differences. The participants employ three strategies to do this: framing difference as imposed upon the person by external forces;

framing difference as an equalising characteristic; and providing credentialing statements to reorient back to their ‘good person’ status. In this way, as stated, the participants can remove their own agency from the differences experienced by people with learning disabilities but also can add agency as needed in order to maintain their ‘good person’ status.

The consequence of such framing and credentialing is that the participants implicitly reduce being to one homogenous experience. The focus groups’ talk implies that this way of being is the same as their way of being, or the majority able-minded way of being, without any consideration that alternative ways of being might exist. In maintaining their commitment to the ‘good person’ identity, the focus group participants’ talk must fit people with learning disabilities into this way of being. This perhaps explains why people with more severe learning disabilities were largely ignored in the participants’ talk. To fit people with severe or profound and multiple learning disabilities into this homogenous, normative way of being would be difficult and could challenge the participants’ ‘good person’ status further. As Ryan (1980 p.149) states ‘the path to greater acceptance is seen through some kind of normality’. This has never been more true than it is presently in the UK, where the principles of neoliberalism currently pervade the social, cultural and political worlds experienced by the focus group participants (Goodley 2014). In casting people with learning disabilities as being the same as people without learning disabilities on the grounds that difference is a characteristic of all humans, and thereby, fitting people with learning disabilities into a normative way of being, the participants demonstrate the shared need for people not to have learning disabilities at all. The participants’ talk changes people with learning disabilities in some cases beyond recognition. In doing so the participants demonstrate an implicit desire for people with learning disabilities to be 'normal'.

The underlying desire for people with learning disabilities to be 'normal' is also reflective of the approach taken in recent social policy, as discussed in the literature review. Here people with learning disabilities are presented in the same way: they can make informed choices and they can take responsibility for their own lives. Moreover, as Klotz (2014 p.101) tells us, people with learning disabilities are made to 'conform to normative social practices and behaviours as a means of their social inclusion and acceptance'. When the participants talk about difference, they do acknowledge fundamental variations between the lives of people with learning disabilities and people without, such as: the need for carer support; capacity for independence; increased propensity for physical and psychological health problems etc. When the participants' used the *people with learning disabilities are the same as me* repertoire to caveat their talk about such differences, however, the similarities they put forward either did not reflect the status of the differences they had raised or surpassed these differences by reducing all people to functional organisms that 'have all got blood' and 'all need 'oxygen' [Student Social Workers (a)].

The reasons the participants provided as to why people with and without learning disabilities are the same as each other generally involved: shared enjoyment for social activities such as eating out, watching the football and going to the cinema, and the shared ability to express emotion such as laughter and pleasure. Moreover, the participants tended to focus on small-scale similarities and disregard the bigger social picture. Their justification for sameness is again reflective of their desire to normalise people with learning disabilities in order to aid the participants' acceptance of people with learning disabilities as equals. Fundamental to this, and indeed to all of the ideological dilemmas that the participants encounter is the basis of the participants' shared construction of equality as sameness. In working so hard to present as 'good people' the participants have constructed all people as the same without the consideration that alternative ways of being could exist and hold equal value. In their desire to present a moral identity, the participants tie themselves in rhetorical knots that require the rejection of the reality and materiality of learning disability.

Key findings

In applying the framing strategies above, the participants once again manage to avoid addressing the learning disabled body and what it can do. It is this avoidance and consequent absence of the material body in the participants' talk that leads them in to the ideological dilemma experienced in their use of this repertoire pair and indeed, the previous repertoire pairs. In this way, the reality of the learning disabled body and its consequent abilities and inabilities becomes the 'elephant in the room'. To reiterate the point made in the concluding section of the chapter addressing *I know what learning disability is/learning disability is a confusing term repertoire,* it is not simply the case that the material learning disabled body is something the participants are not familiar with: the majority of the participants encounter this reality regularly as part of their professions. Indeed, the participants know that people with learning disabilities encounter differences in their lives as compared to people without. As demonstrated, however, their absolute desire to present as 'good people' prevents their acknowledgement of material or biological difference.

In order to be able to talk about and acknowledge the material reality of learning disability and the consequent differences that ensue, sociological perspectives of learning disability must acknowledge the learning disabled body. Bodies should not be feared as the focus groups fear them. Talk of bodies does not require the absolute application of the medical model of disability nor does it mean that history will repeat itself. As seen in the literature review, material bodies exist prior to social interaction and also play a significant role in social interaction. The biological need not be considered in terms of binary relationships but can be seen as a platform for embodiment (Williams and Bendelow 1998). As seen, in order to accommodate the learning disabled body and what it can do, more is needed than simply casting everyone as the same. Multiple ways of being and their materiality need to be acknowledged and afforded equal status. The next chapter addresses the 'elephant in the room' via the presentation of the photovoice analysis.

Chapter 8: Photovoice analysis

This chapter uses Drew and Guilemin's three stage interpretive engagement framework to analyse the participants with learning disabilities' visual and verbal portrayal of their understanding of learning disability. The chapter begins with an overview of the visual data to provide context. The participants' talk about their photographs (stage 1) is then discussed in relation to the repertoire pairs used by the focus group participants to co-produce their understandings of learning disability (stage two). These interpretations are then re-contextualised in relation to the theory discussed in the literature review (stage three).

Context

The table below provides a reminder of the demographic breakdown of the participants with learning disabilities and provides information on the photovoice process to complement the analysis that follows.

	Name	**Age**	**Ethnicity**	**Learning disability**	**Gender**	**No. of photos**	**Support to take photos**
1	Alleyah	20s	Asian British	Moderate	Female	171	No
2	Robert	30s	White British	Mild	Male	28	No
3	Mitesh	40s	Asian British	Moderate	Male	104	No
4	Janaya	20s	Black British	PMLD	Female	4	Yes
5	Lydia	20s	White British	PMLD	Female	10	Yes
6	Leo	20s	Black British	PMLD	Male	4	Yes
7	Theo	20s	White British	PMLD	Male	12	Yes
8	Tim	20s	White British	PMLD	Male	11	Yes
9	Ross	20s	White British	PMLD	Male	7	Yes
10	Hassani	20s	Asian British	Moderate	Female	29	No
11	Dave	40s	White British	Mild	Male	18	No
12	Kay	40s	White British	Moderate	Female	27	No
13	Lorna	20s	White British	Mild	Female	11	No
14	Mathew	30s	White British	Mild	Male	9	No
15	Tom	50s	White British	Mild	Male	4	No
16	Emma	30s	White British	Mild	Female	12	No

In total the 16 participants with learning disabilities took 461 photographs of their everyday lives. Across the participants' individual collections of photographs the content of the images generally followed similar topics such as: home, self, family, activities and objects. Within these general topics their photographs included a range of subject material including images of: the participants engaged in activities such as, drawing, music, craft, shopping, playing snooker, going to the cinema and trampolining; the participants being driven to places such as the gym, a relative's house and a day centre; support environments, such as day centres, group homes, and sports centres; living spaces, such as bedrooms, living rooms, dining rooms, prayer areas, kitchens and gardens; objects such as, collections, certificates, trophies, college folders, shoes, televisions, washing, trains, model aeroplanes, a fish tank and Christmas decorations; holidays; and friends and family.

A summary of the images, quantified below, shows that the majority of photographs were taken in support settings, including the home[1]. It is important to note that most of the photographs have been assigned multiple categories.

Self	**Number of photographs**
Self alone at home	12
Self alone out	18
Self with friends out	7
Self with family at home	1
Self with family out	1
Self with support worker out	3
Total	**42**

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[1] The home has been considered as a support setting for the reason that the participants were generally of an age when people are usually living independently

Family	**Number of photographs**
Family at home	20
Family out	13
Total	**33**

Friends and others	**Number of photographs**
Friends at home	5
Friends in a support setting (could be others at a group and/or support worker/s)	24
Friends out (not support setting)	4 (3 were taken by same person of same family friend on a family holiday)
Friends without LD	5 (3 of same person, family friend of 1 participant)
Friends with LD	33
Support workers	1
Total	**72**

Home	**Number of photographs**
Objects in the home	149
Domestic tasks	11
Friends	5
Family	20
Events	5
Participants' bedrooms	16
Parent's bedrooms	1
Lounge	17
Kitchen	9
Bathroom	1
Office	4
Prayer room/area in house	15 (taken between 2 participants)
Outside space	8
Interior architecture (door frames, skirting boards, coving)	15
Total	**276**

Out and about	**Number of photographs**
Support settings – include mainly activities organised by day centres i.e. craft groups, walking groups, theatre groups, social groups, lunch clubs and snooker groups. One participant went to the sauna and the cinema with a support worker and another went to the gym with a support worker.	153 (77 of which were Alleyah's trip to the gym with her key worker)
Being driven	78 (77 as above)

Everyday settings	6 (all were trips with a support worker)
Holiday	19
Socialising outside of support settings	4 (these were taken by the same person at a Halloween party)
Friends	20
Family	24
Self	29
Attractions/visits	34 (all were either support settings or with a support worker/carer)
Street scenes/roads	90 (76 were of Alleyah's trip to the gym)
Sky	3
Total	**479**

Objects	**Number of photographs**
Beds	5
Televisions	23 (21 of Alleyah's television)
Collections (teddy bears, snowman pottery, tapes and dvds)	2
Awards	3
Religious objects	9
Clocks	1
Computers	4
College folders	3
Bookshelves	9
Sofas	3
Exercise equipment	40 (all of Alleyah's treadmill)
Hobbies (train spotting, sports, model making)	11
Gas fire	3
Christmas decorations	12
Kitchen objects	1
Cassette player	1
TV guides	1
Food	11
Family photos in frames	5
Cleaning items	1
Fish tank	1
Total	**149**

Interpretive engagement analysis

Photographs have multiple layers of meaning and can mean different things to different people (Drew and Guilemin 2014). For this reason each stage of the interpretive engagement analysis of the photovoice findings highlights an additional layer of meaning allowing both the image as a symbolic representation and the social and cultural norms that inform them to be considered.

Stage one: participant talk about their photographs

This stage of analysis reveals a particular layer of meaning in terms of how the participants understand their photographs. Emphasis is placed on the images the participants have produced and their talk about them (Drew and Guilemin 2014). The aim here is not to interpret or theorise the participants' talk and images but to present them as interpretations in their own right (Drew and Guilemin 2014). At this stage the participants with learning disabilities' construction of learning disability appears to be much the same as the focus group participants. The content of the photographs and the participants' talk about them present learning disability to be a broad term, and show the lives of the participants to be 'happy' [Student Social Workers (a)] and 'full of hobbies' [Student Teachers] just as the focus group participants constructed.

As seen in the summary above, the collection of photographs as a whole present a heterogeneous image of learning disability as described when the focus group participants used the *I know what learning disability is/learning disability is a confusing term* repertoire pair. The images show people with different types of learning disabilities, with different interests and ways of living. Some participants liked trampolining, one liked snooker, another liked train spotting, another liked wrecking his room, and so on. Some participants lived independently, some lived in group homes, some lived with parents and one lived with his brother. Some participants relied on wheelchairs, some did not. Some participants were religious, while others were not. Some participants had recently been on family holidays and others had not. This range of content and the heterogeneity that this suggests is not only consistent with the focus groups' initial construction of learning disability but also echoes previous research addressing the lives of people with learning disabilities (Deguara et al 2012, Bane et al 2012, Tilly 2012) whereby it is reported that people with learning disabilities do not form a homogenous group and have different likes and dislikes (Deguara et al 2012).

Similarly, the photographs show the participants leading what appear be 'full', 'fruitful' and 'happy' lives, 'full of hobbies', as described by the focus group participants when drawing on the *people with learning disabilities are the same as me* repertoire. The photographs illustrate a wide range of interests and hobbies, and present an image of the participants having active lives and being surrounded by family and friends. The whole collection of photographs included three family holidays, six Christmas parties, a Halloween party, family get-togethers, train rides, a trip to the cinema, trips to the gym, a family road trip to London and various group based activities such as snooker, amateur dramatics and crafts. It should be noted, however, that the presence of images of a range of activities within the participants' photographs could be a reflection of the recruitment process, whereby the participants were recruited from support groups. People with learning disabilities who already attend a support group are perhaps more likely to have access to such activities than people who are either not in receipt of support or who do not attend such services.

When talking about their photographs the participants expressed happiness and excitement, again mirroring the focus group participants' constructions of learning disability as a happy state of being. The examples below illustrate the participants' enthusiastic talk about their images.

Robert: Ah now that's at Buxton!
Facilitator: Oh, ok.
Robert: Yeah, I went on a rail tour up to Buxton.
Facilitator: So was that the train you were on?
Robert: That's the train I was on, it had [unclear] seats on it
Facilitator: And why did you take this photo?
Robert: Erm, because I liked the tour.
Facilitator: You were having a good time?
Robert: Yeah I was.

Facilitator: Ok let's look at the next one. Ah, your trophies. Can you explain these to us?

Dave: Erm well, the cup was

Facilitator: This one? (big cup)

Dave: yea. The first trophy I won for throwing the javelin when I was throwing the discus and they said 'do you wanna try the javelin?' and I said 'yea'. I wasn't number one but I trained hard and this is just to prove that there was something that I trained hard.

Facilitator: So you threw discus before javelin and then you tried javelin and it turned out you were quite good at it?

Dave: Well I was quite good at everything I did because my trainer said that 'do you want to try hoop?' and I said 'yea I'll try it' and I tried it and he said 'is there anything in sport that you are not good at?' and I said 'not really', because it came from my Mum being, when she was young she was, she ran for the North East and I think I am the only one in my family who enjoys it.

Facilitator: So you got the sporting genes from your Mum?

Dave: Yeah.

Facilitator: What's this one? (Shield to the left)

Dave: Erm that's for doing a bit of canoeing and we had a bit of a competition and we still do canoeing now to see how quickly we could go. And they said 'have you got an engine in your canoe? you're quicker than everyone'.

Facilitator: That must make you feel good.

Dave: Erm, well yeah. I'm good at all sports when I give them a try I can just do it. It's why I was the first to play wheelchair basketball with cerebral palsy, we have been all over playing.

Facilitator: There's your Mum.
Kay: Yeah!
Lorna: Was it cold?
Kay: Yeah, it was windy.
Support worker: It's a nice sky.

Kay: Yeah I like colour.
Facilitator: Is it at Holkham?
Kay: Yeah.
Facilitator: I like Holkham.
Kay: It was that windy, I thought if I get ma digital camera I'm alright
Facilitator: so how does this make you feel?
Kay: Happy! Cos its my Mum.

Each of these presentations demonstrates the participants' enthusiasm for the content of their images and the part they play in their lives. Their talk explicitly and implicitly alludes to this; both Kay and Robert told me how they feel about the image and what it represents as when Kay says 'Happy!' and Robert told me he was having a good time. Dave's enthusiasm is seen in his lengthy talk about the image. Both Dave and Robert spoke at length throughout the photo sharing session about their respective interests in sports and trains. Of Robert's 28 photographs, 12 were of trains that he had spotted at various locations. Dave unfortunately had been ill with a cold over the week he had the camera and so hadn't managed to take any photographs of the training sessions he attends. He told me that had he not had the cold, he would have taken as many photographs as he could at these sessions.

While the above suggest happy emotions, one participant did begin her talk about her set of photographs by saying that all of her photographs were boring. As demonstrated in the extract below, this was not because she thought her life was boring in general.

Lorna: All of mine are boring.
Facilitator: Don't worry boring can be interesting, there is lots to say about boring.
Lorna: I just went round my house taking pictures. I did take a picture of some cooking!
Facilitator: Well that's not boring, I love cooking.
Lorna: If you had asked me to do it next week I'd have loads to say. Next week I'm going to Alton Towers, I'm going on a treasure hunt, I'm going out for dinner and then I'm going to see Jessie J! I'm well busy next week.

Lorna’s talk shows that her life isn’t ‘boring’ but that she has a very busy social life, not reflected by the atypical quietness of the previous week.

In all of the examples presented above, the photographs and participants’ talk firmly aligns this presentation of the reality of learning disability with the focus groups’ construction of the lives of people with learning disabilities as ‘full’ and ‘fruitful’. People with learning disabilities are seen to have hobbies and supportive families just as the focus group participants described. Their talk further emphasises this consistency, in that the participants talk about enjoying themselves, being ‘happy’, and being ‘good’ at things. Importantly, the images show the participants with learning disabilities doing things that people without learning disabilities might do, further affirming the focus groups’ use of the *people with learning disabilities are the same as me* repertoire.

In addition to their talk demonstrating ‘full’ and ‘happy’ lives, in all of the photographs of the participants themselves, they are either visibly happy with smiles on their faces or they are engaged in their hobbies, as seen in the three examples below.

Participant smiling

Participant smiling at a Halloween party

Participant engaged in drawing, her favourite thing to do.

None of the photographs of the participants showed emotions other than happiness, enjoyment and enthusiasm. While this image of people with learning disabilities echoes the focus groups' construction of how people with learning disabilities experience life, it also implicitly negates their use of the *people with learning disabilities are the same as me* repertoire. It is unlikely that the focus group participants would report their own lives to be full of joy at all times. The construction of people with learning disabilities as ubiquitously happy, however, allows the focus group participants to maintain their 'good person' status. Acknowledging the specific frustrations that people with learning disability encounter (Shelly 2008) would necessitate talk about differences that the focus group participants were less willing to consider.

As well as showing how learning disability is experienced, the photographs also facilitated talk about how the participants who could express their thoughts verbally understand the term learning disability. The participants' talk about this was also heterogeneous. Some of the participants talked about the broad nature of learning disability, some talked about people with learning disabilities being the same as people without learning disabilities, some talked about the stigmatising consequences of the label and some talked about the difficulties that having a learning disability can present. The participants' talk often mirrored the focus group participants' constructions, particularly when drawing on the *people with learning disabilities are different to me* repertoire to frame difference as an equalising characteristic. Some of the participants' talk, however, challenged this repertoire by presenting learning disability as something that can be very difficult. Each of these differing constructions are presented and discussed below.

Learning disability is a broad term

When discussing their photographs, the participants talked explicitly about the broad nature of learning disability, just as the focus group members did. Like the focus group participants, the participants with learning disabilities talked about having friends and family members with learning disabilities and discussed how their learning disability can differ to their own. Such talk can be seen in the two extracts below.

Kay: Because I've got a learning disability. And Jessica, she can speak but she can't say what's wrong with me.
Facilitator: So she has got a different type of learning disability to you?
Kay: Yea. Cos she was saying 'where is my Mum today?' and I was trying to tell her something but it din't work very good because my my speech was terrible today, urgh. [Digression about another activity omitted]. I'm really learning difficult, I am.

Here, Kay is talking about one of the photographs she had taken of her best friend Jessica. Jessica also has a learning disability. Kay clearly states that she identifies with the label learning disability, stating 'because I've got a learning disability' and 'I'm really learning difficult'. She is also aware that learning disability comprises different levels of ability and uses her friend Jessica as an example; telling the group, 'she can speak but she can't say what's wrong with me'. Indeed, the photograph of Jessica (see p.273) shows a person with different needs to Kay.

In the following extract, Alleyah is talking about a photograph of her brother and sister which has prompted her to talk about her wider family, including her cousin who also has a learning disability.

Alleyah: I know, I know because my, my cousin, he is more disabled. Soon as I see him he is more disabled than me.
Facilitator: And does he have a learning disability?
Alleyah: Yeah. Worse, than me.
Facilitator: Yeah.
Alleyah1: I have to do one to one with him if I visit. I can't leave him on his own, I have to sit with him. At dinner time or break time, all the time. In the sports stand I have to be with him, like in Guajarati, because he doesn't understand English or anything.
Facilitator: So would you say, there are different types of learning disability?
Alleyah: Yeah. He is married but he doesn't know why he is married.

Here Alleyah uses the example of her cousin to show her knowledge that learning disability is a broad term that incorporates different levels of ability. She tells the group that her cousin has a learning disability ‘worse than me’ and demonstrates this by talking about the level of support he requires and his lack of understanding.

Learning disability doesn’t make you any different to anyone else.

The participants with learning disabilities’ discussion of learning disability also mirrored the focus groups’ construction of learning disability as an equalising characteristic, as when Mainstream Teacher 3 said ‘we’ve all got needs’ and Social Care Provider 1 said ‘we all have something we can’t do’.

In the extract below, Lorna is sharing her thoughts on having a learning disability.

Lorna: I just think everybody has got one. We’ve all got something wrong with us. We’ve all got, you know, ok that is the name for people who have got disabilities but erm we’ve all got something wrong with us.
Facilitator: That’s true.
Lorna: We’ve all got something we can’t do.

Here Lorna’s talk can be seen to be identical to the focus group participants’ framing of difference as an equalising characteristic when drawing on the *people with learning disabilities are the same as me* repertoire. In much the same way as the focus group participants expressed that ‘people are people’ and ‘we all have needs’, Lorna tells us ‘we’ve all got something we can’t do’ and ‘we’ve all got something wrong with us’. Lorna’s talk further echoes the focus group participants’ in that the difference that she shows as equalising is framed in terms of deficit, things that are ‘wrong with us’ and things ‘we can’t do’. Indeed the medical model featured implicitly throughout the participants with learning disabilities talk just as it did in the focus groups’ talk, as demonstrated below.

Learning disability is an individual problem

When talking about their knowledge and experience of having a learning disability, the participants who could verbally communicate tended to talk in terms of an individual problem that they all live with. Such talk is demonstrated in the extracts below.

Dave: 'When I hear people saying it [learning disability] I just think well, it's a problem that for some reason I've got'.

Kay: 'I've got a learning disability…I'm really learning difficult, I am'.

Donna: 'We've all got something wrong with us'

Hassani: 'Too disabily, I [means for] work [referring to herself]'

In each of these extracts, learning disability is located within the individual and is framed in terms of something that they own, as illustrated in their use of 'I' and 'we' to prefix their talk about learning disability. In addition to this, learning disability is also framed in terms of deficit; it's a 'problem', it's a difficulty, it's something that is 'wrong' and it's something that prevents things like working. As with the focus groups' use of the *I know what learning disability is* repertoire, the participants' talk here is reflective of the discursive dominance of the medical model within their shared social and cultural worlds. The participants did not talk explicitly about the cause of their learning disability, whether social or biological, rather their talk demonstrated their acceptance that learning disability is something negative that is part of them. This presents a direct contrast with the focus group participants who worked hard to gloss over the potentially negative aspects within the lives of people with learning disabilities.

Learning disability is a confusing term

Some of the participants with learning disabilities talked about the confusion that the term learning disability can cause for other people, as when the focus groups drew on the *learning disability is a confusing term* repertoire. Dave's thoughts on the term learning disability below, exemplifies this commonality well.

> Dave: It's a problem that for some reason I've got and some can explain more than others. Some are more open and aware to my disability more than others. To me when I hear learning disability I just think well that's something I've had to grow up with having and I've overcome barriers that I've had to overcome and I've become with the family and friends of mine who have supported me through the disability. I think the word learning disability, it's a bit hard to try and explain sometimes you hear it and you think 'do you know what, what disability is?'

Here, Dave is telling the group that learning disability can be a confusing term that can be used incorrectly, just as the focus group participants discussed and feared when drawing on the *learning disability is a confusing term* repertoire. He tells the group that while learning disability is something he has grown up with, it can be 'a bit hard to try and explain' and that 'some can explain more than others'. He also talks of the confusion of others by talking about his thoughts when he encounters such confusion, telling the group that he thinks to himself 'do you know what disability is?' In doing so, Dave casts himself in a position of increased knowledge; in growing up with a learning disability and becoming the person that he is, he knows what learning disability is and finds the confusion of others annoying at times. Here Dave demonstrates the reality of the focus group participants' fear: in getting it wrong they really can be seen to be 'ignorant' [Local Authority Councillor 2]. Dave, however, does recognise that even though he knows what learning disability is, it 'can be a bit hard to explain'. Here, Dave's talk mirrors the *I know what learning disability is/learning disability is a confusing term* repertoire pair, in that although Dave knows what learning disability is, 'It's a problem, that for some reason I've got', it can be hard to explain.

Learning disability is a stigmatising label

The participants with learning disabilities' talk was also similar to the focus groups when they talked about the stigmatising consequences of being labelled as a person with a learning disability. It is here that the participants' talk mirrors the focus groups' use of the *I don't like labels* repertoire, to construct disability as a stigmatising label. The extract below provides an example of this.

Dave: Yea and I, my family are fed up of people in general talking to my Mum or sister and they say, 'he has got a head on his shoulders and he can speak'. Because they'll ask my Mum how I am.
Facilitator: Even though you are there with her?
Dave: yea. They're talking over me head. You want to say 'well I am here! I have a mind too!' I think a lot of the negative people and parents, they haven't told their children about disability, that you could wake up with a disability.

In this extract, Dave is telling the group about the frustrations he has experienced as a consequence of other peoples' reactions to his learning disability. Other people, people who Dave refers to as 'negative people' and 'people in general', fail to include Dave in conversations that address himself when he is present. The 'negative people' and the 'people in general' have made assumptions about Dave based on their lack of knowledge of his disability. Dave talks about the dehumanising effect of this by telling the group that he feels like saying ‘I am here! I have a mind too!’ Here Dave’s talk confirms the focus group participants’ fear when using the *I don’t like labels* repertoire to construct learning disability as a stigmatising and dehumanising label. Dave’s talk in this extract, is also consistent with the focus groups’ use of the *people with learning disabilities are different to me* repertoire to frame difference as a consequence of other people’s lack of knowledge. The ‘negative people’ and the ‘people in general’ do not associate Dave with someone who ‘has got a head on his shoulders’, ‘who can speak’ and who has ‘a mind too’, resulting in his dehumanisation and exclusion from conversation.

Having a learning disability can be hard

In contrast to the similarities between the participants with a learning disability and the focus groups’ constructions of learning disability discussed above, the participants’ talk also challenged the focus groups’ constructions, in that their talk revealed differences that the focus groups glossed over as equalising. The following extract exemplifies such differences.

Emma: It’s hard because people don’t understand you. Like when you are in hospital or anything like that.
Facilitator: Do you mean hard with communication?
Emma: Yeah, cos whenever I go into hospital they automatically get told [that Emma has a learning disability] and they [learning disability support workers] come down to see me.
Facilitator: And if you didn’t have that now, what do you think would happen?
Emma: Yes, cos they are horrible to ya.
Lorna: They were a bit abrupt at one point. One woman just came in shoved something in her face and we were like ‘what the hell is this?’
Emma: Kept shoving morphine and whatever down me and I din’t realise.
Facilitator: Without telling you?
Emma: Yeah until I told them I had learning disabilities to the lady that came and seen me and she had a go at them.
Facilitator: So they weren’t communicating with you like you felt they might with someone else without a learning disability?
Fiona: No and then they made my learning disability lady really cross.

In this extract, the first difference that becomes apparent is the fact that Emma is often in hospital as when she says ‘whenever I go in to hospital’, implying that this is a normal and regular occurrence. The second difference that is highlighted is that Emma has experienced being treated differently as a result of her learning disability rather than factors external to it, as constructed by the focus groups. Because of this, Emma starts this extract by sharing that learning disability is ‘hard because people don’t understand you’. Unless referring to people with profound and multiple learning disabilities, the focus groups did not include adjectives like ‘hard’ in their constructions of learning disability, instead referring to ‘fruitful’, ‘full’ and ‘happy’ lives. Emma’s (a woman with a mild learning disability) talk, moreover, is in direct contrast to the focus groups’ positive constructions.

Similarly, Haasani’s talk about a photograph of her sister, also challenges the focus groups’ positive construction of learning disability.

Haasani: Sometime, I hope to work a carer at home. I also can’t job home. I am family. Too disabily I work.
Facilitator: Some day you hope to be a carer, Haasani?
Haasani: Yea, erm I love to help somebody else because er it’s not fair that I can see Bhavika [Sister]. Sister and is she an is Bhavika a she’s college, she’s at work. It’s not fair she work.
Support Worker: It’s not fair?
Haasani: Nooo she is working and is help somebody.
Support Worker: Are you saying you have done nothing wrong so why do people treat you differently, why can your sister work and you can’t?
Haasani: Yeah Hhhhh.
Facilitator: You would like to go to work like your sister does?
Haasani: Yeah.

In this extract, Haasani is sharing her frustration at not feeling able to achieve her hopes to be a carer. Haasani has moderate learning disabilities and requires quite a lot of support in her everyday life. She is not able to prepare her own meals and cannot use public transport on her own. Consequently, the option of being a carer would not be possible for Haasani. Haasani knows this, she tells the group that she is ‘too disabily I work’. She also tells the group that ‘it’s not fair’, revealing the frustration she feels about this. Hassani’s unemployed status, therefore, can be seen to be a consequence of her cognitive ability and need for support rather than the structural barriers outlined by the focus groups.

At this stage of analysis the content of the photographs and the vast majority of the participants’ and carers’ talk about them appear to be generally consistent with the focus groups’ construction of learning disability as a broad term, a negative label and a happy way of being. As seen, however, some of the participants’ talk differed significantly from this construction, revealing learning disability to be ‘hard’, ‘not fair’ and to cause feelings such as frustration and being ‘fed up’. The injustice of having a learning disability, the options that are closed to people with learning disabilities and the frustration that this can cause for people with learning disabilities is not something that the focus groups considered for long in their talk. The focus group participants in contrast tended to frame such differences as equalising, as when Student Social Worker 1 said ‘well that’s just life, life isn’t rich all the time for any of us’. As discussed in the discourse analysis chapters, considering these differences further would have challenged their ‘good person’ status.

Stage two - researcher analysis

The challenges revealed at stage one of the analysis are further emphasised at this second stage whereby the focus of analysis shifts from the participants’ interpretations to the researcher's. This shift in focus is designed to facilitate the development of themes and relationships within the data corpus. In general, the content of the photographs and the participants' talk about them, revealed significant differences in the lives of people with learning disabilities in comparison to the lives of people without. These were differences that can sometimes be explained by the structural, social and cultural barriers discussed by the focus groups, but were also differences that challenge this thought process.

The following themes were observed in the content of the photographs and the participants' talk about them:

- The dominance of support settings.
- Distinct absences in content.
- The portrayal of multiple ways of being.
- Bodily difference.

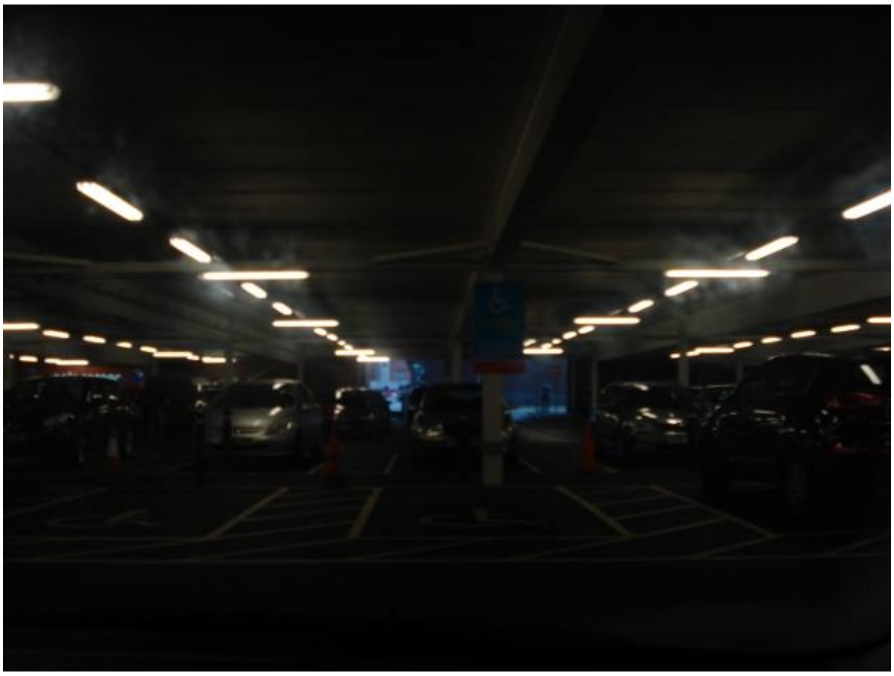
Each of these themes are discussed below.

The dominance of support settings

As seen in the summary on pages 239-241 the majority of the photographs taken showed support settings, including: learning disability support groups such as - craft groups, a drama group, a snooker group, and a walking group; trips out with key workers; family home life; trips to the cinema and gym with carers; and day centres. The photographs taken at home have also been included as support settings for the reason that the majority of the participants either lived in the family home or in a group home. While some of the participants were young adults, the average age of the participants was 30 years old. By 30 years old the majority of people without learning disabilities do not live in the family home (ONS 2012). Only two participants lived independently, however both received some degree of support with their household management.

While some of the photographs of support settings were obvious, such as the photographs taken in day centres and support groups, it was not always obvious that other photographs were taken in support settings, such as the photographs taken from passenger seats in cars and photographs taken of scenery and public places. The participants' talk about their photographs added this layer of meaning. At face value most of the photographs taken in support settings could be considered to show images that would also feature in the lives of people without learning disabilities, such as shopping, going to the gym, family, friends and hobbies. The participants' talk about the images and the researcher's interpretation, however, reveal significant differences between the lives of people with and without learning disabilities. The two images discussed below provide examples of this.

A jewellery sale



Tesco car park

Both of the photographs presented show images related to shopping, something that people generally experience as part of their everyday lives. From this perspective it could be said that the lives of the participants who took the photographs are no different to the lives of people without learning disabilities. The photograph of the jewellery sale could lead some observers to draw the conclusion that the photographer has ‘a better life than mine’ [Parent Carer 3], in that he has the time and money to attend a jewellery sale. The participant’s carer’s talk, however, provided further detail that highlighted a number of differences that challenge the focus groups’ construction of learning disability as a bodily experience no different to any other body’s experience.

The photograph of the jewellery sale was taken by a support worker on behalf of Mark, one of the participants with profound and multiple learning disabilities. The support worker provided the following detail about the photograph: ‘this is a jewellery sale at [group home where the participant lives]. We get people to come in and have stalls with gifts that the residents can buy for Christmas presents for people’. This detail gives a different meaning to the content of the photograph. The photograph is now re-contextualised in a support setting, the participant’s group home. The shopping experience has been brought to him in his own home and this experience has been organised by someone else because the residents cannot easily access shops. The participant’s Christmas shopping choices are, therefore, limited in a way that would be unusual for someone without a learning disability.

The photograph of the Tesco car park was taken by Tom, a man with a mild learning disability, who lives independently and who drives his own car. Tom told the group that he took the photograph ‘because I do my shopping every week with my key worker’. He also told the group that his car is parked in the car park and that he drives with his keyworker to the supermarket each week. Again, Tom’s explanation of the photograph provides an extra layer of meaning to its content. While shopping at a large supermarket is a weekly experience for many people, attending the weekly shop with someone who is paid to support you in doing it, is not.

Each of these photographs and the participants' talk about them transforms their initial presentation of a more or less everyday shopping experience into a shopping experience that is circumscribed as a consequence of their learning disability. Both photographs present positive images that could be interpreted to show choice and relative independence in the lives of the participants as the focus groups discussed: Tom is able to do his weekly shop with the support of a key worker and Mark can choose Christmas presents he likes the look of. The everyday experience that shopping is, however, is significantly different for these participants. This level of difference is glossed over by the focus groups in order to maintain their 'good person' status.

Absences

There were also notable absences in the subject matter depicted in the participants' photographs. As Drew and Guilemin (2014) point out, the content of participant generated photographs is deliberately chosen by the participant. The participant photographers are able to choose what they take photographs of, and conversely, what they do not. While this is a benefit of the photovoice method because it allows for a rebalancing of power relations between the researcher and the participants (Booth and Booth 1997), it is also important to be cognisant of why the images do not show certain things.

The exclusion of certain subject matter of the participants' choosing may be a deliberate choice on the part of the participant (Drew and Guilemin 2014); however, in the case of people with learning disabilities, it should also be noted that it might also be a consequence of circumstance. For example, not being able to get to a place they would like to photograph due to a lack of transport. For this reason, the participants were all asked if there was anything they would have liked to have taken photographs of but couldn't. Only one participant reported that this was the case. Over the week he had been debilitated by a cold which had prevented him from taking photographs of himself at basketball training because he hadn't been able to attend the session.

While the participants did not note absences in their collections of photographs themselves, there are a number of notable absences from an observer's perspective. Of the 461 photographs, there were no images and very little talk of partners, independent living or employment. Only two participants lived independently, one participant had a partner and only one participant was in paid employment (this was the same participant). When the participants talked about children, it was always with reference to family members' children. When asked about partners and sexual relationships, all of the participants who could respond reacted by giggling and showing embarrassment. Consequently, the participants spoke very little about relationships. One participant had a long term boyfriend and another had been in a relationship in the past but this had ended, he reported that this was due to his girlfriend's parents' disapproval of him being a wheelchair user.

As seen in the previous three chapters, the focus group participants did address some of the differences missing from the participants' photographs, however, these differences were framed as equalising and a consequence of social and cultural barriers. In light of the themes discussed, however, to claim that the lives of people with learning disabilities are the same as the lives of people without is not reflective of the reality presented here.

The portrayal of multiple ways of being

The content of the participants' photographs and their talk about them showed multiple ways of being that differed between themselves and highlighted differences when compared to the lives of people without learning disabilities. This is not to say that there are not multiple ways of being for people without learning disabilities, but rather to make the point that the photographs highlight difference that the focus group participants either framed as social constructs or as equalising in order to manage and gloss over their presence. The different ways of being shown in the photographs provide a contrast to the homogenous way of being constructed for all people by the focus group participants and challenge the focus group participants' construction of sameness. In order to show this, three challenges are presented and discussed below.

1. Friendship.

Knox and Hixon (2001) tell us that friendship is commonly seen as a stronger relationship than an acquaintanceship. When exploring friendships among adults with learning disabilities living in residential homes, Emerson and McVilly (2004) included the following activities as being commonly associated with friendship: having friends to stay and staying over at their houses; having friends over for food; eating out with a friends; going out for the day with friends; and being visited at home by friends. Images of friends did not feature very often in the participants' photographs. When the participants' photographs did show images of people they told the group were their friends, however, the concept of friendship, as suggested above, was expanded to include relationships that might not typically be considered friendships.

The images of friendship generally showed other people with learning disabilities in support settings, such as other people with learning disabilities attending the same craft group. For people without learning disabilities, peers in hobby groups can of course become friends: however, those only seen in these settings are more likely to be afforded the status of colleagues, acquaintances or associates. This is not, however, to say that the people photographed as friends are not actually friends, rather that the concept of friendship differs. A photograph of Kay's best friend and Kay's talk about her provides a good example of the concept of friendship found within the participants' images and talk.

Kay's best friend Jessica

Kay placed great emphasis on the status of her friend Jessica as her best friend; she repeatedly told me that Jessica is her best friend. When we spoke about Jessica, Kay told me that they met at their day centre where they see each other once a week. Kay and her best friend had never seen each other socially or otherwise outside of the day centre. Kay didn't know where her best friend lives, if she lives with her parents or elsewhere. Despite this, Kay demonstrated a strong affection for her best friend, repeatedly referring to her as a 'brilliant woman'. Kay lives at home with her parents and depends on them a lot for support. By virtue of the circumstances created by both Kay and Jessica having a learning disability, their capacity to develop their friendship beyond the confines of the support group they attend is very limited. It is not easy for Kay or Jessica to invite each other over for dinner or to go out on a day trips, as Emerson and McVilly (2004) suggest is typical of the behaviour between friends. Indeed, as Kay told me, activities like this did not feature in her friendship with Jessica. For Jessica and Kay to eat out together or to go on a day trip together, for example, a number of other people and supports would need to be involved. Neither Jessica nor Kay can use public transport on their own and it is unlikely that either of them would be able to negotiate the financial side of eating out or going on a day trip. Nor is it likely that they would manage the geographical aspect of these activities alone, such as finding the restaurant. In addition to this, it is likely that a changing places facility would be needed for Jessica. For all of these reasons, Jessica and Kay would be unlikely to be able to manage the typical activities of friendship alone. If either Kay or Jessica stopped attending the support group, their friendship would be over.

Throughout the participants' and the carers' talk about the photographs the category 'friend' was often applied to people only seen at support groups by virtue of them both having a learning disability. When talking about the friendships among the participants with profound and multiple learning disabilities, the terms friend and resident were used interchangeably to discuss the relationship between the participants and the people they share the group home with, as can be seen in the example below.

Facilitator: Lydia looks happy in this photo.
Carer: Yeah she was happy to see Ross. I think he had just whispered in her ear.
Facilitator: Do they live in the same house?
Carer: No Ross lives in the other bungalow.
Facilitator: So are they friends?
Carer: Yeah they get on she gets on with them all really especially the boys.
Facilitator: So she likes Ross?
Carer: Yeah, I think he is the favourite resident at the minute.

In this example, Lydia is smiling as a result of interacting with Ross, her ‘favourite resident’. Ross and Lydia, however, only get to see each other at organised events such as the Christmas party shown in the photograph. As with Kay and Jessica’s friendship, Lydia and Ross’s friendship is facilitated by others both in its beginning and in its development. Both Lydia and Ross have profound and multiple learning disabilities. Ross’s verbal communication is limited to ‘yeah’ and ‘no’ and Lydia cannot verbally communicate at all. Consequently neither Lydia nor Ross can ask each other round for dinner, to go on a day trip or just to visit. This is a restriction of their cognitive ability and also of their circumstance in that they are dependent upon other people to facilitate their friendship.

Only six photographs showed images of the participants' friends outside of support settings. These photographs were all taken by three participants, and three of the six images were of the same participant's (Kay) parents' friend. Only one of the participants (Robert), notably the most able of the participants, talked about having friends from school that he sees socially on an occasional basis. This participant's collection of photographs contained images of him and his old school friends at a Halloween party that had taken place at a friend's house. The photograph below shows one of Robert's friends at the party.

When asked to explain what this photograph showed, Robert said the following:

Robert: That's my friend dressed as Freddy Krueger (Laughing)
Facilitator: Was it for Halloween?
Robert: Yeah at a party at my friend's house.
Facilitator: How do you know your friend?
Robert: From School
Facilitator: So you are all friends from school?
Robert: Yeah from [name of mainstream school]

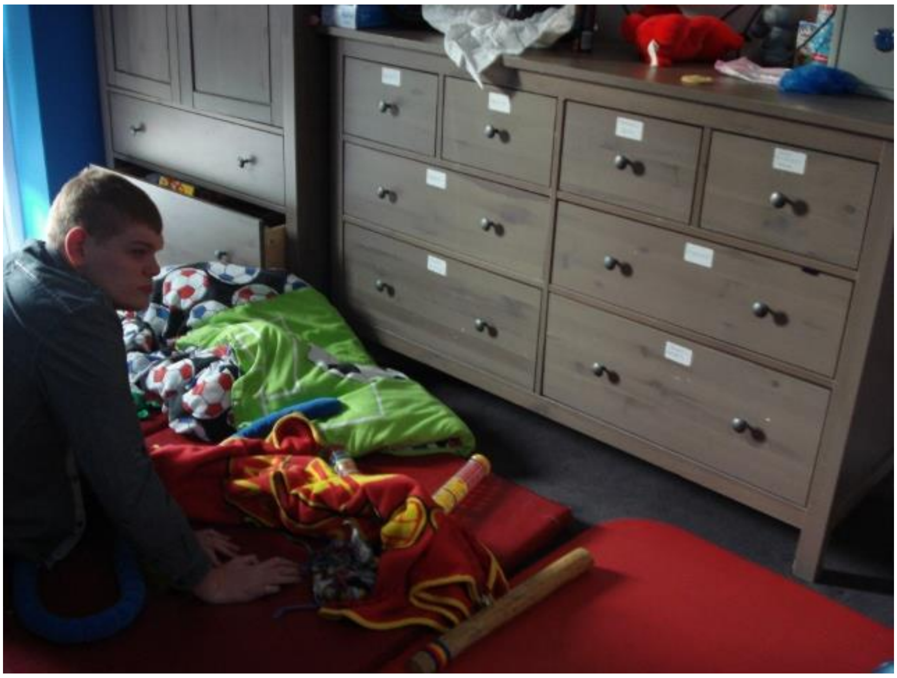
Here it can be seen that Robert's friendship with his school friends follows the definition of friendship presented above. Robert's photographs and talk, however, were a one off. None of the other participants' or their carers' talk presented friendship in this way.

In the main, the participants' photographs and their and their carers' talk about them shows that the commonly held concept of friendship is altered due to circumstance/limitation. Fundamentally, the participants' lacked agency over their friendships. Often the participants were only friends with the people they called friends because they attended the same support group or lived in the same accommodation. Not only are their friendships unable to spread beyond the confines of where they began, they are also limited as to where they can begin and when they end. By virtue of their different ways of being, friendship is experienced differently among the participants with learning disabilities.

2. Space

As stated, all but two of the participants lived with family members or in group accommodation. As a consequence the only private space they could occupy or photograph was their bedrooms. Only a few participants took photographs of their bedrooms; the photographs that were taken show that even the participants' bedrooms are not entirely private spaces but rather are shared spaces that other people also use with regularity. The images below show how this was presented and talked about.

Theo’s bedroom



Tim’s bedroom

In many ways both Tim and Theo’s bedrooms are organised in a similar way to what might be expected of other young adult men. Both rooms contain typical bedroom furniture. In Theo’s room there is art on the wall, there are alcoholic spirits on his chest of drawers, there are trainers by the bed and there is an ‘I heart NY’ mug. Although Theo has a single bed, many young adult men sleep in single beds. If living in a bedsit, in student halls or even still in the family home the beds are likely to be single. Theo's bedding could be thought to be childish, however, many adults retain an interest in comic book characters such as Spiderman. While most people's bedrooms are tailored to their own need i.e. some people use an alarm clock to wake up in the morning, some people have a reading light by the bed etc, the tailoring of Theo's and Tim's rooms, however, reveals fundamental differences about what their bodies can do. Moreover, Theo's bed has a strap to stop him falling out and it can be raised up and down as needed; and Chris has padded mats on his carpet to protect him from carpet burning his face. Such features would be unusual in the bedrooms of young men without learning disabilities.

In addition to these slightly unusual features, when looked at closely both Theo and Tim's private spaces are also organised around the needs of other people. It is this that highlights a fundamentally different way of being. In both rooms the chests of drawers are labelled to show what they contain. This is not for Tim or Theo's benefit, since neither of them can read let alone comprehend the abstract concept of tidying up. The labels are for Tim and Theo's carers. Both Tim and Theo also have locked medicine cabinets in their rooms. Again, these are not for Tim and Theo's use but are for their carers use. In Theo's room there is a wall file containing what his carer told me are his 'notes'. His carers complete these notes and refer to them amongst themselves. Once again the notes are not in Theo's room for his own use but for the ease of other people who also occupy his private space.

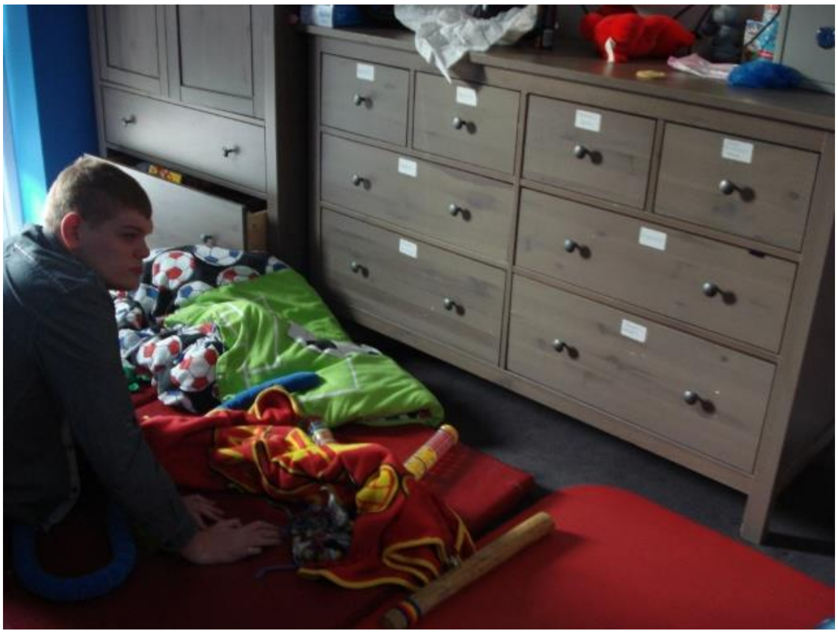
Because the vast majority of participants did not photograph their bedrooms, it is impossible to comment on how they were organised. The images shown, however, present a different organisation of private space than might typically be expected of such spaces occupied by adult men.   Such organisation is both a reflection of the way of being lived by Tim and Theo, that of requiring support for all aspects of life, and also of the organisation of the care both Tim and Theo receive in their group home.   Their bedrooms are organised so as to promote independence, for example Theo's carer told me that he was able to choose his bed sheets and Tim's carer told me that Tim had chosen the colour on the walls, however, by virtue of their cognitive and physical needs both of their bedrooms must be organised to accommodate the significant presence of other people.

3. Activities

While many of the participants' photographs showed them engaging in the activities that the focus group participants' associated with people with learning disabilities, such as hobbies and family life, these photographs and the participants' talk about them often revealed aspects that were related to the needs presented by their cognitive ability; something the focus groups glossed over. The photographs discussed below present examples of how this was so.

Jessica at her support group

In this photograph Jessica can be seen to be wearing a full body bib, holding a beaker designed for children. When talking about this photograph, Kay told me that Jessica is ready for lunch. While Kay did not tell me this, it is likely that Jessica wears a bib and drinks from a beaker because of the physical manifestation of her learning disability. The bib and beaker will help to prevent her from getting her clothes dirty while also allowing her some independence when eating and drinking. The way that Jessica experiences the act of eating therefore, is different to the way that the focus group participants are likely to experience this, by virtue of her learning disability and her social circumstances. In other words, Jessica's learning disability prevents her from eating/drinking without spilling and her social circumstance allows her to manage this via the use of supports like a bib and a beaker. A similar pattern in seen in Tim's photograph below.



Tim in his bedroom

Tim's carer's talk transformed this image of a man in his bedroom into an image that shows a particular way of being. As discussed above, Tim cannot verbally communicate. His carer described him as having 'a lot of autism'. He also told me that while Tim can no longer walk, he can crawl for a short distance. When asked to describe what is happening in this image, Tim's carer told me that one of Tim's favourite things to do is to 'wreck his room' and that this photograph shows Tim in the process of doing so. His carer told me that Tim loves to pull his bed sheets and duvet from his bed and throw them on the floor and that he pulls things out of drawers and his wardrobe and throws these onto the floor too. In addition to showing Tim wrecking his room Tim can also be seen to be sitting on all fours on a red mat. I asked Tim's carer why Tim has these mats in his room and he explained that the mats are there to stop Tim from rubbing his face on the carpet. When I asked why Tim rubs his face on the carpet, his carer said he thought it was because Tim has under floor heating in his bedroom and he likes to feel the warmth on his face. For Tim, wrecking his room is part of his normal life. It is something he enjoys doing, something he does often and something that is a consequence of his learning disability. Tim does not have the cognitive ability to understand that wrecking a room is not generally considered to be acceptable behaviour in an adult. Although none of the focus group participants spoke about wrecking a room, based on social norms addressing adult conduct, it is unlikely that any of them do this on a regular basis. Because of their cognitive ability it is more than likely that they know that this is not usual behaviour for an adult and that it would have consequences if they did it. Tim's way of being is not the same as the focus group participants' nor is it the same as some of the other participants with learning disabilities. This, however, was not considered by the focus groups who, as stated, constructed learning disability in terms of heterogeneity of interest and sameness of being.

Mitesh's weekly visit to a sauna also exemplifies how life for people with learning disabilities can be different to the lives of people without learning disabilities.

This photograph shows the park Mitesh walks across to get to the sauna he was visiting. When asked to explain what the photograph shows, Mitesh told the group that he was on his way to the sauna with his support worker and that this is something they do together every week because it is something Mitesh enjoys. While going to the sauna is something that many people without learning disabilities do, most people without learning disabilities do not go to the sauna with someone else who is paid to accompany them. Mitesh's support worker helps Mitesh to negotiate the social norms of attending a sauna, such as paying at reception and putting your clothes in a locker. Mitesh requires this support because of his cognitive ability.

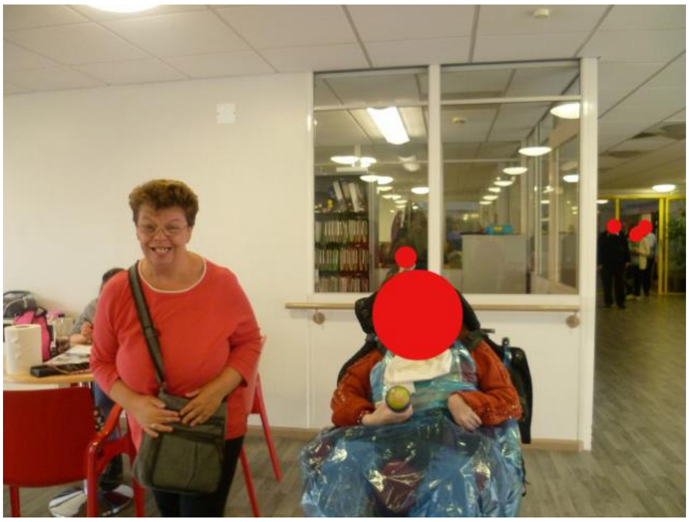
In all of the images and talk presented in this section, moreover, learning disability as a material and embodied reality is present. While all of the examples undoubtedly are influenced by social, cultural and environmental factors, learning disability is also revealed as a factor in the differences presented. The interaction of the learning disabled bodies in the settings discussed and the embodiment of different ways of being cannot be denied. Moreover, the photographs shown here challenge the focus group participants' social construction of difference and reveal the additional need to acknowledge the role of the body. This need is discussed further in the section below.

Bodies

Within the focus group discussions, bodily difference was conspicuous in its absence. It was widely agreed across the focus groups that learning disability does not present physically as when Social Care Provider 4 said 'differences, they are hard to come by, it's not a physical thing and you can say yeah, they can't hear or they can't see erm, in the case of some impairments, you can't see them so its kind of difficult to measure what the differences are'. Nor was learning disability considered to be something that can be identified visually as when Student Journalist 1 said: 'if someone says something to you then you might start to notice it but erm I don't think that erm just on appearances that you would notice anything different'. In contrast to this, such difference was clearly visible in the participants with learning disabilities' self-portraits. Not all of the participants included photographs of themselves, however, of those who did, their self-portraits show a range of body types that present in a variety of physical presentations as seen in the photographs presented below.

Alleyah (left) with her sister at home

Mitesh at home



Kay (left) and her best friend at a day centre

Theo at trampolining

Ross at a Christmas party.

Dave (in wheelchair) at his walking group

Like the focus group participants, the participants with learning disabilities and their carers generally did not talk about bodily difference. The photographs presented above, however, clearly show a variety of bodies. Each image, presented above, shows a different type of material body. The photographs show bodies that can walk and bodies that cannot, bodies that are shorter than average, bodies that drool, bodies that move pre-intentionally, bodies that need glasses and bodies that are overweight. Of the 16 participants 8 were wheelchair users, only 1 of whom could walk independently for short distances and 5 of whom relied on other people to push their wheelchairs, 5 could not verbally communicate, 2 could not feed themselves, 6 were incontinent, 4 participants' bodies moved pre-intentionally and made pre-intentional sounds and 7 could walk, communicate coherently and perform acts of self-care independently.

While the lack of talk about bodily difference on the part of the participants with learning disabilities and their carers is perhaps a reflection of the normality of bodily difference in their social settings, it is a considerable yet convenient omission for the focus group participants. In not talking about bodily difference, the participants' 'good person' status is easier to maintain. The bodies shown in these photographs challenge this subject position; after all, how is it possible to say that someone with a body like Theo, for example, experiences life in the same way as someone without his cognitive and physical impairments? The images presented, and the participants themselves, moreover, clearly demonstrate the heterogeneous continuum of ability inferred by the term learning disability. While learning disability is a broad term, the material body should not be separated from it. This argument is discussed further in stage 3 below.

Stage three – re-contextualisation and conclusion

This final stage of analysis involves the application of the data discussed in stage two to wider theoretical frameworks. In this case, the findings presented in stage two are applied to the literature discussed in the literature review: namely: models of disability and their intertextuality found within social policy and research; and theories of the body. This stage also serves to bring the analysis to a conclusion.

The previous two sections have identified a disjuncture between the construction of learning disability co-produced by the focus groups and the reality of learning disability presented in the photovoice images and talk. When thought about in conjunction with the literature presented in the literature review, this disjuncture can be seen to have implications for both everyday understandings of learning disability and the application of these understandings to practice, including research and professional practice.

The photovoice findings render the learning disabled body undeniable. The learning disabled body is ontologically present both in the images and the participants', carers' and researcher's interpretations. The materiality of the learning disabled body features in the participants' need for support, their alternative experience of friendship, their private spaces, their behaviour and their physical presentation. In contrast to this, the learning disabled body is relatively absent from the focus group constructions. While learning disability is initially located in individual bodies, the overriding presence of the focus group participants' shared commitment to the 'good person' subject position renders the learning disabled body ontologically invisible. For the focus group participants, the body is the 'elephant in the room'. To talk about the body (inclusive of the brain) and fundamentally to associate difference with the body could compromise their 'good person' status as they have constructed it. The differences that become real as a consequence of the acknowledgement of the bodies and the embodied actions presented and talked about here, rather than the social constructions the focus group participants felt most at ease talking about, challenge their construction of the 'good person' subject position.

The people with learning disabilities shown in the photovoice findings, moreover, bear little resemblance to the people with learning disabilities talked about in the focus group discussions, for the primary reason that their bodies are visible and in most presentations are visibly different. While structural, social and cultural external factors undoubtedly play a part in the participants with learning disabilities' lives, their bodies are also present at these moments. As cited in the literature review, Coleman-Fountain and McLaughlin (2013) tell us that acknowledging that the body is present in all social interaction helps us to know why some bodies are stigmatised and others are not. Further to this, Wendell (1996) also presents disability in terms of the interaction between the biological and the social. In Hassani's talk (seen on p.256), for example, her frustrated unemployed status is a consequence of exactly this. Hassani cannot work because she does not have the cognitive ability to work in a neoliberal economy. Moreover, her unemployment is a consequence of the interaction between her body in terms of what it can do (Coleman-Fountain and McLaughlin 2013) or its limits (Wendell 1996) and external structural, social, economic and cultural factors. Prior to industrialisation and the changes to the workplace and social expectations that this created, Hassani might have been able to contribute to basic roles within family collectives. If very poor, however, she might have died.

As seen at the beginning of the literature review, people with learning disabilities have experienced a long history of segregation, prejudice and mistreatment associated with the medical model of disability. As a consequence recent theories of disability, such as the social model in all its forms have sought to refute the medical model and avoid any connectedness to it. This approach to disability complements popular moral values of fairness and equality. In this way the positive and socially acceptable discourse of the social model is recontextualised in everyday understandings of learning disability found in the social policy and the social scientific research discussed in the literature review and also in professional practice as seen in the focus group discussions. All of these re-contextualisations demonstrate a strong desire to disassociate from learning disability's negative past. The literature review shows how social policy seeks to present people with learning disabilities as 'normal' citizens, how research seeks to promote the voices of people with learning disabilities and their involvement in the research process and the focus group talk shows how professionals work to see people with learning disabilities as the same as everyone else. While a break away from previous damaging approaches to learning disability is of course desirable, this has been at the expense of acknowledging the body and what it can or cannot do. As Wendell (1996 p.45) tells us ‘we need to strike a balance between….thinking of bodies, abilities and limitations as given by nature and/or accident as immutable and uncontrollable and …thinking of them as constructed by society and culture’.

The bodies presented in the photovoice findings do not have to be considered problem bodies that require normalising, as emphasised in a medical approach to disability (Freund 2001). The difference these bodies present, however, does need to be acknowledged. To ignore the presence of the learning disabled body risks further marginalisation. Learning disability cannot be fully understood, supported and empowered without the acceptance and acknowledgement of the body. Policy, research and practice that ignores the body and the differences it presents risks fitting people with learning disabilities into a mould that does not reflect their reality. Acknowledgement of the material body does not require a dualistic biological approach, since biology can be seen as an active basis for being in the world (Williams and Bendelow 1998). In Williams and Bendelow’s (1996) example of pain, discussed in the literature review, the body is rendered ontologically material but epistemologically cultural. The learning disabled body, as seen here, can also be used to show this interaction. The learning disabled bodies in the photovoice findings are present in the world, but the understanding of these bodies is socially and culturally orientated. A clear example of this can be seen in the participants’ understandings of learning disability that reflect both their bodily limits and the discourse of the dominant models of disability. The key finding here, moreover, is that the photovoice images and talk relocate the material body in wider social and cultural contexts. In this way the learning disabled body is liberated from the confines of the medical model, allowing the body to be ontologically present and epistemologically social.

Chapter 9: Conclusion

The research project has sought both to highlight how learning disability is defined by those experiencing the 'real world' of learning disability and also to re-evaluate this epistemological orientation in order to redress some of the associated theoretical tensions discussed. In order to do this the following research questions were asked:

What does learning disability mean in the real world?

(a) How is learning disability theorised and conceptualised in sociological and policy discourse?

(b) How is learning disability understood by both people with learning disabilities and people without learning disabilities who work in learning disability practice or who have the potential to influence this practice?

(c) What is the relationship between the constructions of learning disability produced by participants with and without learning disabilities and how can this contribute to a re-evaluation of sociological perspectives of learning disability?

The argument presented in the literature reviewed, in answer to research question (a), positioned the thesis philosophically. Consequently, the empirical work carried out was based upon two philosophical positioning statements: that learning disability is both an embodied reality *and* a social construct; and that people's views, perceptions, and understandings are meaningful reflections of social reality. In order to answer research questions (b) and (c) a combination of focus groups, photovoice, discourse analysis and interpretive engagement have been used to access situated, empirical evidence of the resources used in the 'real world' to construct understandings of learning disability.

The previous four analysis chapters, moreover, have presented a number of conclusions that help towards the re-evaluation of sociological perspectives of learning disability. In this concluding chapter, the findings outlined in the analysis are summarised in relation to the research questions and also the wider sociological contribution to disability studies that can be made. This contribution is further discussed in relation to the limitations of the study and areas for future research.

Common across the conclusions made in the discourse analysis of the focus group talk was the presence of an overriding shared desire to present as 'good people' when talking about learning disability. The focus group talk constructed this identity in terms of an 'acceptable' and an 'unacceptable' way of seeing learning disability. Whereas the 'acceptable' way was perceived to reflect popular moral values of fairness and equality, the 'unacceptable' way was perceived to reflect an individualised, deficit approach to disability that the participants associated with learning disability's negative social history. Indeed, it has been argued that the focus group participants drew on all of the interpretive repertoires identified in order to manage and maintain this identity.

Each of the focus group analysis chapters presents this identity work in terms of the tensions presented when the participants' ideal encounters the material learning disabled body in general and the brain in particular. In light of these tensions, it has been further argued that the participants' co-produced construction of learning disability is premised upon the prioritisation of the epistemological over the ontological in order to maintain their desired 'good person' identity. Being in the form of the material learning disabled body is necessarily ontologically absent from their understandings of learning disability. As such, the differences experienced by people with learning disabilities are framed as social constructions that can be overcome with the right support.

In chapter 5, moreover, it was concluded that the focus group participants' use the *I know what learning disability is/learning disability is a confusing term* repertoire pair to position themselves as 'good people' who see learning disability in the 'acceptable' way. Indeed, participants used both of the repertoires to frame learning disability as a social construct. Despite their commitment to this standpoint much of their talk implicitly reflected a medical approach to disability. This tension is argued to evidence a re-contextualisation of the theoretical tensions between the medical and the social models of disability presented in the literature review.

In working hard to position themselves as 'good people', the participants can be seen to encounter an ideological dilemma that is based on the tension between their desired identity and their knowledge of learning disability that is shaped by the discourses they seek to reject. In managing this ideological dilemma the participants organise their talk so as to avoid the material body including the brain. Indeed, it is argued in this chapter that the acknowledgement of the learning disabled body presents a challenge to the participants shared desire to identify as 'good people'. When the participants do talk about the body, as when they talk about brains, they remove the material from their talk, instead talking about the brain as an ethereal entity that is separate from both the body and the self. In this way the participants are able to construct their understanding of learning disability in terms of social model principles despite their professional interaction with the learning disabled body and the material reality this presents.

(Mis)understanding of learning disability was presented as a major feature of this repertoire pair that serves to highlight that learning disability is not universally understood by the focus groups. Indeed, it was argued that such (mis)understanding is likely to be a reflection of their ontological rejection of the body from their desired understanding of learning disability.

In chapter 6 it was concluded that the focus group participants draw on the general argument made in labelling theory to further emphasise their 'good person' status. The participants used the *I don't like labels* repertoire to align themselves with the idea that labels have the potential to change a person's self-identity for the worse. In this way the participants are further able to position themselves with their desired self-identity set up in their use of the *I know what learning disability is/learning disability is a confusing term* repertoire pair. Their ideal, however, is challenged when considered in practice. It is here that the participants encounter another ideological dilemma in the form of a theory practice disjuncture; whereby the participants ideal presented in their use of the *I don't like labels* repertoire is challenged when the reality of learning disability is considered. Moreover, the participants used the repertoires to negotiate this dilemma. The participants credentialised or 'passed off' their use of the *labels are useful* repertoire, where they acknowledged their own use of the label learning disability for practical reasons, by asserting their personal commitment to the *I don't like labels* repertoire.

In chapter 7 it was concluded that the focus group participants construct equality in terms of sameness in order to maintain their commitment to the 'good person' identity. It was further argued that in casting everyone as being the same, the participants' talk is representative of a wider societal need for normality that is underpinned by a neoliberal discourse. Once again, the participants encountered an ideological dilemma when their constructed ideal of equality faced the reality of learning disability. It is argued that the participants draw on the *people with learning disabilities are different to me/people with learning disabilities are the same as me* repertoire pair to manage this dilemma and ultimately do so by avoiding any consideration of the material learning disabled body. In doing so difference is framed in terms of external factors that are out of the control of the person with learning disabilities; once again the body is ontologically removed from the participants understanding of learning disability.

Considering the fact that many of the participants work directly with people with learning disabilities and therefore encounter their material bodies and what they can and cannot do regularly, their glossing over of difference and their unwillingness to talk about the learning disabled body appears strange. When considered in relation to the socio-cultural worlds shared by the participants and the discourses that predominate within these worlds, as highlighted in the literature review, this strangeness can begin to be understood. As seen, learning disability has a long history of mistreatment and marginalisation premised on the medical model of disability. This is a model that the focus group participants, and also the social scientists and policy makers presented in the literature review, do not want to be associated with. In this way, the learning disabled body has become a taboo subject that those working in learning disability practice seek to avoid. Indeed, in working to avoid this, the social model of disability constructs disability in terms of social barriers. This emphasis on social construction allows the body to take a back seat; no longer is disability a individual problem to be remedied it is now a collective issue that can be equalised. In constructing learning disability in this way the focus group participants are able to both distance themselves from and tie themselves to learning disability as is necessary to maintain their desired ‘good person’ subject position. The participants can remove agency from the learning disabled body by framing it as a social construct and can also unite bodies by way of framing being in terms of sameness.

In contrast to the focus group participants’ talk, the learning disabled body was undeniably present within the photovoice findings. Indeed the participants with learning disabilities’ bodies were both a fundamental part of their participation in the research process and also of the images they portrayed and elicited. Consequently, it was concluded in the photovoice analysis chapter that the material learning disabled body is always present within social interactions and, therefore, is of fundamental consequence to social interaction and the sociological understanding of what learning disability is.

In answer research question (b) *How is learning disability understood by both people with learning disabilities and people without learning disabilities who work in learning disability practice or who have the potential to influence this practice?*, moreover, the research findings suggest that there is a disjuncture in how learning disability is constructed by those working in or with the potential to influence learning disability practice and how learning disability is presented and lived by people with learning disabilities. As seen, the disjuncture that the analysis reveals is premised upon the location of the learning disabled body and the reasons for this location. The relevance of this to the sociological theorisation of learning disability is presented here in terms of three overall conclusions based on the arguments made in the analysis and the literature review. These conclusions function to answer research question (c) and include: an epistemological conclusion; a methodological conclusion and a theoretical conclusion. Consequently, the sociological contribution of this thesis to disability studies is threefold.

Epistemologically, it is argued that in order to know learning disability, the body (inclusive of the brain) must be acknowledged as fundamental to the social interactions that form this knowledge. The argument made in the literature review shows that the biological need not be considered as purely material or objective but that the biological can serve as a platform for the theorisation of embodiment (Bendelow and Williams 2001). While ultimately pre-social the biological is also socially layered; we know the biological through our social interactions. Here Bendelow and Williams's (2001) argument is applied to learning disability in order to present the learning disabled body as a socially layered body.

Learning disability, moreover, need not be seen in terms of an either/or relationship where either it is the problem of individual bodies or it is a social construction. As seen in the photovoice findings, both the learning disabled body *and* socio-cultural factors have a part to play in how learning disability is lived and experienced. As stated, the photovoice findings have been used to argue that the material learning disabled body is present in all social interactions. This relationship between the body and the social should not be thought of in terms of a reflection of learning disability's negative history. It is argued here, moreover, that the acknowledgement of this relationship is necessary to ensure people with learning disabilities are not further marginalised by current social policy and research discourse that seeks to normalise people with learning disabilities in to one way of being.

As outlined in the literature review, ‘best practice’ in learning disability care and support is currently presented in terms of a discourse of choice and personal responsibility that is underpinned by the hegemony of a mind/body dualism and neoliberal values. This approach encounters a number of problems when applied to the material learning disabled body. Such discourse may not be as fundamentally problematic for the bodies of other minority groups who are cognitively able. This difference is by ultimate virtue of what certain bodies can do. Indeed, it is essential to remember that learning disability is primarily cognitive. It has been argued throughout this thesis that this specific bodily location fundamentally challenges current ideas of ‘best practice’ or ‘acceptable’ ways of seeing learning disability. Learning disability presents a reminder that the brain is also part of the body and can result in significant limits in what bodies can do. In this way, learning disability cannot be understood solely as a social construct that can be overcome via actions of the self. The body and the brain within must be acknowledged when making sense of learning disability. Making such an epistemological claim generates two further contributions to the sociological theorisation of learning disability: a theoretical contribution and a methodological contribution.

The epistemological claim that learning disability can only begin to be known through the acknowledgement of the role of the body in social interaction has important implications for learning disability research, policy and practice. In acknowledging the role of the body in social interaction and therefore the understanding of learning disability, this thesis, contributes theoretically to the growing body of theory within disability studies that seeks to reorient the body as a non-dualistic site for understanding and provides an empirical basis for this.

The call for disability studies to acknowledge the body is not new; indeed, the literature review presents a number of similar observations that have been made using a variety of theories (Hughes and Patterson 1997, Wendell 1996, Shakespeare 2001, Coleman-Fountain and McLaughlin 2013). It must be acknowledged, however, that this call has rarely been made within research that specifically addresses learning disability (Maldenov 2014), despite as has been illustrated, learning disability providing a useful platform on which to make this claim. In addition to the need to relocate the body within theory it is argued here, through the provision of the empirical findings, that there is also a need to break from the dualism implicit within the mind/body and disability/impairment dialectics found within the medical model and the social models. Further to this, it is argued that this change requires the transcendence of social model discourse in order leave its connotations behind. The words disability and impairment are now so associated with both the social model and the medical model that their connotations as such are difficult to avoid. Consequently, as has been argued, the focus group participants talk reflected a recontextualisation of the theoretical tensions between the medical and the social model of disability presented in the literature review. In attempting to present as 'good people' the participants' commitment to social model principles limited what they could talk about when forming their constructions of learning disability. This was in spite of their awareness of the learning disabled body, found in their implicit location of learning disability within individuals and their talk of personal experience and professional practice. Consequently, to borrow Bendelow and Williams's (1998 p.1) critique of post-structural approaches to disability, the learning disabled body is both 'everywhere and nowhere' within the focus group participants' co-produced understandings of learning disability. Its everywhereness being consequent of the discursive hegemony of the medical model and its nowhereness being consequent of the influence of the social construction of learning disability applied in the social model.

These discursive influences in the focus group participants talk are argued here to be of detriment to what the focus groups participants could say. Furthermore, their (mis)understanding of learning disability and their 'passing off' behaviour is likely a consequence of this. As presented in the literature review, disability is not only social and impairment is not only material. The two exist in a co-constitutive relationship. Although others have already made this point (Hughes and Patterson 1997), here it is argued that the language of disability and impairment needs to be reformulated to reflect this relationship. Moreover, a purely social constructionist approach requires reconsideration. It is time to stop thinking about disability and impairment as separate entities underpinned by an contradictory discourse. In order to do this, it is argued that the epistemological claim made above, that biology is socially layered, is applied to the body. In this way, it is hoped that an embodied understanding of learning disability, and indeed disability as a whole, can be achieved.

Furthermore, it is argued here that this reformulation of the understanding of learning disability, as a consequence of a rejection of social and medical model discourse, allows the acceptance of multiple ways of being. People with learning disabilities do not need to be normalised into one way of being in order for them to be accepted. Although problematic, the focus group talk demonstrates an enormous desire to accept people with learning disabilities as does the inclusive research agenda. To echo the argument made by Coleman-Fountain and McLaughlin (2013) the acknowledgement of the presence of body and what it can do in all social interactions, allows for a plurality of ways of being to be accommodated. In this way, people with learning disabilities can be included in society based on the reality of what their bodies can do.

This epistemological and theoretical reorientation of the learning disabled body also has implications for research practice. If learning disability is thought about in these terms, as it was in this research project, the limits of the learning disabled body that are as Wendell (1996) states, immutable, can be acknowledged without fear. In this way people with learning disabilities need not be made to conform to normative ways of being in order to be accepted. By adopting this approach to learning disability, for example, this research project was able to fully include people with a range of learning disabilities in the research project. By acknowledging that people with profound and multiple learning disabilities require the support and voice of their carers to enable them to take part in research, details about their lives that could not have been gained otherwise were able to be included in the study. Without a mediated approach to the research process that allowed for a plurality of voices without the fear of speaking for people with learning disabilities, this would not have been possible. In this way it can be recognised that some learning disabled bodies, because of their specific limits, are not conducive to normative approaches to research. Seeing learning disability as a constitutive relationship between the biological and the social, therefore, allowed for this difference and for a necessarily mediated approach to research to be accommodated.

Approached in this way, empirical research can be used add weight to the theoretical contribution discussed. A mediated approach to research that acknowledges and accommodates for what bodies can do by applying a non-dualistic approach to the body allows learning disability to be better represented, in that bodily reality is not avoided. In this way, material bodies can be seen as well as theorised to be of importance to the social interactions that give them meaning. Indeed, this thesis provides an example of how this is possible.

This particular epistemological and ontological approach to learning disability also has direct implications for learning disability policy and practice. As has been illustrated throughout the thesis, the discourses constructed by particular models and theories of disability are recontextualised within policy and practice rhetoric. The discourses of the social and medical models for example are readily seen within current social care rhetoric, described in the literature review. As highlighted in the analysis of the focus groups, such rhetoric is of direct consequence for how practitioners and lay people alike construct their understandings of learning disability. Indeed, the ‘good person’ subject position is reflective of this influence, whereby the focus group participants wanted to align themselves with the social constructivist approach to disability, characterised by the social model.

If the body is repositioned within disability theory as ontologically material and epistemologically social, this non-dualistic discourse has the potential to influence learning disability policy and practice as the social and medical models have done. This potential for change brings a number of benefits for people with learning disabilities. If learning disability is viewed in this way by practitioners and policy makers, learning disability can be better represented. The problems of misrepresentation associated with the dualisms implicit in both purely physical and purely social constructions of learning disability, highlighted across the thesis, can be overcome. In this way, the real needs of people with learning disabilities and what their bodies can do can be acknowledged and accommodated for without fear of a return to the past and the stigmatising consequence of this.

These conclusions should all be considered within the limitations of the research study. First it must be acknowledged that the epistemological and ontological starting points of the project and the final conclusions are the same. Following the literature review to answer research question (a), the project started by asserting the materiality of the learning disabled body and ended also doing this. The final conclusions are based on the application of the literature reviewed to the research findings. While my own positionality within the research project undoubtedly played a part in this, ultimately the research findings and conclusions were driven by the 'real world' constructions provided by my participants.

The project also has methodological limitations that could potentially be overcome if further research were conducted. The sample used presents a number of potential limitations. As identified in the methodology, the focus group participants were mainly white females. While such demographics do not present a diverse sample they are likely to be reflective of the general demographics of the participants sampled. In addition to this, that the sample included a number of students could have resulted in more talk than might usually be expected about their own dyslexia due to this being of immediate consequence to their daily experience and the location of these experiences in a learning environment. Although age was not disclosed, it is estimated that the vast majority of the focus group participants were between the age of 20-50. Had the sample included more participants over the age of 50 the talk produced might have taken a different direction that included a longer temporal experience of learning disability. This, moreover, was the case for the participants who were in their late 60s and 70s. The majority of the parent carers fell in to this estimated age category (they spoke of having children aged 50+). This group, for example, discussed historical labels such as mentally handicapped in terms other than disdain; as these were terms they had once used on a regular basis. In terms of further study, however, a project that explicitly sought to compare generational constructions of learning disability could provide further insight in to the sociocultural nature of the discourses used to construct understandings of learning disability. Indeed, such a study could yield interesting results in terms of the material body.

It is recognised that a different range of professionals might have been recruited for the focus groups. The inclusion of other professionals and lay people would certainly be interesting, however, it is not thought that their exclusion is of detriment to the project, particularly because there was very little difference in the constructions of learning disability provided by the individual focus groups. Indeed, once twelve focus groups had been conducted, the overall similarity in the participants' talk suggested there wasn't any further need to conduct additional focus groups. This was further clarified when carrying out the discourse analysis and the same interpretive repertoires were found in use across the focus groups.

In addition to the demographic limits of the sample, as seen in the focus group analysis chapters, the focus group participants' talk followed a general consensus and did not highlight any particular differences in the discursive resources used to construct their understandings of learning disability. This is likely a reflection of the choice of method. As seen in the methodology, focus group talk is publically produced and can lead to the creation of a group consensus (Clavering and McLaughlin 2007). It was initially thought that the organisation of the focus groups by area of knowledge/experience would highlight any differences in talk. The shared desired to present as 'good people' and the ideological dilemmas encountered as a consequence of this, however, were consistent across all of the focus groups. It is not thought that conducting mixed interest focus groups would have resolved this issue due to the similar patterns of talk across the focus groups. An ethnography of the different groups, however, might reveal any distinctions in the constructions of learning disability between the groups, in that this would allow an insight in to the working practice of the use of the term learning disability and the discourses that preside within this practice. The time required to conduct such a study, however, would not have been possible within the constraints of a PhD. In terms of further study, an ethnography of the different focus groups involved would make an interesting contribution both to disability studies and also to the sociology of health and illness literature that considers professions.

In terms of the overall conclusions, another area of further study that would make a useful contribution to an area of disability studies that is currently under researched is the understanding of severe and profound and multiple learning disabilities. Given the general absence of people with profound and multiple learning disabilities in the focus group talk, such a project could ask: what does severe and profound and multiple learning disability mean in the real world? Such a study could provide an interesting contrast to this study, in that, hypothetically, it would be much harder for talk to avoid the body.

In answer to the main research question, *what does learning disability mean in the 'real world'?*, moreover, it is argued that although different people use the term to refer to different bodily conditions there is a greater issue at stake. Ultimately, it is argued that the 'real world' understandings of learning disability presented by the participants without learning disabilities are shrouded in fear; fear of appearing to uphold an 'unacceptable' way of seeing learning disability. Such fear has the consequence of obscuring the material learning disabled body and the realities this presents in terms of difference or what bodies can do. While including different conditions under the term learning disability is 'officially' incorrect and can lead to confusion, avoiding the body can result in the transformation of this (mis)understanding into a (mis)representation that in turn acts to further marginalise people with learning disabilities. The original problem, highlighted in the introduction, that learning disability means different things to different people, moreover, can be seen to be a secondary issue in relation to the wider problem revealed in the empirical work: that 'real world' understandings of learning disability constructed by those with intellectual power tend to obscure its reality in favour of upholding particular popular values and portraying a 'moral' identity. It is argued, therefore, that a sociological understanding of learning disability must re-orientate the body within a non-dualistic framework that locates the body and the brain within as both ontologically material and epistemologically social. In doing this the learning disabled body can be thought of in terms of a co-constitutive relationship between the material and the social, whereby the learning disabled body can be firmly located within the social interactions that serve as resources for understanding it.

Appendix A – Focus group participant information sheet

What does learning disability mean in the real world?

Participant Information Sheet

Thank you for agreeing to take part in the following focus group

………………………………………………………………………………………………..

It is expected that the focus group will run for no more than 1 ½ hours and there will be time for a break within this time. You are not required to bring anything with you. Refreshments will be provided.

The focus group will be faciliatated by myself, Victoria Smith, Ph.D student, School of Sociology and Social Policy, University of Nottingham. Prior to beginning any discussion you will be asked to sign a consent form to confirm your willingness to take part in the research. This is not a permenant contract, you can withdraw from the research at any time. Anything you say will be anonomysied, your name, workplace or any other personal details will not be used.

The purpose of a focus group is to discuss a predetemined topic, in this case learning disability, within a group setting with an emphasis on group interaction. Please feel free to agree, disagree or contribute new thoughts to the discussion. As facilitator I will ask a number of questions in order to start the conversation. The aim is for an informal, free flowing conversation.

Please remember that this is not a test of your knowledge. I am interested in how different groups talk about learning disability rather than whether or not they are fully up to date with the latest research.

Thank you again for agreeing to participate. Your support is invaluable. If you have any queries or find you are no longer able to attend the focus group please contact me on lqxvs2@nottingham.ac.uk or 07709818922.

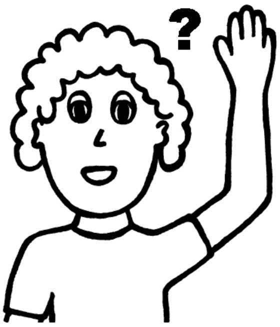
Victoria Smith

Appendix B – Accessible participant information sheet

What does Learning Disability mean in the real world?

Project information

	My name is Victoria Smith.
	I am a researcher from the University of Nottingham.
 	I would like to invite you to take part in some research. Research is a way of finding things out.
	I would like to visit you to you about your life.

	You can ask David to help decide if you want to talk to me.
	I will ask you to sign a form to say you are choosing to talk to me.
	I will ask you to take photos of your life so that we can talk about them. I will give you a digital camera to borrow for a week.
	I will make a record of what you have said to me. If you agree, I will video record what you are saying.

	I will write a report about what you say to me. This might contain some of your words and photos.
	I will not use your name in my research, so nobody will find out about your private information.
	After about a year your photos they will be shown in an exhibition. You, your family and your friends will be able to come and see the exhibition.
	The report and exhibition will be used to help tell other people about the lives of people with learning disabilities.
	If you feel worried about any part of the project you can talk to David.

If you want to find out more about this project, here is how to get in touch:

	**Write to** School of Sociology & Social Policy University of Nottingham Nottingham NG7 2RD
	**Email** lqxvs2@nottingham.ac.uk

Appendix C – Example letter and information sheet for parents/carers

Faculty of Law and SocialSciences
School of Sociology and *Social Policy*
University Park
Nottingham
NG7 2RD
Tel +44 (0) 115 951 5234
Fax +44 (0) 115 951 5232

Dear Parent/Carer

What does learning disability mean in the real world?

The Lake Enders group have been invited to take part in a research project called "*What does learning disability mean in the real word?*" The project will use photography and group discussion to explore the lives of people with learning disabilities. At the end of the project the photographs will be displayed in a public exhibition to which everyone will be invited. This is a big project that will involve other groups, so the exhibition will not follow immediately after the Lake Enders' involvement.

Your family member/person you care for has been asked if they would like to take part in the project. This would involve attending an hour of additional activities from 12-1pm, before the usual Lake Enders sessions for three weeks. These sessions will run on 9th, 16th and 30th October. Everyone that takes part will be given a digital camera to take home for a week and will be asked to take photographs of their everyday life. I have included an information sheet that tells you what I hope to find out and how these findings will be used. The sessions will run as follows:

<u>Wednesday 9th October 12-1pm – Lakeside</u>
Introduction to the project and getting to know you.
Consent forms will be collected.
Cameras with simple-to-follow instructions will be distributed and we will practice using them.
Instructions for the coming week – everyone will be asked to use the cameras over the week to take pictures that show their everyday life. People can take photos of whatever they want.

<u>Wednesday 16th October 12-1pm – Lakeside</u>
Cameras will be returned to the researcher, so that the photos can be printed.
We will talk about how everyone got on.

Wednesday 30th October 12-1pm – Lakeside
Everyone will be given printed copies of their photographs and asked to choose their favourites.
Each person will talk about their favourite photos and what they represent.
A group discussion about the photos will be either audio or video recorded depending on the group's preference.

If your family member/person you care for chooses to take part, it is important that they sign a consent form. I have included an accessible consent form to be returned at the first session. No personal information will be used in any of the project reports or the exhibition. All information shared with the researcher will be treated confidentially. Your family member/person you care for can withdraw from the project at any time and their contribution will not be included. It is important that the consent form is returned at the first session. Individuals cannot take part if they have not given consent.

Thank you for reading this letter. If you have any questions about the project please do not hesitate to contact myself on 07709818922 or Ruth Lewis-Jones at The Lakeside Centre on 0115 8232218.

Yours faithfully
Victoria Smith

What does learning disability mean in the real world?

Project Information

What is this project about?

This research is about how people with and without learning disabilities. I want to know how people with learning disabilities live their lives and how people without learning disabilities think someone with learning disabilities might live their life. I am keen to include people of all abilities in the research.

What is the purpose of this research?

The findings from this study will be used to raise awareness about the lives of people with learning disabilities and to promote their voices. An exhibition of the findings will be held in an art gallery. The exhibition will be advertised and will be open to the public.

Who will be doing the research?

A researcher from the University of Nottingham will be carrying out this research. Her name is Victoria Smith. Victoria is a Ph.D. student. She can be contacted by post, telephone or email. She is happy to answer any questions.

Postal address:	School of Sociology & Social Policy, University of Nottingham, Nottingham, NG7 2RD
Telephone:	07709 818922
Email:	lqxvs2@nottingham.ac.uk

Who has funded this research?

This research has been funded by The Foundation for Sociology of Health and Illness. This is a charitable foundation that aims to promote and improve social scientific research. You can find out more about the foundation by visiting http://www.shifoundation.org.uk

How can my family member/the person I care for get involved?

If you and your family member/the person you care for are happy to be involved, I will work alongside Mosaic to deliver the project. This will involve me attending three of the regular group sessions. I will give everyone involved a digital camera to be used to take photos of their everyday lives over the period of a week. I will then collect the cameras and return to the next group session with the printed photographs. We will look at the photos together on a laptop and choose our favourites.

How can I support my family member/person I care for to take part in the project?

You can support your family member/person you care for by taking photos of their everyday life and involving them as much as possible in this process. Once your family member has chosen their favourite photos I would like to talk to you about them. I would like to know what the pictures shows about your family member/person you care for's life and how the photo makes you and your family member/person you care for feel. I can either meet with you at a time and in a place that suits you or I can telephone you at a time that is convenient to you. I would like to audio record our conversation so that I can remember what we have said. I might include some of our conversation in my research report but you and your family member/person you care for will be given another name and none of your personal details will be used.

If you are happy to be involved in taking the photos and talking about them please complete the attached personal details form and return it to the first session along with the consent form. This information will be used so that I can contact you to talk about the photos your family member/ person you care for has selected as their favourites. Your personal information will not be used for any other reason and will be destroyed once the project is complete.

Why am I asking for family members and/or carers to be involved?

A lot of research about the lives of people with learning disabilities only involves people with mild or moderate learning disabilities. People with severe or profound and multiple learning disabilities are often ignored. I think it is important to represent all people with learning disabilities. As a family member and/or carer you know the person involved best and are in the best position to support their involvement in the project and represent their lives.

Will the research findings be confidential?

Yes. No names, addresses or any other personal details will be included in the research findings. The project has been given ethical approval by The University of Nottingham.

What if I or my family member/the person I care for changes their mind and no longer wants to be involved?

Anyone that is involved in the project can pull out at any time and their photos and anything they have said about them will not be used in the research findings.

How will participants get to know about the research findings?

Everyone who takes part in this research will be invited to a private opening of the exhibition.

Appendix D – Consent form for focus group participants

School of Sociology and Social Policy
University of Nottingham

Participant Consent Form

What does learning disability mean in the 'real world'?

In signing this consent form I confirm that:

I have read the Participant Information Sheet and the nature and purpose of the research project has been explained to me.	Yes ☐	No ☐
I have had the opportunity to ask questions.	Yes ☐	No ☐
I understand the purpose of the research project and my involvement in it.	Yes ☐	No ☐
I understand that my participation is voluntary and I may withdraw from the research project at any stage, without having to give any reason and withdrawing will not penalise or disadvantaged me in any way.	Yes ☐	No ☐
I understand that while information gained during the study may be published, any information I provide is confidential (with one exception – see below), and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. *[If other arrangements have been agreed in relation to identification of research participants (e.g. in a focus group) this point will require amendment to accurately reflect those arrangements]*	Yes ☐	No ☐
I understand that the researcher may be required to report to the authorities any significant harm to a child/young person (up to the age of 18 years) that he/she becomes aware of during the research. I agree that such harm may violate the principle of confidentiality.	Yes ☐	No ☐
I agree that extracts from the interview may be anonymously quoted in any report or publication arising from the research *[Omit if quotes not being used]*	Yes ☐	No ☐
I understand that the interview will be recorded using audiotape/electronic voice recorder/video recorder *[Amend/delete as applicable]*	Yes ☐	No ☐
I understand that data will be securely stored	Yes ☐	No ☐

I understand that the information provided can be used in other research projects which have ethics approval, but that my name and contact information will be removed before it is made available to other researchers. *[Omit if data will not be used in this way]*	Yes ☐	No ☐
I understand that I may contact the researcher *[*or *supervisor]* if I require further information about the research, and that I may contact the Research Ethics Officer of the School of Sociology and Social Policy, University of Nottingham, if I wish to make a complaint relating to my involvement in the research.	Yes ☐	No ☐
I agree to take part in the above research project.	Yes ☐	No ☐

Participant’s name (BLOCK CAPITAL)	Participant’s signature	Date
Researcher’s name (BLOCK CAPITAL)	Researcher’s signature	Date

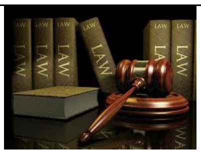
Appendix E – Accessible consent form

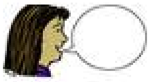
What does learning disability mean in the real world?

Consent form

Before signing this form please read the project information leaflet.

Please show that you understood what you are agreeing to do, by ticking the boxes.

	I have read the project information	☐
	I have had a chance to ask questions about the research	☐
	I understand that it is my choice to be involved in this research, and that I can change my mind at any time.	☐
	I understand that what I say will be recorded	☐
	I understand that what I say will be confidential.	☐
	I understand that my personal information will be kept safe, like the law says it must be	☐

	I understand that what I say will be used in a report and an exhibition	☐
	I understand that the report might include some of my words and photographs, but nobody will be able to tell what I said.	☐
	I understand that when the research is finished, I will be invited to the exhibition.	☐

I agree to take part in this project. I agree for my chosen photographs to be used in an exhibition:

I am signing this consent form on behalf of my family member/person I care for. I agree to be involved in the project, to talk about the chosen photos and for them to be used in an exhibition.

NAME:……………………………………………………………………………………….

NAME OF THE PERSON I AM SIGNING ON BEHALF OF:

…………………………………………………………………………………………………..

SIGNATURE: …………………………………………………………………………….

DATE: ……………………………………………………………………………………….

Appendix F – Demographic breakdown for focus groups

	Focus group	Number of participants	Male	Female	Date
1	Pilot – social scientists	5	1	4	Jan 2014
2	Student social workers with experience	3	0	3	Jan 2014
3	Student social workers no experience	3	0	3	Jan 2014
4	Local authority councillors	2	2	0	Jan 2014
5	Teachers	3	1	2	Feb 2014
6	Student Teachers	2	0	2	Feb 2014
7	Care provider	4	1	3	Feb 2014
8	Student Journalists	2	1	1	March 2014
9	Health Professionals	3	1	3	March 2014
10	Parent carers	7	2	5	January 2015
11	Special school teaching staff	8	0	8	February 2015
12	Psychologists	3	0	3	February 2015

Total number of participants: 42

Appendix G – Demographic breakdown for photovoice participants

	Name	**Age**	**Ethnicity**	**Location**	**Learning disability**	**Gender**
1	Alleyah	20s	Asian British	Leicester	Moderate	Female
2	Robert	30s	White British	Leicester	Mild	Male
3	Mitesh	40s	Asian British	Leicester	Moderate	Male
4	Janaya	20s	Black British	Nottingham	PMLD	Female
5	Lydia	20s	White British	Nottingham	PMLD	Female
6	Leo	20s	Black British	Nottingham	PMLD	Male
7	Theo	20s	White British	Nottingham	PMLD	Male
8	Tim	20s	White British	Nottingham	PMLD	Male
9	Ross	20s	White British	Nottingham	PMLD	Male
10	Hassani	20s	Asian British	Leicester	Moderate	Female
11	Dave	40s	White British	Leicester	Mild	Male
12	Kay	40s	White British	Nottingham	Moderate	Female
13	Lorna	20s	White British	Nottingham	Mild	Female
14	Mathew	30s	White British	Nottingham	Mild	Male
15	Mark	50s	White British	Nottingham	Mild	Male
16	Emma	30s	White British	Nottingham	Mild	Female

Gender

Female:	7
Male:	9

Age range

20-51
Average age: 30

Learning disability breakdown

Mild:	6
Moderate:	4
PMLD:	6

Ethnicity

Asian British: 3
Black British: 2
White British: 11

Location

Leicester: 5
Nottingham: 11

Total number of participants

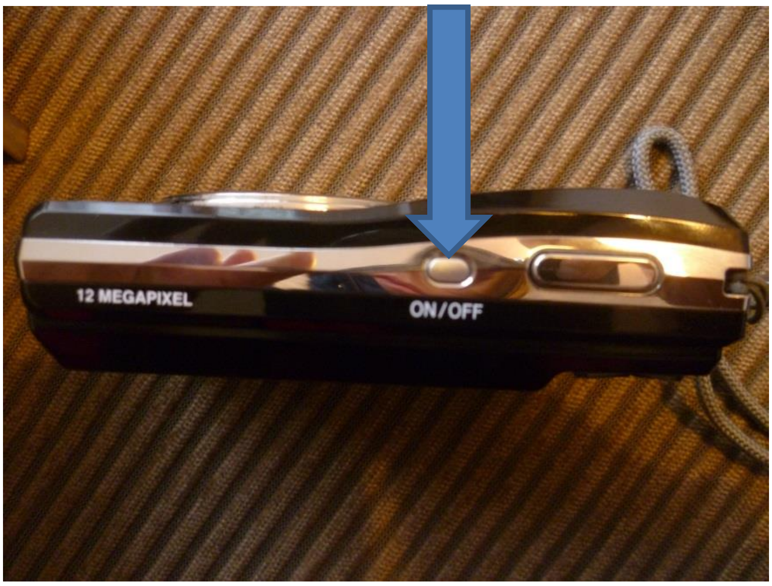
16

Appendix H – Accessible camera instructions

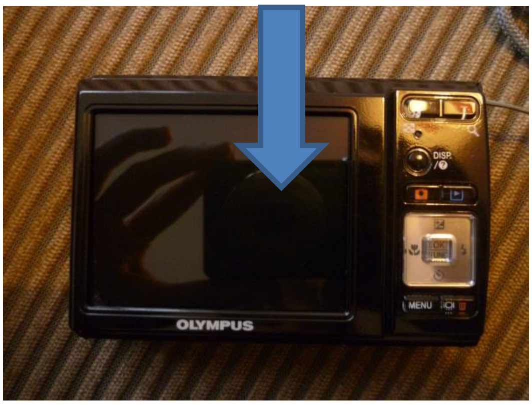
Instructions for Olympus X42

This is your camera for the week

You turn it on by pressing here

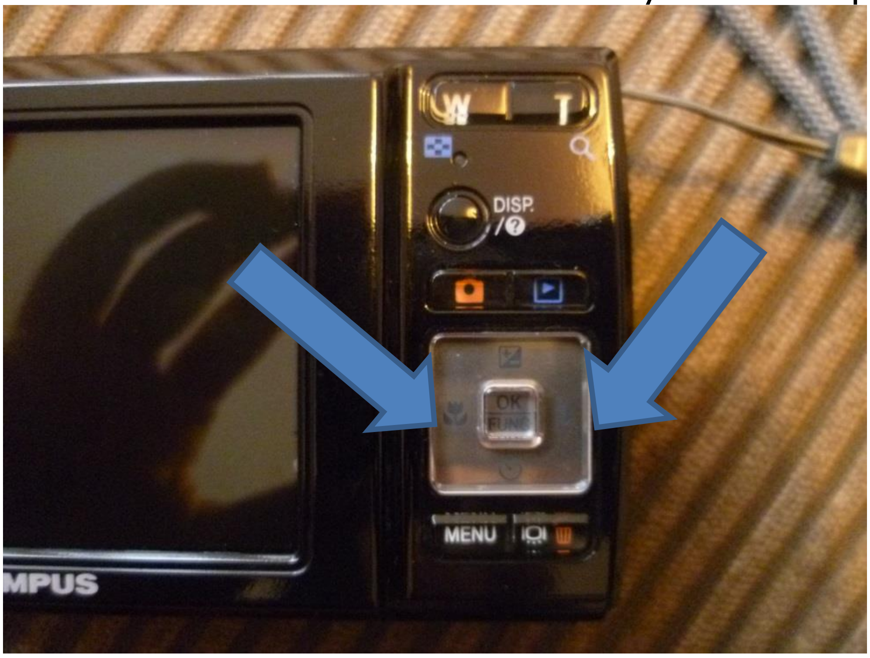


You take a photo by looking here and pressing here

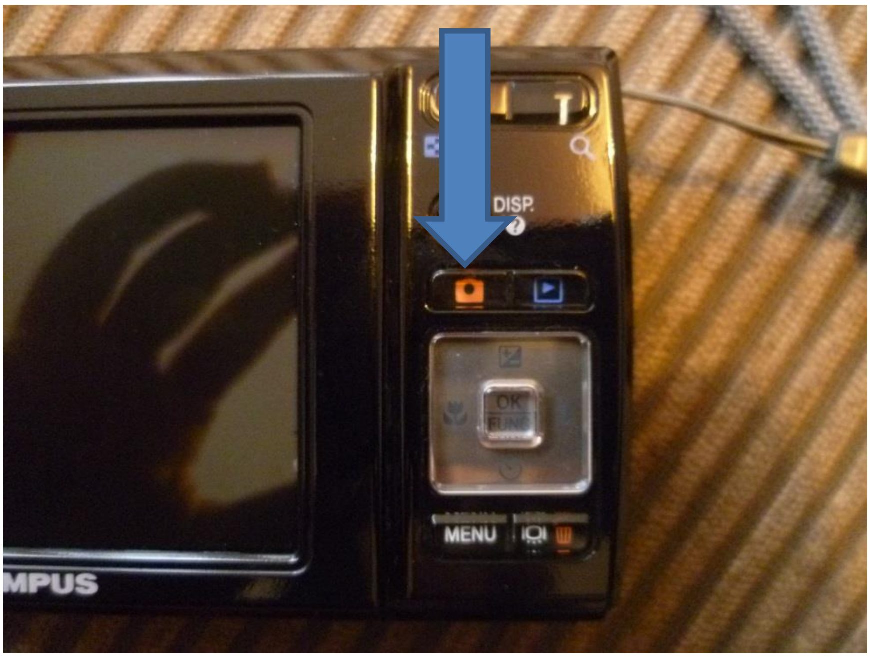


After you have taken some pictures you can look at them by pressing here

You can use these buttons to see your other photos



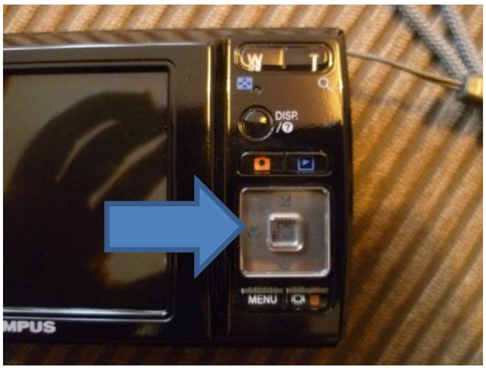
To take more pictures, press here

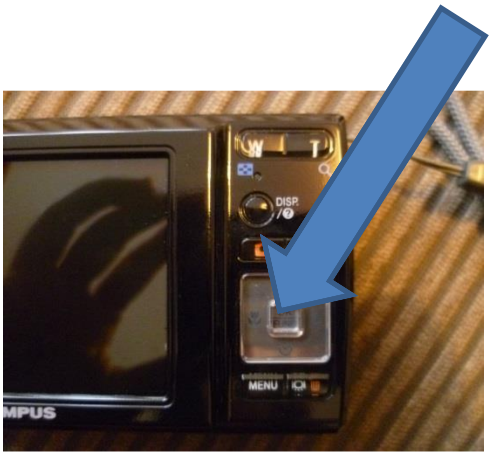


If you don’t like one of your photos you can get rid of it by first pressing here….

and then pressing here for YES

and here for OK





Don’t forget to turn your camera off when you are not using it.
Press here to turn it off

Batteries

The batteries are kept in the bottom of the camera in here

Slide the door to the right to get to the batteries
If the batteries run out, take the old ones out and put the new ones in.
I have given you two spare batteries if they run out.

Appendix I – Discourse analysis codes

The 27 initial codes included the following:

1. Alternative terms
2. Barriers
3. Learning disability is a broad term
4. Definitions of learning disability
5. Differences between people with and without learning disabilities
6. Empathy
7. Equality
8. Feelings about intellectual disability
9. Feelings about the word disability
10. Speakers identifying as 'good' people
11. Instances of terms used synonymously
12. Invisible people
13. Labels
14. Learning disability = academic ability
15. Learning disability = a childhood disability
16. Learning disability is located in the brain
17. Misunderstandings of learning disability
18. Optimism
19. Personal experience of learning disability
20. Quality of life
21. Self- fulfilling prophecy
22. Similarities between people with and without learning disability

23. Stigma

24. Subaltern

25. Support

26. Uncertainly

27. We all have needs

Appendix J – Exhibition proposal for The New Art Exchange, Nottingham

Project proposal

Project title: What does learning disability mean in the real world? Re-evaluating concepts and definitions of learning disability

Exhibition title: What does learning disability mean in the real world?

Number of photographs: 23 max.

Size of photographs: all a3 (although this can be changed as necessary). Each image will be accompanied by a short description/quotes from the group discussions.

Number of artists: 14 (16 people with learning disabilities took part in the project, 14 consented for their images to be used in the exhibition).

When: Ideally, the exhibition would take place in the autumn/winter of 2015. I would be open to holding the exhibition earlier or later if this better fits the schedule for the exhibition space.

Duration of exhibition: Ideally, I would like the exhibition to be open for at least two weeks in order to allow a diverse audience to view and interact with the images. However, I am open to any time period available.

Exhibition opening: I would like to invite all participants and their family and friends to the exhibition opening as well as key local learning disability decision makers such as social care providers, education providers, medical professionals, academics and local authority councillors.

Exhibition promotion: I would like to promote the exhibition to local schools, colleges, community groups, day centres, health care providers and universities.

Other information: The project has received University of Nottingham ethics clearance. All participants included in the exhibition signed a University of Nottingham accessible consent form, giving permission for their images to be used in an end of project exhibition. Proxy consent from a carer and/or family member was given for participants who were unable to provide written consent. The project is funded by The Sociology of Health and Illness Foundation.

Project statement

'What does learning disability mean in the real world?' seeks to highlight the lived experience of learning disability by showing images of everyday lives, taken by people with learning disabilities and their carers. Learning disability can and does mean different things to different people. It can be an educational label, a medical diagnosis, a term of abuse and a lived experience. While diversity of meaning can be positive, it can also be problematic and lead to misunderstanding. How societies define learning disability is of enormous psychological, economic, political and social importance to those who identify with the label. This visual presentation of the everyday life of people with learning disabilities aims to stimulate, challenge and inspire how the viewer thinks about learning disability.

I have worked with four groups of people with learning disabilities, including people with mild, moderate, severe and profound and multiple learning disabilities, located in Nottingham and Leicester. All participants were given a digital camera to borrow for a week and asked to take photographs of their everyday lives. For those with profound and multiple learning disabilities, carers took the photographs, involving the person they care for as much as possible. The photographs were then discussed in groups and individuals were asked to choose one or two favourite images to be used in the exhibition.

The exhibition is part of a wider project, titled - *What does learning disability mean in the real world? Re-evaluating concepts and definitions of learning disability*. This project addresses both the lived experiences of learning disability and external perceptions of this experience. Two methods of investigation have been used, focus groups with professional groups and auto-driven photovoice with people with learning disabilities. It is the photographs taken as part of the auto-driven photovoice method that comprise this exhibition, although it is expected that quotes from the focus groups will be used to complement the images.

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