Meeting the Aspirations of Learning Disability Policy:
The Role of the Support Worker

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This thesis is submitted for the degree of Doctor of Philosophy

February 2020

Preface

This thesis is the result of my own work and includes nothing which is the outcome of work done in collaboration except as declared in the Preface and specified in the text. It is not substantially the same as any that I have submitted, or, is being concurrently submitted for a degree or diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text. I further state that no substantial part of my thesis has already been submitted, or, is being concurrently submitted for any such degree, diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text. It does not exceed the prescribed word limit for the relevant Degree Committee.

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Summary

This study investigates the research question: *What role do support workers play in enacting learning disability policy in England?* Social care policy has developed from a culture of paternalism and institutionalisation, to one that advocates enablement and community-based care. Government policy emphasises choice, independence and inclusion for people with a learning disability but does not recognise the extent of the role that support workers play in enacting such policies.

This study uses a qualitative research multi-method approach to explore the relationship between government policy and support worker practice. The study consists of four parts: 1) an examination of the definition and diagnosis of learning disability, and how these have influenced policy; 2) a documentary analysis of care policy, to establish the representation of support workers in government policy; 3) a systematic review of empirical studies to establish the degree of academic interest in the research question; and 4) observations and interviews of support staff to explore their views and experience of working in care.

The study findings show that changes in the definition of learning disability are reflected in a policy shift away from a medical framework focused on need, towards a social model focused on ability. Despite this shift, government policy still does not reflect the emotional and enabling role that support workers play in the lives of people with a learning disability, or the needs of support workers themselves. The role of support workers in enacting policy in England is also under-represented in academic research, with studies instead focusing on specialised areas of support work, such as challenging behaviour or stress. The fieldwork identifies tensions between policy and practice exacerbated by resource pressures, with staff reporting that they feel stressed and undervalued. Staff say they are in care work to make a difference but find it challenging to promote choice and inclusion for people who lack mental capacity to engage.

This study concludes that in order for government policy to be meaningful and achievable, it must accurately reflect the work and needs of learning disability support workers. In addition, government must engage support workers directly when formulating policy that serves the interest of *all* people with a learning disability, without compromising the wellbeing of the people who support them.

Acknowledgements

It is impossible to acknowledge adequately all those who have contributed to this research. However, I would like to extend thanks, in particular, to my supervisors, Professor Anthony Holland, and Dr Marcus Redley for their guidance and support and to my advisor Dr Neil Stott.

I am grateful to the care provider in this thesis and its staff for their generosity of time and engagement with this work.

I would like to thank Barry Horne and Bill Mumford for their confidence in me and for their graciousness in supporting my PhD application.

Finally I would like to thank my family and friends for their support, patience, encouragement and belief in me when I needed it most. I dedicate this thesis to my brother Lovin.

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Chapter 1: Introduction

Over the past century, learning disability policy in England has evolved from framing people as 'deficient' (Mental Deficiency Act, 1913) and requiring institutionalisation, to advocating inclusion and participation in society and community-based support (The Care Act, 2014). This development in policy has been accompanied by changes in learning disability services, including the provision of smaller residential care homes which support people in a group living environment, and supported living accommodation which support people who are tenants of their own home to live independently. Any evolution in policy requires an evolution in practice; the roles and responsibilities of the social care workforce have needed to adjust from a paternalistic model focused on process and protecting people, to a model of support that empowers people to realise their potential.

The link between policy, provision, and practice is fundamental. In order for policy to be effective, the right services must be provided, and care practice and policy aspirations must be aligned. If policy is to be meaningful and achievable, it must consider the views and experiences of the practitioners who support people with a learning disability. This study hypothesises that support workers are critical in enacting policy but government policy in England does not reflect the extent of the role that support workers play in the lives of people with a learning disability, or the needs of support workers themselves. This lack of recognition and engagement undermines the credibility of learning disability policy. The study applies a range of research methods to examine the representation of support workers in policy and academic research, and explores the perspectives and practice of support workers through field observations and interviews. The implications for policy and future research are then considered.

This study was motivated by my personal and professional experience of learning disability. In 2011, I became guardian to my older brother who has a learning disability, and I have held management and executive director positions with national learning disability social care providers. It was while working for a social care provider examining better practice in 2014 that I became interested in the relationship between learning disability policy and practice in England, and aware of the lack of academic insight in this specific area.

1.1 Study aims and objectives

The aim of this study was to address the following research question: *What role do support workers play in enacting learning disability policy in England?* Specific objectives were:

- To explore the definitions and diagnosis of learning disability and identify tensions
- To trace the development of social care policy, and conduct a documentary analysis of policy from the Community Care Act (1990) to The Care Act (2014)
- To systematically identify empirical studies that explore the role of learning disability support workers in enacting policy
- To conduct a study exploring the perspectives and practice of learning disability support workers in residential and supported living services
- To establish the relationship between government policy and support worker practice.

1.2 Thesis structure

I begin Chapter 2 by exploring the terminology, definition, and diagnosis of learning disability which has been influential in informing the development of social care policy and practice. In Chapter 3 I examine the development of social care policy since The Poor Act in 1601, and undertake a documentary analysis of policy between 1990 and 2014 examining the representation of support workers. This date range was chosen because it spans the introduction of the National Health Service and Community Care Act (1990) which restructured care provision and emphasised the involvement of people requiring support, and The Care Act (2014) which was presented by the Government as the most significant reform of social care in 60 years. In Chapter 4 I conduct a systematic review of empirical studies to identify existing knowledge of the role of support workers and consideration of the relationship between policy and practice in England. In the final chapters (5 and 6) I discuss the design and results of my fieldwork which involve interviews, observations and analysis of staff in residential and supported living services for adults with a learning disability. I conclude the thesis (Chapter 7) with a discussion of the principle findings across the study, comparing findings with existing literature, and outlining strengths and limitations. I conclude with recommendations, and the implications for further research. The research design for this study is summarised in Figure 1.1 (p. 11).

Figure 1.1 Research design
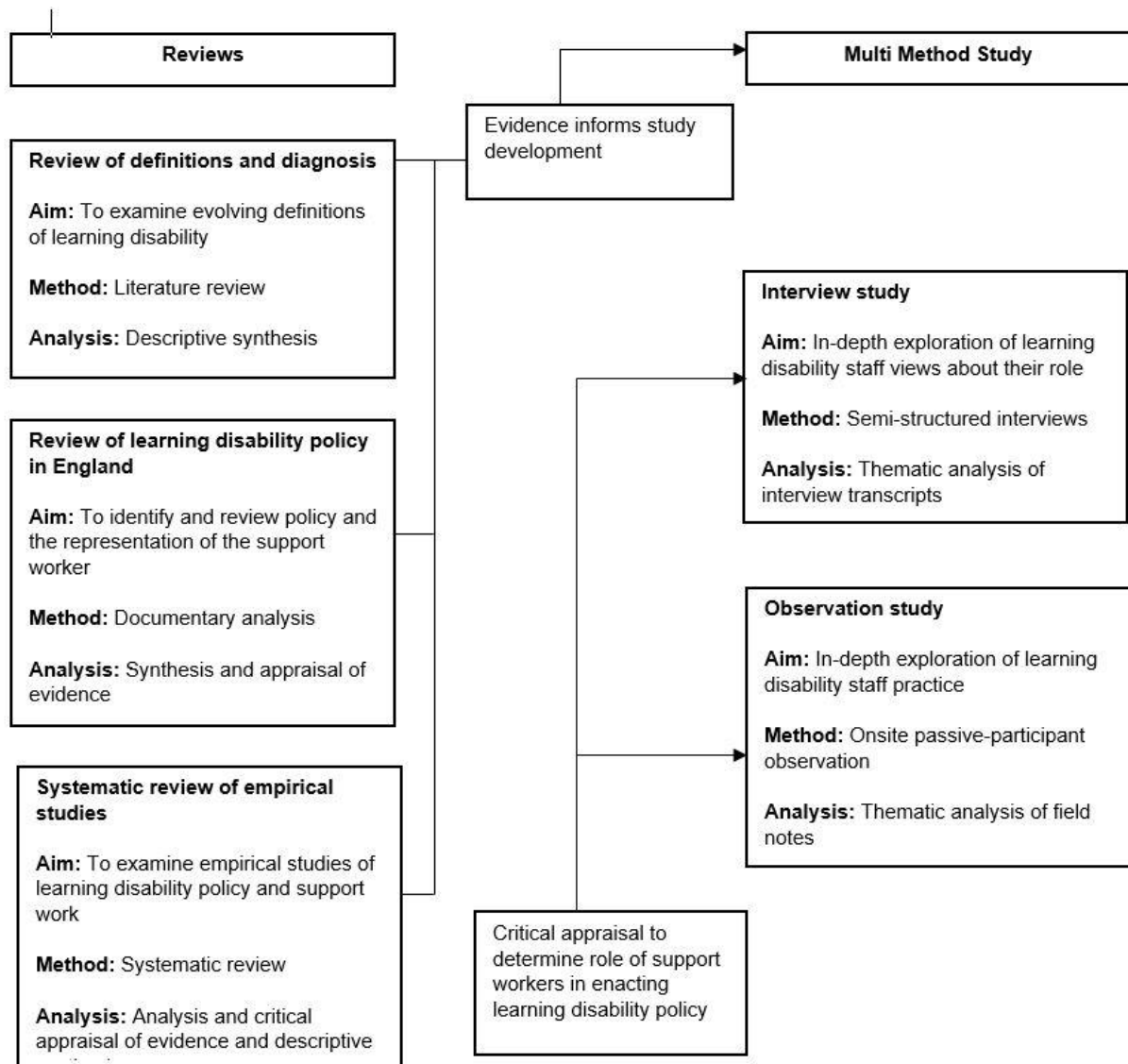
Chapter 2: Definitions and diagnosis of learning disability

The definition and understanding of learning disability is important in establishing the development of social care policy and practice. There are many lenses through which disability can be viewed. For example a medical and social frame of reference will inform clinical and non-clinical approaches to intervention and care. This study is concerned with understanding the role of the learning disability support worker and their role in enacting policy in England. In examining the changing definition and classification of learning disability, this chapter provides a context for understanding the development of policy and practice. This will help inform analysis of government policy and support worker perspectives and practice in subsequent chapters.

The chapter starts by examining changes in terminology. I then discuss the prevalence and classification of learning disability. The three main diagnostic criteria used for classifying learning disability are considered: the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association), The American Association on Intellectual and Developmental Disabilities, and the ICD–10 Classification of Mental and Behavioural Disorders (World Health Organisation). I then highlight key criticisms of classification. This is followed by a discussion of the influence of the social model of disability on the understanding of learning disability.

2.1 Terminology

Terminology concerning learning disability in the UK has evolved in line with social change. Over the years terms 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" (Cluley, p. 26). In the UK "learning disability" has been accepted use among people with and without learning disabilities alike for over 20 years (Gates & Mafuba, 2016). I will use the term 'learning disability' in this study unless using direct quotations or references, since the focus of this study is support workers, and this is the term they used during my fieldwork. Recently, the term "intellectual disability" and "intellectual developmental disability" is increasingly being used in replacement of or synonymously with "learning disability" and is now increasingly visible in UK professional discourse (Cluley, 2018). This is a reflection of the changing international context; "intellectual disability" has been particularly pronounced in the USA (Cluley, 2018). The term "intellectual" is well understood and is broadly acceptable

in the context of clinical and policy applications, and the term "developmental" emphasises the dynamic nature of intellectual developmental disorder (Carulla *et al.*, 2011).

Few topics in the field of learning disabilities have evoked as much interest or controversy as have those relating to the definition of the condition (Hammill, 1990). Diagnosis plays a significant role in the shaping of individual identities and the quality of life for people with learning disabilities and their carers. While diagnosis can create access to support and resources it can also lead to dehumanising treatment, and the severe restriction of opportunities (Gillman *et al.*, 2000). Leyin (2010) asserts that the term 'learning disability' is a culturally constructed concept. The approach to diagnosis is criticised for being impairment-based and focused on the individual, rather than the relational, social or structural context (Gilman *et al.*, 2000). As a result, 'few groups have been so completely subject to medicalisation in our society as people with learning difficulties' (Globe, 1998, p. 834). Examining the role of medical professionals in controlling diagnosis, Gillman *et al.*, (2000) argue that the temptations of certainty encourage professionals to seek biological explanations for mental disorder, and to make biological links between, for example, the causes of learning disability and the higher incidence of mental disorder in people with learning disabilities (p. 390).

Learning disability is recognised, identified, subtyped, and labelled differently by different sectors such as education, advocacy, and law. There is no consensus as to the definition of learning disability or its diagnostic criteria, despite worldwide consensus as to its validity (Hale *et al.*, 2010). The purpose of identifying learning disabilities varies across sectors. In medicine, particularly psychiatry, the purpose is to enhance the effectiveness of clinical activity (to determine what is wrong with the patient, the diagnosis or diagnoses, and what intervention is likely to help). By contrast, in education, the purpose is to identify students with special educational needs and determine eligibility for special education and related services. Advocacy groups aim to define learning disabilities in terms of legislation, standards and practices to protect individuals' rights and access to services. In most countries, service eligibility and treatment selection for persons with a learning disability are heavily influenced by diagnostic classification. Persons with a learning disability are more likely to receive the services they need if health workers in the settings where they are most likely to be seen have a diagnostic system that is reliable, valid, clinically useful and feasible.

Hammill (1990) makes a distinction between the conceptual and operational definition whereby the conceptual definition establishes learning disability theory which can then be

operationalised for use in everyday situations. He argues that the lack of a widely accepted definition is creating confusion among professionals as to who does and does not have a learning disability and indeed whether learning disability exists. He refers to 11 different popular definitions of learning disability (1990, p. 75). All definitions adhered to an idea that an individual with a learning disability is an under-achiever.

Criticising the lack of an agreed definition of learning disability Siegel (1999) describes the field of learning disability as 'chaotic'. She argues that definitions are too general and there is no way to operationalise them to make decisions about an individual. Gillman *et al.*, (2000) argue that the arbitrary definitions and thresholds which have been employed in relation to people with learning disabilities are at least partly responsible for the fixed and stigmatised social positions they often come to hold. They examine critical questions relating to efficacy of diagnosis: 'Who has the power to 'name'? Who seeks diagnosis and why? How reliable are diagnostic systems? What part does diagnosis play in the maintenance of professional power? What role does diagnosis play in creating potential and restricting possibilities for people with learning difficulties?' (p. 391). People with learning disabilities suggest that categorisation by syndromes and labelling is stigmatising, and can lead to the exclusion of individuals from mainstream society (Sutcliffe & Simons, 1993).

2.2 Prevalence

Historically, learning disability has been defined by significant cognitive deficits, which has been established through a standardised measure of intelligence, in particular with an IQ score of below 70 (two standard deviations below the mean of 100 in the population) and also by significant deficits in functional and adaptive skills. Adaptive skills involve the ability to carry out age-appropriate daily life activities.

The worldwide reported prevalence of learning disability is 16.41 per 1,000 persons in low income countries; 15.41 per 1,000 persons in middle income countries; and, 9.21 per 1,000 persons in high income countries. The male to female ratio for learning disability is 2:1. In a family with one child affected with 'severe intellectual disability' (see Table 2.1), the recurrence risk for a subsequent child to have a learning disability is between 3% and 9% (Patel, 2018).

Learning disability begins in the first two decades of life. The identification of children with more severe intellectual disability (what previously would have been termed severe and

profound mental retardation) typically occurs early in life. Individuals with severe intellectual disability may show delayed motor, language, and social accomplishments within the first 2 years of life. Individuals with 'mild intellectual' disability may not be recognised until early school age because that is when their difficulties with academic learning become apparent. Depending on its cause, intellectual disability may be stable and non-progressive or it may worsen with time. After early childhood, the disorder is chronic and usually lasts an individual's lifetime; however, the severity of the disorder may change with age. For example, visual or hearing difficulties, epilepsy, childhood psychological or head trauma, substance abuse, and other medical conditions may affect the course of the disorder. Conversely, an early intervention may improve adaptive skills (Boat and Wu, 2015, p. 172).

2.3 Classification

There are three essential components to the main diagnostic criteria used for classifying learning disability: 1) evidence of significant intellectual impairment assessed using a valid assessment and normally considered to be present when there is a score less than two standard deviations below the mean; 2) evidence of significant impairment in adaptive functioning; and 3) the disability originating in childhood (Geddes *et al.*, 2020).

Two different systems for classifying intellectual disability used in the United States are that of the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Diagnostic and Statistical Manual of Mental Disorders, which is published by the American Psychiatric Association (APA). Both systems classify severity of intellectual disability according to the levels of support needed to achieve an individual's optimal personal functioning (Boat and Wu, 2015).

The Diagnostic and Statistical Manual of Mental Disorders (DSM), first published in 1952, and now DSM-5 (APA, 2013) state that intellectual disability involves impairments of general mental abilities that impact adaptive functioning in three domains. These domains determine how well an individual copes with everyday tasks: The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory; the social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities; the practical domain centres on self-management in areas such as personal care, job responsibilities, money management, recreation, and organising school and work tasks. While intellectual disability does not have a specific age requirement, an individual's symptoms must begin during the developmental

period and are diagnosed based on the severity of deficits in adaptive functioning. The disorder is considered chronic and often co-occurs with other mental conditions like depression, attention-deficit/hyperactivity disorder, and autism spectrum disorder.

The APA updated the definition of learning disability ('specific learning disorder') in DSM-5 (2013) as part of its reorganisation of the constellation of 'mental disorders' and changes in knowledge in the field of learning disability. Culminating a 14-year revision process, DSM-5 was instigated to address major criticisms of DSM-IV including a lack of clear separation between the defined disorders, excessive comorbidity, overreliance on the "not otherwise specified" category, and inadequate consideration of changes across developmental stages (Tannock, 2013). The guiding principle of DSM is that it is designed primarily to be an evidenced-based tool to guide clinicians in assessment and diagnosis of psychiatric disorders.

DSM-5 classifies Intellectual Disabilities under the category of Neurodevelopmental Disorders and describes three diagnoses: (I) Intellectual Disability (Mild, Moderate, Severe, and Profound); (II) Global Developmental Delay; and (III) Unspecified Intellectual Disability. Global Developmental Delay is a diagnosis given to children under the age of 5 who are not able to participate in standardised assessment procedures due to typical developmental limitations for the age or delays in development. Unspecified intellectual disability is a diagnosis reserved for children over 5 years of age who could not be assessed due to multiple factors, such as a physical disability or co-occurring mental illness. These two diagnoses require reassessment at a later date. The DSM-5 diagnostic criteria include deficits in intellectual functions such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience. Deficits in adaptive function affect communication, social participation, and independent living activities (Patel, 2018). Scanlon (2013) argues that learning disability should also be recognised as a neurocognitive disorder which includes cognitive decline rather than just neurodevelopmental which has its origin in the developmental period.

DSM-5 emphasises the need to use both clinical assessment and standardised testing of intelligence when diagnosing intellectual disability, with the severity of impairment based on adaptive functioning rather than IQ test scores alone. By removing IQ test scores from the diagnostic criteria, but still including them in the text description of intellectual disability, DSM-5 ensures that they are not overemphasised as the defining factor of a person's overall ability, without adequately considering functioning levels. The assessment of intelligence

across three domains (conceptual, social, and practical) is to ensure that clinicians base their diagnosis on the impact of the deficit in general mental abilities on functioning needed for everyday life. This is especially important in the development of a treatment plan (American Psychiatric Association, 2013).

The DSM-5 definition of intellectual disability encourages a more comprehensive view of the individual than was true under the fourth edition, DSM-IV. The DSM-IV definition included impairments of general mental abilities that affect how a person functions in conceptual, social, and daily life areas. DSM-5 has placed more emphasis on adaptive functioning and the performance of usual life skills. Intellectual disability as a DSM-5 diagnostic term replaced "mental retardation" used in previous editions of the manuals. In addition, the parenthetical name "(intellectual developmental disorder)" is included in the text to reflect deficits in cognitive capacity beginning in the developmental period. Together, these revisions bring DSM into alignment with terminology used by the World Health Organization's International Classification of Diseases.

The American Association on Intellectual and Developmental Disabilities (AAIDD) has refined and modified intellectual disability diagnostic criteria since 1921. The AAIDD definition and APA definition are quite similar. The primary criteria remain the same although the labels are slightly different, for example AAIDD labels adaptive functioning as adaptive behaviour which also comprises conceptual skills, social skills, and practical skills (AAIDD, 2010). Both systems use severity codes, however, instead of classifying by the severity of functional limitations, the AAIDD assesses severity based on the intensity of supports that are needed. These needs are typically identified using a standardised support need instrument such as the Supports Intensity Scale (AAIDD, 2004). The AAIDD system evaluates a person's strengths and abilities, not just their limitations. (See figure 2.1).

Figure 2.1: The American Association on Intellectual and Developmental Disabilities model of intellectual disability (AIDD-II model). Copyright holder is the American Association on Intellectual Disabilities.

In 1980 the World Health Organization (WHO) proposed a system of classification that attempted to overcome the limitations of other earlier methods of classification, and that aimed to guide intervention. In this system, learning disability can be conceptualised at both biological and social levels. In 2001, WHO replaced this system of classification with a new system that switched from a system that was seen as just characterising the negative to a system of classification that also emphasised the positive: what an individual is able to do, rather than just what they cannot do. WHO's Clinical Descriptions and Diagnostic Guidelines for ICD-10 Mental and Behavioural Disorders define a "disorder" as a "clinically recognisable set of symptoms or behaviour" that is usually associated with interference with personal functions or with distress. The term places intellectual disability at the same level of other major disorders such as dementia or schizophrenia.

Figure 2.2: The World Health Organisation's International Classification of Functioning Disability and Health model of intellectual disability (WHO ICF model). Copyright holder is The World Health Organisation.

2.3.1 Severity of intellectual disability

The long-held theory that learning disability could be measured by an aptitude-achievement discrepancy has been soundly disputed as an inadequate theory and has been discredited empirically (Scanlon, 2013). The updated definition in DSM-5 favours educator's practice over psychological science with cognitive skills becoming a determining factor. This shift represents an important change in thinking about what it means to be disabled. Severity levels (see Table 2.1) are discussed in relation to levels of support needed, however, this revised approach risks subjectivity in how people with a learning disability are labelled, which in turn can impact access to services.

Table 2.1 Classifications of Severity. Copyright holder is T. F. Boat and J. T. Wu.

2.3.2 Sub-classification of intellectual disability

There is ongoing ambiguity and disagreement about how to define and describe learning disability; this includes confusion regarding sub-classifications of learning disability (see Table 2.2). In some circumstances different terminology such as "intellectual disability" and "learning disability" are interchangeable labels, but they may be operationalised differently by different services. For example, healthcare services employ the definitions in the diagnostic

manuals, while social services apply them as a prerequisite for assessing whether someone is eligible for social care support; educational services employ a separate legal definition of special educational needs (Leyin 2010).

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Table 2.2: Sub Classifications of learning disability. Copyright holder is A. Leyin.

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Confusion also arises from the differing cut-offs for severe learning disability as benchmarked by systems in the UK (IQ 50–55) and internationally (IQ 35). This is an issue of some importance as the cut-off for severe learning disability has been embedded in many cultural contexts. "Although a 15–20 point difference may seem of little consequence, the difference in the number of people represented by the respective cut-offs is large" (Leyin, 2010, p. 36). This confusion is reflected in UK policy documents, such as the Government's key learning disability strategy Valuing People (2001), which quotes population estimates for people with 'severe and profound learning disabilities' and for those with 'mild/moderate' learning disabilities, which implies adoption of the international system, but from the figures cited one can infer that the population described as 'severe' actually relates to the national classification (Leyin, p. 37). Such figures inform service developments and can impact the lives of people with a learning disability. For example, Leyin points to inconsistency between international and national classification concerning government benefits legislation. Referring to Department of Work and Pensions legislation he states that "authorities looking for clarification on which system should be used would be misguided. If this implied guidance were to be followed, it would result in a significant number of people being refused their entitlements" p. 37).

2.3.3 Criticisms of classification

The debate regarding the differing conceptualisations of learning disability gained momentum and importance in the context of the last revision of ICD-10 and the APA's Diagnostic and Statistical Manual of Mental Disorders. If Intellectual Developmental Disabilities are defined solely as disabilities and not as a health condition it would have a

major impact on the visibility of Intellectual Developmental Disabilities, on national and global health statistics, on health policy, and on the services available to this population. This is because the ICD classification is widely used by the 194 WHO member countries to define the responsibilities of governments to provide health care and other services to their citizens. ICD categories, including categories related to Intellectual Developmental Disabilities, are used throughout the world to specify which people are eligible for what health care, educational and social services under what conditions. Conversely, if Intellectual Developmental Disabilities are considered solely as a health condition, then the term "disability" should not be used to refer to them. But this would be at odds with the position already adopted by many governments and international organisations (Carulla *et al.*, 2011).

Any classification raises questions around validity. Manion and Bersani (1987) argue that people with a learning disability are defined as such by others because they differ from a culturally defined idea of 'normal' intellectual functioning. Learning disability is not an illness or disease and its classification captures an extremely broad range of people whose learning disability can differ in extensive ways, such as the presence or absence of secondary disabilities which will inform the approach to intervention. Comorbidity is increasingly becoming important in the conceptualisation of learning disability. In many cases a learning disability does not occur as an isolated phenomenon (Büttner and Hasselhorn, 2011). Many neurodevelopmental, psychiatric, and medical disorders co-occur with intellectual disability, especially communication disorders, cerebral palsy, epilepsy, and various genetically transmitted conditions (APA, 2013).

Critics of learning disability classification have long been concerned that the resulting definitions are social constructs that creates difference and boundaries that are lasting (Harris 1995; Banton 1983). Williams (2001) argues that aspirations for equality should appreciate difference rather than strive for sameness. Given the heterogeneity of people with a learning disability and the varied and multiple health and support needs, it is clear that no single classification system is fully adequate, and the value of classification depends on the reason for its use. If the question is about the type of support to be offered this will be better characterised through the lens of a more interactive and dynamic model in which barriers to that person's full participation and inclusion in society are the focus of enquiry. However, if the question is about the cause of a child's significant developmental delay, then the focus will be more on an accurate description and characterisation.

Although the use of classification systems has be subject to criticism, there are positive benefits to an individual being assessed as having an intellectual disability. These include:

the prospect of going on to identify the exact cause of a person's intellectual disability; identification and treatment of associated health problems; access to specialised educational support; and additional financial support through the benefits system. The greatest challenge in defining learning disability is remaining current (Scanlon, 2013).

2.4 Social model of disability

The social model of disability has had a fundamental impact on how learning disability is defined and understood. This section details the emergence of the social model, why it has been important and influential, and its impact on public policy.

In the 1900s in England, the characterisation and classification of people with a learning disability resulted in their segregation and institutionalisation. However, over time thinking about how people with a learning disability should be supported has evolved, leading to acceptance of people being supported outside of institutional settings (see Section 3.1 for a history of care policy). The 1960s saw the emergence of concepts such as normalisation (Nirje, 1982) and social role valorisation (Wolfensberger, 1983) as principles that should guide the support of people with a learning disability. These concepts were concerned with promoting autonomy and supporting disabled people to maintain valued roles in society. These social ideas were being formulated alongside advances in genetics, neurosciences and better understanding of the environmental causes of learning disability and have been highly influential in the development of social policy in relation to deinstitutionalisation and community care for people with a learning disability (Chappell, 1992). Whilst normalisation and social role valorisation has had some material benefits in terms of improved quality of services, it maintains the dominant societal position that people with a learning disability need to conform to the norm, thus devaluing difference and diversity of those concerned (Gillman *et al.*, 2000).

Social model accounts of disability were developed by disabled people in response to the prevailing medical model that saw disabled people as 'the problem', and placed responsibility on people with impairments to adapt and fit in with mainstream society. A social model of disability was first developed in Britain by disability activists in the 1970s. In particular, the Union of the Physically Impaired Against Segregation (UPIAS) published their Fundamental Principles of Disability (1976), followed by Finkelstein's exposition of the oppression that disabled people face (1980). The social model defines disability in terms of the social barriers people experience instead of physical impairments that people have.

UPIAS argues: 'society disables people who have impairments: Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society' (UPIAS 1976, p. 4). Supporting this view, Oliver (1998) highlights that 'impairment is the functional limitation within the individual caused by physical, mental or sensory impairment; disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (p. 1447).

Supporters of the social model have been vociferous about its transformational impact: 'The social model of disability has been an emancipatory force in the lives of many disabled people… it has shown how the previously taken for granted, naturalistic category 'disability' is in reality an artificial and exclusionary social construction that penalises those people with impairments who do not conform to mainstream expectations' (Tregaskis, 2002, p. 457). Tregaskis asserts that the social model has allowed disabled people to make sense of their experience and that the discrimination and social exclusion they face is not their fault. Advocates of the social model argue that disability is not a product of bodily pathology, but of specific social and economic structures. It is a social construct and by removing social barriers disability can be eradicated (Finkelstein, 1980).

Oliver (1990) examines ways in which British capitalist society disables people with impairments arguing that if you are unable to work you are defined as being 'in need'. As a result 'disability' has become a structural boundary category between work-based and needs-based distribution systems, which has in turn often been used as an oppressive and stigmatising tool against disabled people (p. 40–41). According to Oliver (1996), it is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation (p. 32). Shakespeare (2001) asserts that the social model of disability was important to the disability rights movement because it shifted the focus from a medical cure or rehabilitation for disability, to a strategy for social change. This social definition strives for the liberation of disabled people by encouraging a discussion of social oppression and inequality, rather than a discussion of disability in terms of physical deficit. In this framework disabled people do not need to change, society does (p.11).

The social model has been influential in public policy relating to disability. The distinction between impairment and disability has been used in a methodological way to understand the psychological and social dimensions of disability. In recognising the social model, the World

Health Organisation definition states: 'disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society' (WHO, 2017).

Kattari *et al*., (2017) argue for the incorporation of the social model in relation to social work stressing that social workers should consider key aspects of the social experience of disability, including what is disabling from the environment and context. They examine educational approaches for social workers, highlighting that they serve clients with disabilities across all age groups in social service settings involving child welfare, schools, health, mental health, and aging services. For many of these settings, the specialty training, terminology, and practice rely on foundational medical models of care with a focus on diagnosis, impairment, and individual coping. This model, they claim actively pathologises those who are disabled and by operating on this model, social work inherently places disability as 'less than, or even something to be fixed' (p. 870). A major critique of the medical model has been the influence that medical professionals and scientists have over the treatment of individuals with disabilities in society. Medical personnel act as important gatekeepers in society and use diagnoses and labelling to determine which individuals receive services. The medical model conflates individuals with disabilities with the sick role and discusses disability as a deficit (Haegele & Hodge, 2016, p.196).

2.4.1 Criticisms of the social model

'The way in which disability is understood is important because the language people use to describe individuals with disabilities influences their expectations and interactions with them' (Haegele and Hodge, 2016, p. 193). The social model of disability has been used effectively by political activists, enabling disabled people to challenge discrimination and marginalisation (Owens, 2015); but this model has also been characterised as an outdated ideology in need of development. The chief criticism is that the social model is not a theory, and that it does not provide an explanation for the disablement process (Beckett and Campbell, 2015). Moreover, the social model has been criticised for its focus on physical impairment at the expense of learning disability. Owens (2015) argues that people with learning disabilities may be excluded by a social model analysis because, for them, adjusting to the social environment is not always possible.

Impairment, dependence and interdependence

Social model perspectives suggest that problems associated with disability may disappear if societal attitudes toward individuals with impairments change, and if public policy focuses on the removal of environmental barriers (Haegele and Hodge, 2016). The social model has sought to effect a complete division between impairment and disability, but in doing so the model has not fully accounted for the lived experiences of disabled people. Several studies have criticised the social model for this failure to recognise the full scope of impairment and dependency. For instance, examining the relationship between carer and cared for, Kittay (2011) postulates that dependency is a feature of all human life, and that caring relationships of dependency 'can transform otherwise unpleasant intimate tasks into times of trust and demonstrations of trustworthiness, gratifying, and dignifying to both the caregiver and the recipient of care' (p. 54). She asserts that the denigration of care and dependency leads to an attitude that renders the work and value of carers invisible, thus creating one oppression in the effort to alleviate another.

Niemeijer and Visse (2016) question the social model's emphasis on independence, and the resulting discourse in which the language of 'rights' comes to dominate. Such a focus on independence may create a backlash against dependence of any sort, 'with those in need of care susceptible to the pejorative meanings associated with illness, dependence or disability' (p. 173). Similarly, Barnes (2011) argues that 'devaluing care risks devaluing those in need of care… Social justice will not be achieved by starting from an assumption that we are all equal precisely because this ignores the real inequalities experienced by those who are dependent on others' support for their very survival' (p. 165).

Kittay (2011) argues that dependence should not be viewed as inherently negative and that it can entail important benefits, such as the prevention of isolation, and enabling the inter-connection of individuals. The care worker can play a critical role in upholding the dignity of people with disabilities, and in mediating between the individual and society at large. Bunting (2006) remarked on a cultural preoccupation with independence and a profound aversion to dependence, vulnerability and need. Yet, in much social care research, there is a recurring emphasis on valuing vulnerability as a human quality, and on challenging the idealisation of independence and self-determination. In their examination of friendships and profound disability, Redley *et al*. (2011) consider the value of dependency in human relations; they propose that 'moral standing does not depend upon having a capacity for purposive action. Rather, it is about being human, where the essence of humanness is vulnerability and dependency on one's fellow human beings… Through becoming friends with adults with

profound disabilities, it is suggested, others can learn to value vulnerability and dependency. In this way, they will come to recognise the humanness of adults with profound disabilities while becoming more truly human themselves (p. 199).

Subsequent chapters in this thesis examine more fully dependency and the role of paid carers in the lives of people with learning disabilities. The fieldwork and discussion in Chapters 6 and 7 identify specific challenges that care workers face when trying to enable individuals who are non-verbal and often lacking mental capacity to have some form of independence in their lives, and question the value of such efforts. Additionally, the reviews of policy and empirical research in this thesis underline the low status of care work and the emotional demands associated with such work. In the context of the value of dependency discussed by Kitty (2001, 20011), the relationship between care staff and those they care for is further highlighted by the intrinsic motivating factors that care staff cite in the fieldwork interviews: they often view those they care for as kin, and find reward in caring for and 'making a difference' to those who depend on them. One could argue that, in the absence of material reward, care staff are dependent on people they support to feel good about themselves (see Chapter 6 for fieldwork results).

There is a tension between the historical narratives of the Disabled People's Movement arguing that care is disempowering, and of feminist thinkers advocating the ethics of care and dependency. Hughes *et al.,* (2005) identify a tendency for feminist writers to valorise the caring relationship, yet for the Disabled People's Movement, care is often demonised and represented as a significant barrier to the independence of disabled people. As Williams (2001) states, 'for many, the very concept of 'care' embodies an oppressive history in which the practices and discourses of paid carers… have maintained disabled people in a position of, at worst, unwanted dependency' (p. 478). However, Fine (2005) observes that 'in place of the hierarchical pattern in which care is seen as requiring the assumption of responsibility and control by the carer, and passivity and gratitude by the care recipient… a more engaged, active, conception of the relationship is emerging, based on the recognition of the rights of both parties as individuals' (p. 257).

This focus on disability rights and empowerment, also causes the social model to neglect the role of those who are critical in supporting such rights. Kittay (2001) argues that the 'dependency relation', between the carer and the person being supported is such that it is unjust to advocate for the person being cared for without also advocating for the carer: the needs and wellbeing of one inevitably impact the other. She asserts that 'those who advocate for vulnerable persons must ask what conditions would encourage an attitude of

care in the caregiver – all the while respecting the caregiver's own needs and desires' (p. 562). Moreover, she states that 'in acknowledging dependency we respect the fact that as individuals our dependency relations are constitutive of who we are and that, as a society, we are inextricably dependent on one another' (570).

Some feminist writers (Tronto, 1993; Williams, 2001) have argued that the concept of independence should be replaced by interdependence. The concept of interdependency draws attention to the ways in which mutual need is embodied in caring activities and caring responsibilities. Williams (2001) argues that 'the processes of caring for or being cared for make one aware of diversity, of interdependence, of the need for acceptance of difference, which form an important basis to citizenship (p. 477). However, Williams recognises that the concept of interdependency needs to take account of the fact that collective struggles around care have placed a premium on independence.

Anastasiou and Kauffman (2013) argue that proponents of the social model use the distinction between impairment and disability to reduce disabilities to a single social dimension – social oppression – and that there are negative consequences to downplaying the role of biological and mental conditions in the lives of disabled people. By detaching the biological and mental elements from the disabled subject, and neglecting or denying the underlying biological conditions of people with disabilities, a big part of their existence and activity is excluded. Making comparisons with race and gender, they assert that despite the fact that disability is part of human diversity, it is not just another difference and cannot be equated with social disadvantage: not all differences are equal. (p. 446). In portraying illness and impairment as being distinctly separate entities, the social model of disability neglects the social relational nature of impairment and illness and fails to account for the variety of ways disability may be experienced (Owens, 2015).

The social model has been criticised for separating 'impairment' and 'disability', reflecting divisions between medical and social models, when these should be seen as inter-connected (Swain & French, 2000). Social barriers may limit participation but, irrespective of social change, physical and mental impairments still create genuine limitations. Medical factors can be as critical as social factors; one model should not be a substitute for the other. Shakespeare (2001) argues that individuals are disabled both by social barriers and by their bodies, noting that in some situations medical intervention may be appropriate while in other situations changes to personal circumstances may be required. He remarks that while some activists deny the relevance of the body in their public comments, in private disabled people concede that they talk about 'aches and pains'; the situation is more complex than either/or.

Barnes (1999) also highlights that disability is both a biological condition *and* a social construct. Visible and invisible impairments have different implications for health and personal capacity and elicit different social responses.

The future for the social model

The social model has helped to transform the lives of many disabled people. Since the introduction of the 1995 Disability Discrimination Act, many barriers to the social inclusion of disabled people have been lowered or removed, with organisations making reasonable adjustments to disability (Levitt, 2017). However, Oliver (1996) highlighted the extent to which the social model was 'becoming a straight-jacket for our experience' (p. 31). He remarked that at no point did he claim 'that the social model was an all-encompassing framework within which everything that happens to disabled people could be understood or explained'; furthermore, he has 'never seen the social model as anything more than a tool to improve peoples' lives' (2013, p. 1025).

Shakespeare (2001) contends that the British social model of disability has outlived its usefulness and that 'it is time to put the whole thing to one side and start again' (p. 14). The crux of his argument centres on the assertion that 'we are all impaired', and that acceptance of this offers a different strategy for disability studies. Similarly, Goodley (2001) notes that writers in disability studies are questioning the assumptions that underpin the social model of disability and refocussing attention onto impairment. 'Rather than viewing a turn to impairment as de-politicising, re-medicalising and 'watering down' the social model, more and more writers are arguing that a focus on impairment, alongside an alliance with the social model and disability movement, re-socialises impairment' (p. 208).

Becket and Campbell (2015) refer to the dangerous, and unintended consequences of the social model. They argue that 'the social model has travelled far beyond the movement. It has been co-opted by the state. For example, the current Government's Office for Disability Issues claims to have adopted a social model understanding of disability, but in our view this is an impoverished version of the model that equates to an emphasis on the removal of barriers in order to increase independence and reduce the 'risk' of dependency.' (p. 277). Oliver remarks that despite the positive impact that the social model has had in the past 30 years, the existing economic climate is proving disastrous for many disabled people whose benefits and services are being severely cut back or removed altogether (2013, p. 1024). Oliver contends that these cuts are being justified on the grounds that the intention is to give more to those who are severely impaired (and hence deserving) and not to those who are

not (and hence undeserving). At the same time, he criticises the political campaigning to protect benefits and services for forcing disabled people back into the role of victims, taking disabled people back more than 30 years to the time before the social model came into existence (2013, p. 1026).

Ultimately, the scope and complexity of learning disability argue against ascribing it to a single model or definition; a more effective understanding emerges when considering the interrelation of different ideas around biology, society and physicality. As Anastasiou and Kauffman (2013) remarked, the understanding of disabilities is too complex and multifarious to be unlocked by one-dimensional cultural or biological explanations. What is needed is a unified, and multifaceted understanding of disability that clarifies the relationship between several factors: the biological and cultural, individual and social, psychological and behavioural, intrinsic and external factors affecting the lives of people without obscuring or neglecting any one of these levels of analysis (p. 454).

The social model was rooted in activism, partly as a reaction to the medicalisation and institutionalisation of disabled people and their separation from mainstream society. It represented a paradigm shift in how disability was understood, but at the same time it diminished recognition of people's real dependencies and differences. Beckett and Campbell (2015) argue that in the absence of an alternative, abandoning the social model is likely to destabilise the disabled people's movement, and that new ways of using the social model appropriate to our times need to be developed. Any such development must value difference, recognise and address the negative representation of dependency, and articulate relationships of interdependence between disabled and non-disabled people.

2.5 Chapter summary

The changing terminology and understanding of learning disability, and the different purposes for diagnosing disability, highlight the challenges that arise when trying to identify commonalities in a condition that affects individuals differently, and that is often not the only condition impacting an individual. Development in the understanding of learning disability has been mirrored by the shift in policy from a medical model rooted in segregation and institutionalisation to a social model vested in autonomy and community-based support. Has this shift in understanding and classification contributed to disability policy that better meets the needs of people with a learning disability and those who support them? In the next chapter I examine the policy landscape.

Chapter 3: Review of social care policy

This Chapter is divided into two parts. The first part (3.1) provides an historical overview of social care policy in England, starting with The Poor Law (1601). Drawing on academic literature, I present a policy timeline (see Table 3.1) highlighting key policies that have impacted the provision of care and support for disabled people. The second part of this chapter (3.2) presents a documentary analysis of more recent policy from The National Health Service and Community Care Act (1990), which restructured care provision with a focus on the individual, to The Care Act (2014), which the Government promoted as the most significant reform of care and support in more than 60 years. The purpose of this chapter is to contextualise the development of care and support for people with a learning disability in England, and examine the representation of the care workforce in policy documents. The insight from this chapter will inform the study discussion of the role that support workers play in enacting government policy, and the relationship between policy and practice (Chapter 7).

3.1 A history of care

Poor Law to post war

People with learning disabilities in the UK have been subject to a series of policy developments, which traditionally sought to segregate and exclude them from 'mainstream' society (Simpson and Price, 2010). Historically, care was considered the responsibility of the family, provided in the domestic sphere, with women seen as natural carers and the responsibility falling to them. Before the Second World War, the only publicly funded social care for disabled people was provided through the Poor Law. From 1601, the Poor Law required every parish to levy rates to care for people without family support. The Poor Law was amended in 1834 to withdraw support for people deemed capable of work. By 1845, two-thirds of English and Welsh counties provided publicly funded asylums (Thane, 2009). Confinement of 'the mentally ill' or 'deficient' in institutions against their will, as legislated in Britain in 1845, was characteristic of the social control imposed on this population through the power accorded to physicians (Ravaud and Striker, 2001, p. 504). Swain (2003) attributes the increasing "weeding out" of people with impairments to the Industrial Revolution and its fast-paced production requirements. Such people were 'segregated from mainstream society and confined within workhouses, asylums, hospitals, colonies and special schools' (p. 24). Town planning, such as transport, education, housing, and leisure,

was designed to meet the needs of its workers, the assumption being that people with impairments would have their needs met elsewhere.

By the beginning of the 20th Century, there was a clear division between care provided at home by the family and care provided by the state in institutional settings, the latter often the last resort with little or no family involvement. The British history of social work in learning disability can be traced back to the 1913 Mental Deficiency Act. Although ushering in a nationwide system of institutional care, this legislation also marked the start of community care for people with intellectual disabilities and their families (ibid. p. 5).

The post-war period was characterised by increased awareness of disability and by increasing rights for disabled individuals. Fine (2005) associates the rise of care as a public issue at this time with marked social and economic change, such as the large-scale entry of married women into the paid workforce, which disrupted the expectation of women as default caregivers. Heightened awareness of disabled people following the war and returning injured conscripts led to the Disabled Person's Employment Act of 1944 (Thane, 2009). This Act required employers of more than 20 people to employ at least 3% from a newly instituted Disabled People's Register. The National Assistance Act of 1946 abolished the Poor Law and established a National Assistance Board, which took over responsibility for means-tested benefits. Section 21 of the Act stated the duty of every local authority 'to provide residential accommodation for persons aged over 18 who by reason of age, infirmity or any other circumstances are in need of care and attention which is not otherwise available to them'. Older and disabled people were divided into the sick, who were placed in hospitals, and those needing care and attention who were placed in residential homes, overwhelmingly former workhouses (Thane, 2009). Although NHS services were 'free at the point of delivery', local authorities could levy means-tested charges for social services, and commission fee-charging independent services.

1960s – 1990s: From institutions to individuals

Until the late 1960s individuals with profound disabilities would have been patients in large hospitals (see Chapter 2, Table 2.1, for severity levels). Gradual policy changes were driven by increasing evidence of the damaging effects of large-scale institutions, clinical research that challenged the idea that adults with profound disabilities are uneducable, the growth of social movements such as the disability rights movement (Hughes *et al.*, 2011, p. 198), and the rising cost of care. This led to a move towards the replacement of in-patient with out-

patient care for the mentally disabled. In 1966, the National Assistance Board was replaced with the Supplementary Benefits Commission, which was then absorbed into a new Department of Health and Social Security where it remained until 1988 when a separate Department of Health was established.

Institutional provision dominated until the mid- to late-1970s when new ideas about human rights began the drive towards community care (Bigby and Atkinson, 2010). This was signalled with the publication of the White Paper 'Better Services for the Mentally Handicapped' (1971) which stated an ambition to move from institutional to more local, community care. It committed government to helping people with a learning disability to live 'as normal a life' as possible, without unnecessary segregation from the community. Policies of de-institutionalisation began to gather pace when the ideological tenets of normalisation - concerned with promoting autonomy - coincided with the introduction of free-market economic policy and its expansion into social welfare during the 1990s (see Chapter 2, Section 2.6 for discussion of the social model of disability and normalisation).

Since the 1980s, the UK health and social care sector has developed more inclusive concepts in policy and practice, shifting emphasis from institutions to personalised, community-based care. Hainsley and Webb (2000) state that 'the move from institutional to community care has been one of the most marked shifts in government policy during the twentieth century' (p. 512). The shift from institutional to community care moved faster in the 1980s due to a government commitment to cutting public spending, and its preference for private over public provision. (Thame, 2009, p. 11). The 1986 Disabled Persons Representation Act attempted to give disabled people more input into policy-making at a local level. In the same year, the Audit Commission reviewed community care and found much of it to be seriously uneconomic, inefficient, and ineffective. Following this, the Government decided to set up its own review led by Sir Roy Griffiths, deputy chairman of the National Health Service Management Board. The Griffiths report, published in 1988, suggested radical change to community care. The report recommended that local authorities should assess needs objectively, and buy care which may be provided by private or voluntary agencies. He advised that the Department of Social Services' payment for residential and nursing homes should be diverted to local authorities for providing community care, and the funds should be ring fenced (Griffiths, 1988). Many of the proposals in this report informed the Community Care Act, 1990.

The 1989 White Paper *Caring for People* (enacted in the National Health Service and Community Care Act, 1990), declared that local authorities should be the brokers and care

managers of social care, but not necessarily the direct providers. This led to a reduction in the number of individuals supported in homes provided by local authorities and a significant growth in the private and voluntary sectors, which now provide the majority of state-funded residential care (The King's Fund, 2006, p. 9). The idea of the local authority as broker and care manager, but not necessarily as direct provider was revolutionary at the time. The role of the public sector was now essentially to ensure that care was provided but *how* it was provided required a new way of working for local authorities. Compulsory competitive tendering meant local authorities became purchasers of services provided by others. These measures were accompanied by general reductions in central government funding and penalties for overspending local authorities. Social and economic policies combined to create a new social welfare landscape, which shaped subsequent decades (Simpson and Price, 2010).

The growing influence of the disabled people's movement during the 1980s and 1990s, and the demand for equal rights led to the first Disability Discrimination Act being passed in Britain in 1995. Despite being the most comprehensive anti-discrimination legislation at the time, the Act offered limited protection because not all disabled people were covered by the Act. The Act was amended in 2005 to extend the definition of disability and disabled people's rights in more areas.

Table 3.1 Policy timeline *(sources: Whittington et al., 2009, Thane, 2009, and Grant, 2013).*

1601	*The Poor Law:* makes economic provision for people dependent on charity, which includes disabled people.
1834	*The Poor Law Amendment Act:* ensures that conditions within workhouses should always be worse than the worst conditions outside them; and relief should only be available to those within workhouses. This results in more disabled people being forced into institutions.
1845	*The Lunacy Act and The County Asylums Act:* requires asylums to be registered and have a resident physician.
1886	*The Idiots Act:* allows local authorities to build separate asylums for intellectually impaired patients.
1913	*Mental Deficiency Act:* categorises people with learning disabilities as 'idiots', 'imbeciles', 'feeble-minded' or 'moral defectives'. Institutional separation of 'mentally deficient' who are taken out of Poor Law institutions into newly established colonies.
1944	*The Disabled Persons (Employment) Act:* sets up a quota system requiring employers with 20 or more employees to ensure that at least 3% of their workforce are disabled people.
1959	*Mental Health Act:* aims to establish community-based services for people with mental health needs and to close down long-stay hospital provision.

1968	*Seebohm Report, White Paper:* proposes major restructure of divided social services into a single, unified Social Services Department.
1970	*Social Service Act:* establishes Social Services Department.
1970	*Chronically Sick and Disabled People Act:* places a duty on local authorities to know the numbers and needs of disabled people in their area, and where necessary to make arrangements to meet individual disabled persons' needs.
1971	*Better Services for the Mentally Handicapped White Paper:* outlines government ambitions to move away from institutional settings to local and community care.
1975	*Better Services for the Mentally Ill, White Paper:* seeks the expansion of local authority social services, with specialist mental health services provided through local general hospitals.
1983	*Mental Health Act:* creates the approved social worker role, establishing an independent assessment alongside medical recommendations on the need for compulsory hospital admission. Consent to treatment was not mentioned in the 1959 Act but was a crucial new feature in the 1983 Act.
1986	*The Disabled Persons Act:* strengthens the provisions of the Chronically Sick and Disabled Persons Act 1970 and requires local authorities to meet the various needs of disabled people.
1989	*Caring for People White Paper:* promotes domiciliary care, collaboration between services in the assessment of needs and design of care by local authorities, and support for carers.
1990	*National Health Service and Community Care Act:* makes local authorities responsible for organising community care, emphasising support for people in their own homes where possible. Introduces requirement for local authorities to promote the independent sector.
1995	*Carers (Recognition and Services) Act:* enables unpaid carers to request an assessment of their needs, when the person they are caring for is having an assessment of their needs.
1995	*Disability Discrimination Act:* makes it illegal to discriminate against disabled people in connection with employment, the provision of goods, facilities and services. Service providers must now make reasonable adjustments to enable disabled people to access their services.
1996	*The Community Care (Direct Payments) Act:* introduces powers for certain categories of people to be able to receive a cash payment in lieu of services that they can use to arrange their own support.
1998	*Modernising Social Services, White Paper:* focuses on promoting independence, improving protection, and raising standards.
2000	*Care Standards Act:* aims to protect the interests of service users and carers by introducing new mechanisms for inspection of social care, and regulation of social care staff by national social care councils.

2001	*Valuing People, White Paper:* promotes four key principles of rights, independence, choice and inclusion for people with learning disabilities. Partnership working through local partnership boards and agency cooperation seen as central to achieving these principles.
2005	*Mental Capacity Act:* empowers and provides protection for vulnerable adults who may lack capacity to make their own decisions. Social/care workers acting on behalf of someone who lacks capacity must act in the person's best interests in line with a Code of Practice.
2005	*The Disability Discrimination (Amendment) Act:* extends protection to land, transport, small employers and private clubs; extends the definition of disability; and introduces a duty for public bodies to promote disabled people's equality and inclusion in public life.
2006	*Our Health, Our Care, Our Say: A new direction for community services, White Paper:* sets out a vision for integrated health and social care services. Focus on prevention, health and wellbeing. Emphasises need for staff to have the right skills, and promotes greater choice by extending direct payments, more personalised care, and piloting individual budgets.
2007	*Mental Health Act:* amends the 1993 Act broadening the group of professionals who undertake approved social worker functions.
2007	*Putting People First:* Government protocol which promotes independent living for all adults through a joined-up partnership between local and central government, the voluntary sector, providers and the social care regulator.
2008	*Health and Social Care Act:* creates a new regulator (Care Quality Commission) to provide registration and inspection of health and adult social care services together for the first time, with the aim of ensuring safety and quality of care for service users.
2009	*Valuing People Now:* policy setting out the Government's 3-year strategy to realise the vision of Valuing People.
2009	*United Nations Convention on the Rights of People with Disabilities:* UK ratification
2010	*A Vision for Adult Social Care: Capable communities and active citizens:* policy setting out the Government priorities for improving outcomes for service users, with a greater focus on preventative measures, and personalising services.
2010	*Building the National Care Service, White Paper:* proposes the creation of a National Care Service, places a new duty on NHS bodies and local authorities to deliver integrated adult care services, and introduces a licensing scheme for all social care workers.
2010	*The Equality Act:* replaces the DDA and previous anti-discrimination laws with a single Act. Outlaws direct or indirect discrimination and harassment in employment, vocational education and the provision of goods and services for a total of nine protected characteristics including disability. Provides protection for unpaid carers' rights.
2012	*The Welfare Reform Act:* proposes the replacement of the Disability Living Allowance with Personal Independence Payments.
2014	*The Care Act:* New duties on local authorities concerning assessment, and promoting wellbeing and independence of individuals, safeguarding people from neglect and abuse, and shaping market provision. New regulatory powers to enforce quality and continuity of care. New legal rights for unpaid carers.

3.2 Documentary analysis of policy: The Community Care Act 1990 to the Care Act 2014

3.2.1 Aim

The aim of the documentary analysis was to identify direct reference to paid support workers of adults with a learning disability in government policy in England in the last 30 years. The analysis also reviewed references that indirectly concern paid support workers in relation to learning disability and social care provision. The purpose of the analysis was to provide context and test the premise of this thesis that the voices and contribution of paid support workers are largely absent from government policy, resulting in a gap between policy and practice. The findings from this documentary analysis, along with the systematic review of empirical studies in Chapter 4, have informed my fieldwork, providing insight into policy ambitions as a basis for comparison with actual care practice. The documentary analysis also allowed me to compare findings across different sources of data in the present study, contributing to the credibility of the findings and the discussion of support workers' role in enacting learning disability policy.

3.2.2 Method

For the documentary analysis I examined legislative acts, and White Papers which encompassed learning disability and adult social care. This included legislation and policy that related to disability and social care generally but did not include government documents which were specific to another disability (such as the Autism Act) or a specific area of policy (such as Special Education Needs). The analysis also excluded policy that was broad in scope with no reference to the area of analysis (such as the Disability Discrimination Act). While I did not include Green Papers or other government papers, reference is made to documents that were particularly influential to learning disability care and support. In order to remain focused on government policy as it affects England, I did not consider devolved or specific policies concerning Scotland, Wales or Northern Ireland or laws outside the UK.

The policy documents for analysis were drawn from the policy timeline in Table 3.1, which was primarily informed by previous research undertaken by Whittington *et al.*, (2009), Thane (2009), and Grant (2013). Given the consistency between these papers, I was confident that the key documents concerning adult learning disability and social care had been identified and also consulted my academic supervisor. In addition, I undertook a search of primary

legislation through the HM Government legislation website (www.legislation.gov.uk) using the search term 'learning disability', from 1990-2016. This generated 106 results. I removed results that were not related to this search, such as those concerning children, and others sectors such as education.

A total of 15 documents were identified for analysis. These are summarised in Table 3.2 and detailed in the findings in Section 3.2.3. Three methods of analysis were applied: skimming (superficial examination), reading (thorough examination), and interpretation (Bowen, 2009). I used a combination of content analysis, searching for reference to paid support workers using keyword searches ('workforce', 'workers', 'work', 'care'), and thematic analysis, examining the context in which support workers were mentioned, and/or themes that were relevant to care work, whether or not they were mentioned. These themes were referred to for comparison with the thematic analysis of the fieldwork in Chapter 6. I reviewed academic literature to inform the critique and commentary on the documents included in this review.

Table 3.2 Documentary analysis of legislation and policies (White Papers) concerning adult social care and learning disability

Date	Document	Reference to paid support workers	Relevance to paid support workers
1990	NHS and Community Care Act	None. General reference to the need for local authorities to consult voluntary organisations who represent the interests of people they support.	Indirect impact of greater market competition and pressure on resources. Local authority care plans expected to be tailored to individual needs.
1996	The Community Care Act (Direct Payments)	None.	While this Act does not cover residential care serves, it has workforce implications in that it provides an ability for disabled people to directly employ support staff (personal assistants). There is no reference to the availability and competence of such a workforce.
1998	Modernising Social Services: Promoting Independence, Improving Protection, Raising Standards. White Paper	Workforce referenced in dedicated chapter on improving standards, which is through the establishment of a General Social Care Council and national training strategy. Workforce mentioned in relation to risk of abusing people in their care, and systems that protect the public.	Emphasis on supporting independence, consistency and 'user-centred services'. Partnership working between health and social care emphasised.
2000	Care Standards Act	New requirements concerning registration, regulation and training of social care workforce. Provides for a register of individuals unsuitable to work with vulnerable adults	Provides for care home inspections and new care standards which has implications for how commissioners and providers of care prioritise and allocate resources.
2001	Valuing People. White Paper	Chapter on 'Quality' with subsection on workforce training. Workforce highlighted as unqualified, unskilled, low status, and failing to involve service users in planning. This is to be addressed through workforce strategies and training qualifications.	Focus on four principles: rights, independence, choice and inclusion. Partnership working between health and social care emphasised. Promotes person-centred support, equal access to public services such as health and housing, and advocacy support. Specialist support for people with challenging behaviour.
2005	Mental Capacity Act	None.	Significant implications for support workers who are required to empower people they support to make decisions, understand capacity and – where capacity is deemed to be lacking, support decisions in the individual's best interest.

2006	Our Health, Our Care, Our Say: A New Direction for Community Services. White Paper	Workforce mentioned in generic context as needing the right skills. Also mentioned under risk management in relation to direct payments as an 'untrained', 'unregulated' risk to be addressed by the development of a risk management strategy. The paper repeatedly refers to the lack of qualifications and capacity of the workforce, as well as recruitment and retention issues.	Emphasis on personalisation, independence, wellbeing and choice for service users, use of direct payments, and partnership working between health and social care.
2007	Mental Health Act	None. Amended the 1983 Act.	The MHA was used to amend the Mental Capacity Act (2005) adding new provisions on the restriction of the deprivation of liberty for someone who lacks capacity. This has significant implications for support worker decision-making on behalf of people they support and involves new processes of approval.
2008	Health and Social Care Act	Established the Care Quality Commission (CQC) responsible for registering and inspecting health and social care service. Staffing is mentioned under the Regulations, which requires providers to recruit 'fit and proper' persons, and to support staff to undertake their care duties through a series of measures.	Sets out the remit of the CQC with implications for the standards and procedures care providers and their workforce must meet in supporting service users. The Regulations provide more specific requirements which include person-centred care, and enabling choice and independence.
2009	United Nations Convention on the Rights of People with Disabilities, UK Ratification	None.	Specific Articles concerning protection from abuse, and disabled people's right to independent living, choice in where and who they live with, access to residential and community services, community inclusion, and appropriate financial assistance.
2009	Valuing People Now. Policy document	Focus on developing the skills and values of the social care workforce to deliver personalisation and to support people with personal budgets, who may demand different types of support.	Partnership working emphasised. The four principles of rights, independent living, choice and inclusion, from the 2006 White Paper are reaffirmed.

Year	Document	Workforce focus	Service user / personalisation focus
2010	A Vision for Adult Social Care: Capable Communities and Active Citizens. Policy document	Frontline staff recognised as critical in delivering personalisation and promised greater freedom to improve support for people. Emphasis on improving training and capability of staff, a workforce skills strategy to support personalisation, and tackling recruitment, retention, and sickness absence. Staff wellbeing recognised, and a new occupational health strategy proposed.	Regular reference to ensuring quality of support, personalisation and enabling people to have choice and control, particularly through personal budgets. Partnership working emphasised, especially at a local level.
2010	Building the National Care Service. White Paper	Workforce quality and competence addressed in chapter on 'embedding quality'. Briefly acknowledges staff contribution and focuses on the need to have the right people and skills. References the Independent Safeguarding Authority as excluding unsuitable workers, and the introduction of a licencing scheme for social care workers.	Emphasis on choice and control for service users, personalised support, and partnership working between health and social care.
2012	The Welfare Reform Act	None.	Introduces Universal Credit and Personal Independent Payments which has significant implications for how disabled people are assessed and receive state support. Unpaid carers are acknowledged in relation to state pension provision.
2014	The Care Act	None.	Reform of social care with significant implications for how care and support is delivered. While paid carers are not mentioned in the Act, unpaid carers receive new rights.

3.2.3 Findings

This section summarises the main provisions in the fifteen policies reviewed which impact the care of adults with a learning disability. I highlight where there is specific reference to paid support workers, or to the social care workforce in general.

National Health Service and Community Care Act, 1990

The first two parts of this Act focus on the NHS; part three focuses on Community Care and the provision of accommodation and welfare services. The objectives of the Community Care Act was to stimulate competition in care provision so that the social care needs of people could be more effectively and efficiently met, and to stop the 'perverse incentives' to use private residential and nursing home care (Kwok and Hastie, 1995, p. 259). Under this Act, any adult aged 18 or over who is eligible for and requires services from the local authority has the right to a full assessment of their needs. The services that are provided should be individually tailored to meet those assessed needs. At the local level, joint health and social services are established whose functions include producing an annual community care plan. In preparing the care plan, the Act requires local authorities to consult 'voluntary organisations' and 'private carers' that represent the interest of people receiving their services (paragraph 46). There is no other reference to care providers or care staff in the Act.

The legal changes transferred funding responsibility for residential care from the Department of Social Security to local authority social services. According to Thornicroft (1994) 'one of the key motives behind the legislative changes was to find a way of both limiting and rationalising expenditure on residential and nursing home care... A clear intention of the changes was to enable care managers to buy domiciliary support, rather than residential care where this was both more appropriate and inexpensive' (p. 15).

Walness (2006) claims the 1990 Act left significant challenges for social care. 'Some of these difficulties owed as much to what was not in the Act as to what was…The failure of the Act to address health and social care issues in the round is striking…The failure to address these as an integrated agenda ensured that loose ends dangling from both would eventually unravel and require more fundamental attention' (p. 15). Kwok and Hastie (1995) highlight the risk of a 'mismatch between assessed needs with the provisions that local authorities are able to make (p. 259).

Community Care (Direct Payments) Act, 1996

Following sustained campaigning by the disability rights movement, the Act was passed and enabled local authorities to make cash payments directly to disabled adults. The legislation overturned the prohibition placed on local authorities by the National Assistance Act, 1948 on providing cash payments to disabled people. While the Act did not cover residential services, it was seen as a major breakthrough for disabled people: many found that the services received when controlling one's own resources were superior to those provided by the state (Swain, 2003). Direct payments were seen to empower disabled individuals, enabling them to commission their own care, and to become de facto employers procuring their own support. However, Williams (2001) was critical of direct payments, as it allowed welfare states to distance themselves from the actual delivery of care. Swain (2003) highlighted that individuals with a learning disability were disadvantaged by the Act requiring capacity to consent to direct payments.

While providing for disabled people to directly purchase the support they require, the Community Care Act does not make any reference to the workforce that was expected to provide this support. Scourfield (2005) questioned whether the employment market was suitably skilled and competent and asked: 'with demand set to grow, will there be an adequate supply of reliable workers to employ?' (p. 469).

Modernising Social Services: Promoting Independence, Improving Protection, Raising Standards, 1998

This White Paper set out the Government's vision for improving the provision of social services and supporting social inclusion. It states that 'social services are often failing to provide the support that people should expect' (1.4). The proposals refer to a 'third way for social care' which moves focus from those who provide care to those who experience that care, with the emphasis on supporting independence, creating fairer more consistent services, and ensuring services fit individual needs (1.7).

The first reference to the social care workforce in this document is in the context of risk and staff as perpetrators of abuse and neglect of vulnerable people they care for (1.4). The paper calls for better, consistent safeguards and enforcement, and seeks to address this through the establishment of eight regulatory regional Commissions for Care Standards, and by setting national standards in place of the existing 250 registering authorities.

The social care workforce are a prominent feature in this paper, with a dedicated chapter entitled 'Improving standards in the workforce' (Chapter 5). The core focus of this chapter is raising standards in care staff through the establishment of a General Social Care Council, and a national training strategy. While stressing that people who receive support should be confident that staff are sufficiently trained and skilled, the paper states that 'staff themselves should feel included within a framework which recognises their commitment…' (1.8). The Government recognises that 'people who work in social services have to deal with some very difficult people and many very difficult circumstances [and] often find themselves the target for criticism'. However it goes on to state that '…inspections show that the criticism of the service is justified but…we recognise that the law and the central framework within which social services operate is also at fault. They need to be changed so that they help those working in the services rather than hindering them' (1.5).

This is the only paper in this documentary analysis that considers frontline staff in any detail while acknowledging the criticisms. For example, Section 5 states: 'There are few public accolades for getting it right and virulent criticism for getting it wrong. Staff can feel embattled and undervalued, and their morale suffers… Nevertheless, there are serious problems ... 80% of this large workforce which works directly with very vulnerable people have no recognised qualifications or training; there are no national mechanisms to set and enforce standards of practice and conduct ... [and] the standards and suitability of some education and training in social care do not enjoy general confidence' (5.2-5.3). This chapter also highlights the absence of any accepted 'set of values and ethics or standards of conduct and practice which is reflected in the attitudes of staff as a whole (5.14). The establishment of a General Social Care Council is expected to create appropriate regulation and standards for staff, and for professional social work training. The paper states that 'good social services cannot be delivered without good staff', and introduces an awards scheme to recognise outstanding social care staff (5.40). The paper also identifies that staff will need support by a clear definition of their role by employers, clear objectives, better supervision and management.

The paper sets out to address a number of other failures in provision which include: inflexibility of services as suiting the service rather than the needs of the service user, which can increase dependency and exclusion; consistency in quality of service provision; and lack of clarity among staff of what services and standards should be provided. The priority for improvements in adult services are stated as 'promoting independence, improving consistency, and providing convenient, user-centred services' (1.10).

Care Standards Act, 2000

The Care Standards Act reformed the regulatory system for care services in England. It established a new, independent regulatory body for social care and private and voluntary healthcare services - the National Care Standards Commission (NCSC), and provided for the regulation, registration, and training of the social care workforce by establishing a General Social Care Council for England. The Council is required to promote high standards of conduct and practice and promote high standards of training. The act also provided for a register of individuals considered unsuitable to work with vulnerable adults.

The Act defines a 'social care worker' as: 'a person engaged in work for the purposes of a local authority's social services functions, or in the provision of services similar to services which may or must be provided by local authorities in the exercise of those functions; or a person engaged in the provision of personal care for any person' (55:3). A 'care worker' is defined as: 'an individual who is or has been employed in a position which is such as to enable him to have regular contact in the course of his duties with adults to whom accommodation is provided at a care home; or an individual who is or has been employed in a position which is concerned with the provision of personal care in their own homes for persons who by reason of illness, infirmity or disability are unable to provide it for themselves without assistance' (80:2).

Registered social care workers must abide by a code of conduct and occupational standards. A person who breaches standards of conduct may be suspended or removed from the register. The Act proposes the introduction of management qualifications for care home managers but Nazarko (2001) asserts that this will reduce the available pool of managers and increase wage costs (p. 9). The Act gives inspectors the right to interview any manager, member of staff or resident privately. According to Nazarko (2001), prior to the Act 150 health authorities and 100 local authorities applied different standards, creating a fragmented and muddled system (p. 6). The new Act attempted to change this. Under the old system local authorities were providers, purchasers and inspectors of residential homes. Now, local authority homes would be inspected to the same standards as independent and voluntary homes by an independent body. Rainbird *et al.*, (2011) highlight that the requirements concerning training and standards have consequences for the resources which service providers allocate to training and development within their organisations, as well as resources that are available externally to support the attainment of minimum standards (p. 3728).

Valuing People, 2001

The shift in learning disability policy and ambition was defined by the Department of Health White Paper Valuing People. Published thirty years after the last White Paper on learning disability services, Valuing People sets out the Government's strategy and its focus on the four key principles of rights, independence, choice and inclusion. The paper talks about people with a learning disability being supported to do 'ordinary things', and to be 'fully included in the local community' (Department of Health, 2001, p. 24). Reallocated funding from long-stay health funding would be used for a Development Fund to support more appropriate accommodation for people, developing supported living, implementation of person centred approaches, and specialist support for people with challenging behaviour. The paper outlines measures to support unpaid carers, and improve access to public services such as health and housing, as well as employment for people with a learning disability.

Chapter 8 in the White Paper focuses on quality and sets out a series of measures aimed at improving quality assurance, including care standards, and inspection of services. There is a specific section on Workforce Training and Planning. Objective 10 in the paper is 'To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified, and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce' (p. 26). The paper identifies a number of workforce challenges highlighting that '75% of staff are unqualified, difficulties in recruitment and retention, the low status of care work, few recognised accredited qualifications, and variable involvement of service users and carers in training or planning (8.19). The Government seeks to address this through the creation of workforce strategies, providing a new route to qualification for care staff, and supporting a range of leadership initiatives. The only specified target under this objective relates to the percentage of people (50%) achieving a Level 2 National Vocational Qualification and working in care. The paper mentions the rights of unpaid, family carers and sets a specific objective to support family carers and their wellbeing (2001, p. 33), but the wellbeing of paid support workers is not considered.

Valuing People states that people with learning disabilities lack control over their own lives. It cites a number of challenges that implicate care workers, criticising services for being slow to recognise that people with learning disabilities have rights like other citizens, not involving people with learning disabilities in decision-making, and not being person-centred in their approach (4.1). However the paper fails to recognise the critical role of support workers in

facilitating their ambitions, such as enabling access to healthcare, and employment. One of the Government objectives in the paper is 'to enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships' (p. 76). However the paper makes no reference to the role of paid support workers in achieving this. The impact of challenging behaviour on people with learning disabilities and their unpaid carers is mentioned, and support promised, but again there is no acknowledgment of the impact of challenging behaviour on paid support workers.

Valuing People acknowledges that people with learning disabilities require support to make choices and to be included, but it lacks specificity and evidence as to what choice and inclusion actually mean in the daily lives of people with different capacities, how support staff should balance choice with their duty of care, and what measurable impact choice actually makes on quality of life. In their work to 'decode' Valuing People, Burton and Kagan (2006) find that 'the least impaired people are used in the imagery to stand for all the others… making the real difficulties in providing supports to enable inclusion, autonomy, good health, meaningful activity and acceptance appear insignificant and thereby not requiring substantial additional investment'. (p. 305). They argue that the promotion of person-centred-planning reinforces this view and is positioned as a strategy for service reform, when the way services are funded and the skills of staff should be key to service reform' (p. 306).

In 2007, the Government published *Putting People First,* a protocol setting out the shared ambition of the Government and the health and social care sector to reform social care services. The focus was on providing more personalised services, personal budgets, prevention, better information and advice, and support to build social capital. The document claimed to be a ' 'landmark protocol' (p. 1), which aimed to ensure independent living for all adults through a joined-up partnership between local and central government, the voluntary sector, providers and the social care regulator. The proposals in Valuing People and Putting People First were picked up in Valuing People Now (2002), discussed later in this section.

The Mental Capacity Act, 2005

The Mental Capacity Act (MCA) created new provisions for people who lack mental capacity to make their own decisions, and established a Court of Protection. The purpose of the Act was to empower people to make decisions for themselves, and to protect people who lack capacity by providing a framework that places individuals at the heart of the decision-making process. The Act is underpinned by key principles (Section 1) which emphasise that 'a person must be assumed to have capacity unless it is established that he lacks capacity'

(1:2) and any decision made 'for or on behalf of a person who lacks capacity must be done, or made, in his best interests' (1:5). The Act provides guidance on how to establish lack of capacity and what to consider in determining best interest. There is specific reference to decisions concerning care and treatment. The Act sets out requirements for powers of attorney and appointment of deputies to make decisions on behalf of someone who is deemed to lack mental capacity, and provides for the appointment of independent mental capacity advocates. Section 39 specifically concerns the provision of, or change in residential accommodation by a local authority for a person who lacks capacity to agree to the arrangements.

Alghrani *et al.*, (2016) argue that the scope of the MCA's application was ambitious and its stipulations apply in a wide range of circumstances, pertaining to both lay and professional decision-makers and concerning diverse contexts (e.g. from relatively trivial, to life-changing—and even life-ending—decisions). At the same time they believe that 'few would dispute that the MCA is the defining statute of English medical law in the twenty-first century' (p. 312).

A review by the House of Lords Select Committee for Health (2014) of the Act's implementation, particularly within health and social care, concluded that the MCA's implementation had not met the expectations it raised. The review observed that: 'The empowering ethos of the Act has not been widely implemented. Our evidence suggests that capacity is not always assumed when it should be… The concept of unwise decision-making faces institutional obstruction due to prevailing cultures of risk-aversion and paternalism… The least restrictive option is not routinely or adequately considered. This lack of empowerment for those affected by the Act is underlined by the fact that many responsible for its implementation continue to consider it as part of the safeguarding agenda' (paragraph 104). The Committee found that the presumption of capacity, in particular, is widely misunderstood by those involved in care and is used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm. In some cases this is because professionals struggle to understand how to apply the principle in practice. In other cases, the evidence suggests the principle has been deliberately misappropriated to avoid taking responsibility for a vulnerable adult (paragraph 105). The Committee called for 'a fundamental change of attitudes among professionals in order to move from protection and paternalism to enablement and empowerment' (paragraph 108).

Our Health, Our Care, Our Say: A New Direction for Community Services, 2006

This White Paper claimed to set a new direction for the whole health and social care system. It promised a 'radical and sustained shift in the way in which services are delivered – ensuring that they are more personalised' (p. 6, paragraph 12). To ensure that there are real choices for people, the Government stated it would increase the take-up of direct payments and pilot the introduction of individual budgets (paragraph 17). The paper emphasises collaboration between health and social care to address local inequalities, and joint commissioning of services by Primary Care Trusts and local authorities. It states that the 'longer-term aim is to bring about a sustained realignment of the whole health and social care system… people will have real choices in both primary care and social care; and services will be integrated and built round the needs of individuals and not service providers' (1.28). The Government proposes practical steps to turn into reality its vision for adult social care focused on independence, wellbeing and choice. The paper calls for 'innovative providers – whether state-owned, not-for-profit or independent businesses, like…social care providers – that work as part of a joined-up system…' (1.46).

The White paper endorses eight outcomes that were proposed as part of an earlier consultation relating to adults social care services, based on the concept of well-being. These are: improved health and emotional well-being; improved quality of life; making a positive contribution; choice and control; freedom from discrimination; economic well-being; and personal dignity (2.63).

Staff are mentioned in relation to workforce development with the Government arguing for 'strategies that support radical shifts in service delivery and equip staff with the skills and confidence to deliver excellent services' (1.47). Staff are also mentioned in the context of risk, with the paper raising concerns that proposals relating to direct payments and individual budgets might expose people to unmanageable levels of risk 'via a potentially unregulated and undertrained workforce' (4.41). It therefore proposes working closely with other government departments and stakeholders, to develop a national approach to risk management in social care (4.42).

To encourage service integration, the Government plans to bring skill development frameworks together and create career pathways across health and social care (8.39). While the paper recognises that professionals need to work to support and empower people to make their own decisions, wherever possible (8.41), it is clear in stating that 'we need to build up skills, especially in basic communication, in social care – where only 25 per cent of

employees have a qualification. It is not acceptable that some of the most dependent people in our communities are cared for by the least well trained' (8.47). The paper acknowledges that there are serious recruitment and retention problems to tackle in social care, where vacancy rates and turnover are high. To address this, 'Under the joint Department for Education and Skills and Department of Health Options for Excellence Review, there will be nationally co-ordinated action to improve recruitment and retention in social care' (8.49). Health and social care employers are also targeted in the paper, stating that 'being a good employer is more than simply meeting legal requirements: supporting a good work–life balance, flexible working, childcare provision and healthy workplace policies are important to ensure that staff can perform to their full potential. The Department of Health will work with the Department for Work and Pensions and the Health and Safety Executive to promote healthy workplaces in health and social care, and model employment practices that attract and retain the best staff with the best skills' (8.54).

In their analysis of the White Paper, The King's Fund (2006) argue that an obvious challenge is that resources for redesigning and developing new innovative services are scarce. In addition, commenting on the focus on better integration of health and social care it states that 'the financial climate makes co-operation between health and social care much harder. It increases the temptation to 'cost shunt', moving costs of a service from health to social care, where the lines are often blurred locally… The presence of underlying deficits can often make potential partners wary for fearing of inheriting some of the debt themselves. Both decrease the chances of effective collaborative working' (p. 5).

Department of Health (2008a) issued a circular to Local Authorities on transforming social care, following the publication of the 2006 white paper, and Putting People First in 2007. The document states that the challenge of reforming social care to achieve personalisation should not be underestimated. Drawing on the experience of direct payments, it states 'For the past ten years, direct payments have successfully given some people the ability to design the services they want but their impact has been very limited. The latest figures show that about 54,000 people out of a potential million recipients receive support through a direct payment. Evidence shows major variations in take up across the country, with success determined less by the characteristics of people who use services or the features of direct payments themselves, than by local leadership, professional culture and the availability of support' (paragraph 21). This is a critical point as it recognises the role of professionals as a conduit to achieving government ambitions. However, under the section entitled 'Challenges' the first point the Department of Health makes is that 'the aspirations for the modernisation of social care through personalisation, choice, and control must be set in the context of the

existing resources and be sustainable in the longer term' (paragraph 31). The circular refers to developing an Adult Workforce Strategy and states it is essential that frontline staff, managers and other members of the workforce recognise: 'the value of these changes (personalisation); are actively engaged in designing and developing how it happens; and have the skills to deliver it' (paragraph 37). Skills development for social care staff is addressed through developing 'National Vocational Qualifications to ensure a better-trained and qualified workforce to raise the quality of social care services' (paragraph 39). The development of a Social Care Skills Academy is seen as a route to address leadership, management and commissioning skills. This circular is mentioned in this analysis as it highlights a consistent effort by government to address its aspirations through process change.

Mental Health Act, 2007

The Mental Health Act 2007 amended the 1983 Act. The new Act removed all the different distinctions between mental health conditions and simply defines mental disorder as being 'any disorder or disability of the mind' (Chapter 1). The same Chapter distinguishes people with a learning disability and the application of the Act from people with mental disorders requiring treatment in hospital 'unless that disability is associated with abnormally aggressive or seriously irresponsible conduct'.

Most significant for social care work and paid carers, the Mental Health Act was a vehicle for introducing a new provision to the Mental Capacity Act: the Deprivation of Liberty Safeguards (DOLS) which is intended to ensure there is a legal procedure for authorising deprivations of liberty in hospitals and care homes for adults who lack capacity to consent to admission or treatment. In 2008, the Lord Chancellor issued a Code of Practice to provide guidance for those implementing the deprivation of liberty safeguards legislation on a daily basis.

The introduction of DOLS was in response to what became known as the 'Bournewood Gap' following the case of a man with autism who was detained in Bournewood Hospital in 1997 without having consented to the detention or being made subject to compulsory admission under the Mental Health Act (1983). The patient's carers took his case to the European Court of Human Rights, who ruled that the patient had been deprived of his liberty unlawfully without legal procedures for safeguards or independent appeal. 'The effect of this ruling was that many thousands of people could be considered illegally detained in hospitals or nursing homes, mainly people suffering from severe learning disabilities or dementia' (The King's

Fund, 2008, p. 1).

In March 2014, a ruling of the Supreme Court ([2014] UKSC 19.) had a significant impact on decisions about arrangements made for the care and/or treatment of people who might lack the capacity to consent to their living arrangements. The ruling concerned the criteria for judging whether the living arrangements of a person without capacity amount to deprivation of her/his liberty. Since this ruling, 'DOLS have proved to be a controversial innovation… There has been an explosion in number of applications for DOLS 'standard authorisations' in England' (Alghrani, 2016).

The House of Lords Select Committee for Health's review of the MCA (2014) was highly critical of the implementation of DOLS stating: 'The legislative provisions are poorly drafted, overly complex and bear no relationship to the language and ethos of the Mental Capacity Act. The safeguards are not well understood and are poorly implemented. Evidence suggested that thousands, if not tens of thousands, of individuals are being deprived of their liberty without the protection of the law, and therefore without the safeguards which Parliament intended. Worse still, far from being used to protect individuals and their rights, they are sometimes used to oppress individuals, and to force upon them decisions made by others without reference to the wishes and feelings of the person concerned' (p. 7). In its findings the Committee states that 'The level and breadth of criticism of the Deprivation of Liberty Safeguards, including from the judiciary, demonstrates that the legislation is not fit for purpose (paragraph 257).

The Mental Health Act introduced a number of other significant provisions. A high profile change was the introduction of supervised community treatment (SCT) for suitable patients following an initial period of detention and treatment in hospital (Chapter 4). Community treatment orders may be issued to some patients to ensure they comply with treatment when they are discharged from hospital, and enable staff to take action to prevent a relapse. The Act places a duty on the Secretary of State of Health in England to make advocacy services available to most detained patients and to all patients subject to SCT and guardianship arrangements in the form of new independent mental health advocates (Chapter 3, Section 30).

The Act also set out the creation of 'approved mental health professionals' (Chapter 2, Section 18, 19). Under the original 1983 Act, the professional with the power to apply for the detention of a person in hospital, and obtain the necessary medical agreement, was a social worker specially trained for this task – referred to in the Act as an approved social worker

(ASW). The 2007 Act opened up this role to a wider group of professionals. The Act specifies that 'the codes may also lay down standards of conduct and practice expected of social workers when carrying out the functions of an approved mental health professional' (Section 20).

Health and Social Care Act, 2008

The Health and Social Care Act dissolved the Commission for Healthcare Audit and Inspection, the Commission for Social Care Inspection, and the Mental Health Act Commission to create a single new regulator, the Care Quality Commission. The CQC's function is to provide registration and inspection of health and adult social care services, and to monitor the operation of the Mental Health Act 1983. The purpose of the Act was to achieve the integration and alignment of health and adult social care regulation across all types of providers, whether public, private or third sector. The Act was criticised for pushing the CQC towards a heavy-handed deterrence approach to enforcement (Stirton, 2017).

Under the Care Act, the CQC is responsible for checking continued compliance with the requirements and has a wider range of powers so it can take appropriate action where providers or managers fail to meet the requirements. As well a requirement for service provider registration, the Act requires the registration of a manager of that service. The CQC is required to publish a statement describing how it proposes 'to promote and engage in discussion with service users and carers about the provision of health and social care services and about the way in which the Commission exercises its functions' (5.1). Paid support workers are not included in this requirement and the act specifies that '"carers" means people who care for service users as relatives or friends (5.4(b)).

Providers are required to comply with regulations as provided under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. Section 2 sets out 'fundamental standards' below which a provider must not fall. Regulation 9 refers to 'person-centred care', and describes the action that providers must take to make sure that each person receives appropriate person-centred support that reflects their needs and preferences. 9.3(d) states that people should be supported to make, or participate in decisions relating to their care and treatment 'to the maximum extent possible'. Regulation 10 states that service users must be treated with dignity and respect; this includes providing any support they might need to be autonomous, independent and involved in their local community.

Staffing is addressed in Regulation 18 which states that providers must provide sufficient numbers of suitably qualified, competent, skilled and experienced staff to meet the needs of the people using the service at all times. Staff must receive the appropriate support, training, professional development, supervision and appraisal to enable them to carry out their duties. Linked to staffing, Regulation 19 concerns the employment of 'fit and proper persons' who are able to provide care and treatment appropriate to their role. Providers are required to operate robust recruitment procedures, have a procedure for ongoing monitoring of staff to make sure they remain able to meet the requirements, and they must have appropriate arrangements in place to deal with staff who are no longer fit to carry out their duties.

The Health and Social Care Act 2012 is not discussed in this documentary analysis as it was focused on the extensive, and controversial restructuring of the National Health Service (Timmins, 2012).

United Nations Convention on the Rights of People with Disabilities, UK Ratification, 2009

The Convention builds on the Universal Declaration of Human Rights (1948), and follows a series of Conventions dealing with other forms of discrimination. The Convention does not create new human rights but it does place obligations on governments to take active steps to make sure people with disabilities can enjoy their human rights. The Convention sets out a number of obligations on members, such as the right to life (Article 1), to liberty and security of the person (Article 14) and the obligation to recognise that all persons are equal before the law (Article 5). As well as general provisions there are a number of specific provisions requiring members to take appropriate measures to ensure equal access to transport, communications, justice, independent living, mobility, education, health, work and employment, and equal participation in political and public life and in culture, recreation, leisure and sport. Article 16 requires countries to take appropriate measures 'to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse'.

Two movements have particularly impacted the lives of people with intellectual disabilities and the residential services provided to them since the 1960s: deinstitutionalisation and independent living. The goals of these movements are enshrined in Article 19 of the Convention which states that 'Persons with disabilities must be able to live independently, to be included in the community, to choose where and with whom to live and to have access to

in-home, residential and community support services'. Social protection is addressed in Article 28 which states: 'Countries recognise the right to an adequate standard of living and social protection; this includes public housing, services and assistance for disability-related needs, as well as assistance with disability-related expenses in case of poverty'.

Article 35 requires the UK Government to submit a progress report against each Article within 2 years of ratification. In its initial report (Office for Disability Issues, 2011), the Government claims: 'The UK's approach to independent living goes well beyond the right as described in Article 19 and encompasses increasing choice and control, removing barriers and inclusion in the community' (paragraph 173). The report emphasises its focus on personalisation, and personal budgets, along with its efforts to enable choice and control in relation to different services. The report addresses Article 28 emphasising its commitment to supporting disabled people's quality of life, highlighting new legislation: 'The Welfare Reform Bill, introduced in February 2011, makes the most fundamental reforms to the social security system for 60 years' (paragraph 308), which it states will be simpler and fairer. It goes on to outline plans to reform financial support for disabled people in the form of a new Personal Independence Payment: 'Government's reforms will ensure the benefit remains sustainable and that support is targeted on those who face the greatest barriers to leading independent lives' (paragraph 311). It also highlights the introduction of Universal Credit to replace income—related benefits which will 'simplify the income-related benefit system to make work pay, and combat worklessness and poverty' (paragraph 314).

In 2016, the UN Committee on the Rights of Persons with Disabilities published the results of its inquiry into the impact of the UK Government's policies on the rights of disabled people. The inquiry was conducted under the Optional Protocol to the Convention on the Rights of Persons with Disabilities, to which the UK has been a signatory since 2007. The Optional Protocol allows the UN Committee to investigate a State Party if they have received reliable evidence of 'grave and systematic violations of the Convention'. The UK is the first country to be investigated by the UN in relation to this Convention. The inquiry found that UK Government reforms had led to 'grave and systematic' violations of the rights of disabled people. Paragraph 44 states that the Committee is concerned that UK legislation 'fails to recognise living independently and being included in the community as a human right that enshrines individual autonomy, control and choice as intrinsic aspects of that right'. The report emphasises the impact of changes to Housing Benefit entitlement, eligibility criteria for Personal Independence Payment (PIP) and social care, and the closure of the Independent Living Fund. The UK Government published a response stating it 'strongly disagrees' with the findings (Commons Briefing Papers, 2017).

Valuing People Now, 2009

Valuing People Now is a three-year 'cross-government' strategy to take forward the policies set out in *Valuing People* and in *Putting People First*. The strategy reaffirmed the four key principles of rights, independent living, choice and inclusion, and makes a comprehensive range of local and national recommendations, accompanied by a delivery plan. There is a strong emphasis on partnership working and being user-led.

The strategy states that it 'does not place many new burdens on services or frontline staff' (paragraph 4) but rather promotes best practice. Chapter 2 of the strategy is focused on personalisation and a commitment to improve outcomes, including social inclusion and empowerment for people with a learning disability through person-centred approaches. However, it later states 'implementing Valuing People Now has implications for workers across all areas of public services…Government departments and the appropriate workforce organisations need to consider new ways of enabling a wide range of workers to develop the knowledge, skills and values to provide services to people with learning disabilities with respect and as equal citizens' (5.22). Given the increased focus on more people having personal budgets, the strategy stresses that 'the workforce will need to change… People who choose to purchase their support from a provider may want to purchase different types of support from what is currently on offer. This will have significant implications across a range of service providers, and particularly for the adult social care workforce' (5.23).

Subsequent chapters in the strategy focus on changes required to different public services to improve choice, inclusion, and quality of life for people with a learning disability. National Directors are assigned responsibility for leading the delivery programme for Valuing People Now. The strategy states that the responsibility for commissioning and funding social care for people with learning disabilities will transfer from the NHS to local government (paragraph 29). It also states that the Office of the National Director will work with government departments to support the development of staff who work to deliver support for people with learning disabilities within the context of the National Adult Social Care Workforce Strategy (paragraph 30).

Chapter 5, entitled 'Making it Happen' addresses the areas of leadership and delivery structures. Reflecting on Valuing People, a key criticism in the new paper is the 'failure to deliver in many areas' (5.1). Developing capacity and capability at local levels is seen as key to realising the vision of Valuing People. The strategy points to numerous structures that have been established to change practice and improve support, namely 'Joint Strategic

Needs Assessments, Local Strategic Partnerships, Local Area Agreements, Joint Improvement Partnerships and Comprehensive Area Assessments' (5.5). The social care workforce is addressed through a specific policy objective under the heading 'Developing the Workforce'. The objective is to provide 'appropriate support and training to equip them with the values, skills and knowledge to deliver the Valuing People Now priorities for all people with learning disabilities' (5.21).

Valuing People Now emphasises the need to be inclusive of all people, and specifically addresses people with complex needs. It defines complex needs as 'a range of multiple and additional needs that people with learning disabilities may have (1.2). This can include people with profound and multiple learning disabilities' (p. 38). Dawkins (2009) cautiously welcomes the strategy stating 'That Valuing People Now acknowledges that people with complex needs have largely missed out is a real step forward, but actions must be based on recognition that real inclusion will only be achieved by understanding, acknowledging and meeting the specific needs of people with PMLD (p. 11). Priority services highlighted in the strategy are health, housing and employment. Cooper (2011) highlights that 'people with complex needs have lagged behind in all these areas…Individuals with more severe learning disabilities were more likely to be living in residential care or NHS accommodation, the majority having no choice over where or with whom they lived' (p. 41).

A Vision for Adult Social Care: Capable Communities and Active Citizens, 2010

This policy document sets out priorities for improving outcomes for service users, with a greater focus on preventative measures, and personalising services. The document advocates a shifting of power from the State to the individual through the rolling out of personalised budgets, a broad market of high quality service providers, improving integration between health and social care services, and encouraging better partnership working. This shift of power from the State to community, empowering communities to support its needs was part of the Government narrative branded under its 'Big Society' programme. The Government saw the increased use of personal budgets alongside people funding their own care, as a catalyst for change claiming that 'People will demand the services they want to meet their needs, creating truly person-centred services' (5.1). The document emphasises that local authorities have a significant role to play in shaping the market for social care: 'Councils have a role in stimulating, managing and shaping this market, supporting communities, voluntary organisations, social enterprises and mutuals to flourish and develop innovative and creative ways of addressing care needs' (5.2).

The Government recognises categories of people who might need more support to manage direct payments, and who should be supported to have choice and control over their lives: "People with learning disabilities, autism, disabled people and those with complex needs require person-centred planning to maximise choice and control, and appropriate help in cases where a direct payment is not chosen; people in residential care should have the same entitlement as anyone else to exercise choice and control over their care and how they live' (4.4).

This policy document recognises the role of frontline workers in delivering personalised support: 'Front-line workers and carers are fundamental to the delivery of personalisation – we want to give them the freedom and responsibility to improve care services and support people in new ways' (1.2). There is a specific chapter on the social care workforce which opens with the recognition that: 'The contribution of all those who make up the workforce in adult social care should be celebrated. Over 1.6 million people provide vital services day in day out, working alongside carers to help people live more independently and play a fuller role in our communities' (8.1). However, the chapter then goes on to focus on the same areas of previous and subsequent papers concerning training and capability. Skills for Care are tasked with creating a workforce development strategy to help employers to support staff to provide personalised services. The document highlights the importance of continuing training and skills development, stating it 'is a vital investment in the future' and that it will ensure 'there is a secure and simplified framework for training and skills development within the sector to meet future needs' (8.6). New career pathways are to be developed, including more apprenticeships and a new care worker role in home and residential care, and 'renewed work with employers to maximise recruitment and retention in the sector' (8.7). The document also recognises staff wellbeing stating: 'Good staff health and well-being is important to quality and productivity in social care' and stresses the importance of tackling sickness absence, setting out plans to work with the social care sector to co-produce an occupational health strategy' (8.8).

Building the National Care Service, 2010

This White Paper proposed the creation of the National Care Service 'offering high quality care and support for all adults' (p. 67). The service is to be underpinned by six principles: universal provision; free, based on need rather than ability to pay; partnerships; choice and control for service users; support for families and carers; and accessible. The paper claims to chart a course for the fundamental reform of the care and support system in England.

The social care workforce are specifically addressed under the theme of quality. The paper acknowledges the 'many examples of exceptional and inspirational care – hard-working and dedicated individuals and organisations providing valuable and innovative support to thousands of people across the country (but) we must explore new models and methods for delivering higher quality care…' (p. 100). This is the first paper in this documentary analysis that talks about workforce development using terms such as compassion, diversity, and caring: 'We want a motivated, diverse and compassionate workforce – one that feels valued and rewarded for the important and critical role it undertakes for our society. We are already working to attract more people to take a job, and build a career, in care and support…We are going to work with the sector to make sure that we have the right people, with the right set of skills, working in caring roles' (p. 72).

Looking to the future, the White Paper talks about the need to grow the workforce and encourage people to work in care. The paper also identifies that expectations are likely to rise with a demand for more specialist knowledge of people's needs, observing that 'new types of roles and ways of working are already emerging, which we need to support with more structured training and support… There is likely to be more multidisciplinary working, and the workforce will need to adapt to working within different professional teams, with different cultures and ways of working' (p. 108).

The paper references the introduction of the Independent Safeguarding Authority which provides a means of excluding people who are unsuitable to work in social care, and highlights the need to ensure all staff have the training and qualifications they need to care well. The paper proposes a licensing scheme for all social care workers. The paper also sets out plans to recognise employers who invest in high standards of training with a kitemark under the National Care Service.

Welfare Reform Act, 2012

The Welfare Reform Act legislates for the biggest change to the welfare system for over 60 years (DWP, 2011). A central emphasis is that the Bill will provide a stronger approach to reducing fraud and error with tougher penalties for the most serious offences.

The Bill introduces significant changes to welfare benefits. It provides for the introduction of a 'Universal Credit' to replace a range of existing means-tested benefits and tax credits for people of working age, and introduces Personal Independence Payments to replace the

Disability Living Allowance (DLA). The Government rationale for this reform was that the DLA proved to be unsustainable due to the growing number of claimants and annual expenditures. According to the DWP, 'in nine years the numbers claiming DLA has risen from just under 2.5 million to 3.2 million – an increase of around a third' (May, 2012). The Act also restricts Housing Benefit entitlement for social housing tenants whose accommodation is larger than they need, and caps the total amount of benefit that can be claimed.

Under Section 33, income support, income related employment and support allowance, income-based jobseeker's allowance, housing benefit, council tax benefit and tax credits are all to be abolished and replaced by Universal Credit. Section 70 provides for the abolition of the discretionary social fund (i.e. crisis loans and community care grants) with responsibility passed to local authorities. Universal Credit requires claimants to meet certain criteria, which depend upon the individual's circumstances. The Act imposes work-related requirements on claimants. These work-related requirements include: a work-focused interview requirement, a work preparation requirement, a work search requirement, and a work availability requirement (Section 13).

Personal Independent Payments have two components: a daily living component, which is payable where a claimant has a medical condition that affects their daily living, and a mobility component, payable if the claimant has a medical condition that limits their mobility. Individuals have to apply for this benefit even if they have been receiving the disability living allowance, and will be assessed to determine whether they meet the new requirements (Sections 77-80).

One of the most high-profile changes that the Act makes is to cap the total amount of benefits that can be claimed. The level of the cap will be referenced against the estimated average earnings of a working household. There are various exemptions from the cap. It does not apply to households that receive a disability living allowance (the future Personal Independence Payment) or an employment and support allowance.

According to Makowieski (2015), due to its sheer size, the Welfare Reform Act would have 'a significant impact on multiple sectors of the population, including benefit claimants, local authorities charged with implementing the reforms, and others involved in providing welfare-related services' (p. 267). Universal Credit attracted widespread controversy, including concerns about 'over-ambitious' goals, 'poor value for money' and inadequate IT systems (National Audit Office, 2013). Critics argued that Universal Credit would cause a dramatic increase in hardship and poverty (Gillies *et al.*, 2013), and involved inappropriate

expectations of disabled people (Patrick, 2011). Further criticism comes from Dwyer and Wright (2014) who argued that 'The type and scale of the conditionality changes within Universal Credit represent a fundamental change to the principles on which the British welfare state was founded… The scope and significance of this new system of standardised welfare conditionality is unprecedented in offloading the welfare responsibilities of the state and employers onto citizens who are in receipt of in work and out of work social security benefits' (p. 33).

Criticising government claims that the Act supported their commitment to promoting independence, Millar and Bennett (2017) state: 'This commitment to independence is directly contradicted by the increased control inherent in the Universal Credit design. The current direction of social security policy for people of working age goes beyond the (previous) 'work is good for you' approach… people should always be aiming to be independent of the state, not reliant upon it in any way' (p. 176). Similarly, Dean (2012) is critical of the moral tone of Universal Credit and the welfare reform proposals. He highlights that the Government positioned the reforms against a narrative of a 'Broken Britain' and a 'culture of worklessness and dependency' (p. 353). He says this raises ethical questions since 'The primary focus is on the individual's obligations, rather than their rights; on discouraging dependency rather than recognising the protective responsibilities' (p. 357).

The implementation of Personal Independence Payments (PIP) was also accompanied by controversy. In their research of eligibility for welfare payments, Pybus *et al.*, (2019) found that 'PIP eligibility assessment outcomes show marked differences by health condition, raising questions as to whether the process is equitable'. They also highlight that 'Concerns have been raised by disability charities that the 20% savings target attached to the reforms is arbitrary rather than being grounded in evidence relating to levels of need among the disabled population' (p. 1). A key criticism of PIP has been the delays in decision-making. An independent review of the effectiveness of PIP assessment, as required under the Welfare Reform Act reported that many claimants felt that delays in the assessment process not only caused anxiety but also a deterioration in the health condition for which they are claiming benefit (Gray, 2014, p. 32). The review identified concerns that the claims process could be particularly problematic for claimants with mental health problems, hearing difficulties or learning disabilities. 'Disability organisations including Parkinson's UK and Mencap reported difficulties in supporting claimants through the claims process. This seemed to happen when implicit consent arrangements which allow trusted intermediaries to act for claimants did not work effectively, and the Department or the assessment provider still needed to talk to the claimant directly' (p. 35). The Review recommended that the DWP

should put in place 'a rigorous quantitative and qualitative evaluation strategy… which includes a priority focus on the effectiveness of PIP assessments for people with a mental health condition or learning disability' (p. 63).

The Care Act, 2014

The Government presented The Care Act as the most significant change in social care law for 60 years. Prior to reform, more than 30 Acts of Parliament were relevant to adult social care (Richards, 2015).

The most significant developments in the act concern: new criteria setting out when local authorities have to provide support to people; rights for unpaid carers to an assessment for support; emphasis on prevention and protection – and the establishment of Safeguarding Adults Boards on a statutory footing; advocacy support; and use of personal budgets. The Act places a duty on local authorities for adults who lack capacity, and sets out greater regulation for care professionals, and tougher penalties for those who do not provide care and support of a high enough standard. It places a duty on local authorities to cooperate with other organisations which have functions relevant to care and support such as health, and housing.

Under the Care Act, local authorities have new functions. There is a strong emphasis on personalisation. The Act sets out local authorities' duties in relation to assessing people's needs and their eligibility for support. Under the Act, local authorities should: assess anyone who appears to require care and support, regardless of their likely eligibility for state-funded care; focus the assessment on the person's needs and how they impact their wellbeing, and the outcomes they want to achieve; involve the person in the assessment and, where appropriate, their carer or someone else they nominate; provide access to an independent advocate to support the person's involvement in the assessment if required; consider other things besides care services that can contribute to the desired outcomes (e.g. preventive services, community support); and use the new national minimum threshold to judge eligibility for publicly funded care and support. The Act introduces changes to when and how people will be asked to contribute towards the cost of their care. Section 14 gives local authorities a general power to charge for certain types of care and support, at their discretion but requires a local authority to carry out a financial assessment if they have chosen to charge for a particular service (Section 17).

The Government states that the Care Act helps to improve people's independence and wellbeing. The Act introduced a wellbeing principle that puts the onus on local authorities to promote an individual's wellbeing, broadly defined to include emotional wellbeing, dignity, and control over one's own care, support and personal relationships (1.2). The Act states that the local authority must 'begin with the assumption that the individual is best-placed to judge the individual's well-being' (Section 1.3). Moreover, local authorities are required to assess the wellbeing needs of carers (this does not include paid carers), to review support plans, and to enable individuals to access personal budgets and direct payments. The Act requires local authorities to prepare care and support plans and specifies that the authority must involve 'any carer the adult has' or where there is lack of capacity, 'any person who appears to the authority to be interested in the adult's welfare' (paragraph 25). Richards (2015) states that while the commitment to supporting the perspective of individuals is commendable, it is questionable whether it can be realised, as it increases the duty on local authorities that require more resources which have not been provided.

Considering the social care market, the Act requires local authorities to promote 'diversity and quality in provision of services' (paragraph 5), ensuring there is a variety of quality providers for people to choose from. There is an emphasis on the local authority role in providing information and advice on care and support for adults and unpaid carers. The Act gives local authorities clear legal responsibilities where a care provider fails. It makes it clear that local authorities have a temporary duty to ensure that the needs of people continue to be met should their care provider become unable to continue to provide care because of business failure, no matter what type of care they are receiving. Sections 53-57 set out new duties on the regulator – the Care Quality Commission to assess the financial sustainability of the most difficult to replace provider, and to support local authorities to ensure continuity of care when providers fail.

Slasberg and Beresford (2014) argue that government claims of the Care Act putting people in control of their support 'is fundamentally contradicted by the draft guidance published to support the Act (which) amounts to a formula for maintaining the prevailing resource-limited approach to assessing and meeting needs. This reality is obscured by a welter of choice and person-centred rhetoric' (p. 1677). They cite an example of the guidance failing to address how councils will move from the person's views to their own views on a person's needs other than 'an assessment must be person centred, involving the individual' (p. 1678). They conclude that 'The reality is that the future will continue to be needs, not choice based and that councils will continue to have the power to define needs and have to do so within limited budgets' (p. 168).

In October 2015 the national charity In Control commissioned a survey of social care recipients about their views on the principles of choice, control and wellbeing as set out in The Care Act. It found that 'almost half (45%) of respondents said that their quality of life had reduced and almost a third (30%) said that they had experienced a reduction of choice and control over the past year; half said their need for support had increased' (Independent Living Strategy Group, 2015, p. 3).

3.2.4 Discussion and limitations

There has been a major shift in social care policy and practice over the last 100 years, from institutionalisation to community-based approaches, and from segregation to aspirations for inclusion and empowerment of disabled people. These changes have been driven by a mix of disability rights activism and government imperatives to reform social care in response to economic pressures. The result has been a clear shift in narrative: the separation of the 'mentally deficient' towards the right to inclusion and independence for disabled people; reforms to how care is structured and regulated; and changes in how the cost of care is managed – such as greater local authority responsibility for shaping a competitive care market, promoting personal budgets, and reforms to welfare benefits.

As the provision of social care has become more regulated over time, the responsibility for 'caring' has become less distinct with the introduction of different models, settings and people involved in its delivery. The political, financial and ethical profile of care has increased in line with an ageing population and declining birth rate, both of which are placing additional pressures on formal social care provision (Fine, 2005). The high-profile failures of various services (Cavendish, 2013) have placed the commissioning of care under heightened scrutiny, but the commissioner–care provider dyad is complex and multi-layered. The increasing reliance of local authorities on the independent sector, and ever-shrinking budgets, has led to significant consolidation among care services. Social care providers have faced increasing demands to improve standards against a backdrop of continuing spending controls, placing greater pressure on streamlining processes. Rubery *et al.*, (2013) highlight how some providers are increasingly focusing on compliance with statutory regulations at the detriment of improving care quality (p. 421). Pressure on social care budgets is one of the greatest challenges in the sector (Parrott, 2013).

From the Community Care Act, 1990 to the Care Act, 2014, a common theme across policy and legislation is person-centred support. Partnership working, especially more integration

between health and social care is also emphasised in most papers. Consistent phrases are used - choice, control, independence, personalisation, inclusion, – to embody what good, quality support means. Although the specifics of how these ambitions are realised in practice is not detailed, certain means to achieving these are identified, such as accessing personal budgets, and securing employment. The term 'workforce' is often used to encompass people employed in the social care sector as a whole. When the workforce is referred to, it is to identify the lack of capability and skills; the risk to vulnerable people with respect to abuse and neglect, including financial abuse specific to direct payments; and the challenges with recruitment, and retention. The approach to tackling these issues largely rely on better training, and regulation. While the wellbeing needs and legal rights of just two policy documents in this analysis. The focus is on system and process change and there is a lack of engagement with values, qualities, motivations or relationships. Support workers play a critical role in the lives of the people they support, yet government policy does not engage with the fundamental value of care work, or confront the real needs of frontline workers. Duffy *et al.*, (2015) emphasise the impact of government policy on care workers, and the increased risk of exploitation and injury. They conclude that 'widespread changes to the policies of care will only come when collective pressure is placed on the change makers to recognise and value caring labour' (2015, p. 289).

The documents reviewed in this analysis detail significant reforms and provisions that impact disabled people's rights and how care and support is delivered. These changes have far-reaching implications for everyone involved in social care but the implications are not considered in a broad sense for paid carers at the frontline of providing support. For example, paid support workers in residential or supported living services may need to support people to make choices, access the community and public services such as health and education, help advocate for them, manage finances, and be involved in preparing care and support plans. Where people they support lack capacity there will be an ongoing requirement to consider the person's best interest in making decisions about different aspects of their lives. To what extent does training and regulation support frontline workers with such a variety of responsibilities?

A limitation of this analysis is that it does not consider accompanying or subsequent guidance or other papers that concern implementation. The volume of documentation would form the basis of a thesis in itself and the resource and space limitations of this thesis made this unviable. While such documentation may provide fuller detail on the areas criticised above, it is still significant that paid support workers are represented as one-dimensional in key legislation and policy, without adequate consideration of their complete role. This

analysis is also limited in its focus on English law. It would be interesting to compare differences between devolved administrations. While the UK ratification of the UN Convention is considered, international law is not included in this study and would again provide further insight and comparison with countries outside the UK. However, given the research question of this study, I wanted to maintain a specific focus on the representation of and implications for paid support workers in English law and policy. This Chapter provides a rich foundation for examining the perceptions and practice of paid support workers on the ground.

3.3 Chapter summary

This chapter has examined the development of social care policy in England from the 1601 Poor Law to the present day. In the process the social and economic drivers that influenced changes in the ownership and provision of care for disabled people have come into focus. Following a marked shift in emphasis in the 1980s from institutional to community care, and from a narrative founded in paternalism to personalisation, government policy aspirations have remained consistently focused on the rights of disabled people. Whether these rights are being realised for all disabled people in practice continues to attract controversy and criticism: significant social care reforms have impacted the ability of care providers to deliver, and of disabled people to 'live the lives they choose'. Detailed analysis of legislation and policy since 1990 shows little engagement with, or recognition of the full role of frontline support workers in the lives of people they support. This chapter provides a detailed picture of the policy position. The next chapter will examine what existing empirical research can tell us about the relationship between learning disability policy and support worker practice.

Chapter 4: Systematic review

The review of disability policy in England (Chapter 3) observed scant recognition of the extent of the role that support workers play in the lives of people with a learning disability. This chapter seeks to understand if this lack of consideration is also reflected in academic research. I undertook a systematic review of empirical studies that examine the views and practice of support workers in England. The reporting of the systematic review follows the guidelines proposed by the PRISMA Statement: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Moher *et al.*, 2009), which aims to improve the reporting of systematic reviews (see figure 4.2). Together with the policy review findings, this systematic review has informed the approach and analysis of my fieldwork with learning disability support workers (Chapters 6 and 7).

4.1 Aim

The aim of the systematic review was to identify empirical studies that explore the views and practice of learning disability support workers in adult care settings in England. I was particularly interested in whether any of these studies considered the relationship between government policy and support worker practice. The purpose of this work was: to establish the level of academic interest in learning disability support workers in England and their role in operationalising policy; to provide context for my fieldwork (Chapters 5 and 6); to inform how my study relates to other academic studies; and to understand what new insight my work may contribute to academic knowledge. The findings from this systematic review are considered as part of the wider discussion in Chapter 7.

4.2 Method: Search strategy

The present study was concerned with the role of learning disability support workers in enacting policy in England. I conducted a systematic review to identify empirical studies in the English language, published in peer-reviewed journals in England from 1990 onwards. Studies were shortlisted if they reported the views of support workers about their role working with adults in residential care or supporting living services (see 5.3.1 for description of learning disability services). As this review was concerned with empirical studies only, other systematic reviews, reviews, editorial, and letters were excluded from the search. Studies concerning children, settings other than residential care or supported living, and staff other than learning disability support workers were also excluded. Studies concerning other

disabilities were also excluded. Studies concerning countries other than England were not included. While I recognise there may be parallels between different disabilities, settings, and professionals, this study hypothesises that support workers play a vital role in the lives of people with a learning disability but this role is under-represented in policy and academic research in England. The focus of this systematic review is therefore to test this hypothesis, and provide a context for my fieldwork in Chapter 6.

I chose the date range of 29th June 1990, when the National Health Service and Community Care Act received Royal Ascent and 22nd August 2019, the date of commencing this systematic review. The Community Care Act was identified as a starting point for the review as this Act significantly restructured care provision with a focus on the individual. The Act stated that adults eligible for care services have the right to a full assessment of their needs, should be fully involved in that assessment, and that services should be tailored to meet individual needs. Current social care policy has largely remained within this framework.

I searched empirical studies published between the search period using four bibliographic electronic databases: MEDLINE, Embase, Scopus, and ASSIA. I did not use additional databases to avoid repetition in search results as they cover similar content to the databases I was using, or they were not relevant, such as Cochrane which has a medical focus. I developed the search strategy in MEDLINE (see Table 4.1)**.** With the assistance of a Medical Librarian, and my academic Supervisor, I identified search terms related to the views of learning disability support workers and their work in adult social care settings. In addition, I reviewed the reference lists of included studies for additional sources.

Table 4.1 Search strategy for MEDLINE/Embase

1	"support work*"
2	"support staff*"
3	"carer*"
4	"carer work*"
5	'intellectual disability*"
6	"learning disab*"
7	"learning difficult*"
8	"perception*"
9	"perceive"
10	"motivat*"
11	"view*"
12	"attitude*"
13	"opinion*"
14	**5 or 6 or 7**
15	**8 or 9 or 10 or 11 or 12 or 13**
16	**1 or 2 or 3 or 4**
17	**14 and 15 and 16**
18	**limit 17 to (English language and yr="1990-Current")**

4.2.1 Data extraction

Articles identified from each database were imported in to Mendeley (reference manager software) and duplicates were removed. I screened all titles against the inclusion/exclusion criteria set out Section 4.2. Articles were allocated to a 'discard', 'keep' and 'doubt' folder. Articles in the 'doubt' folder were then further screened by abstract and assigned to the 'discard' and 'keep' folders. Following the review of title and abstract, full text articles were reviewed for all studies identified as potential inclusions. Data concerning the sample, setting, method, and findings was then collated and summarised. The original database search identified 1483 citations. Of the total citations identified, 729 were duplicates. I screened 754 titles and abstracts against the inclusion and exclusion criteria to identify 7 full text articles which were suitable for inclusion in the review (Figure 4.2).

Figure 4.2 Systematic review process
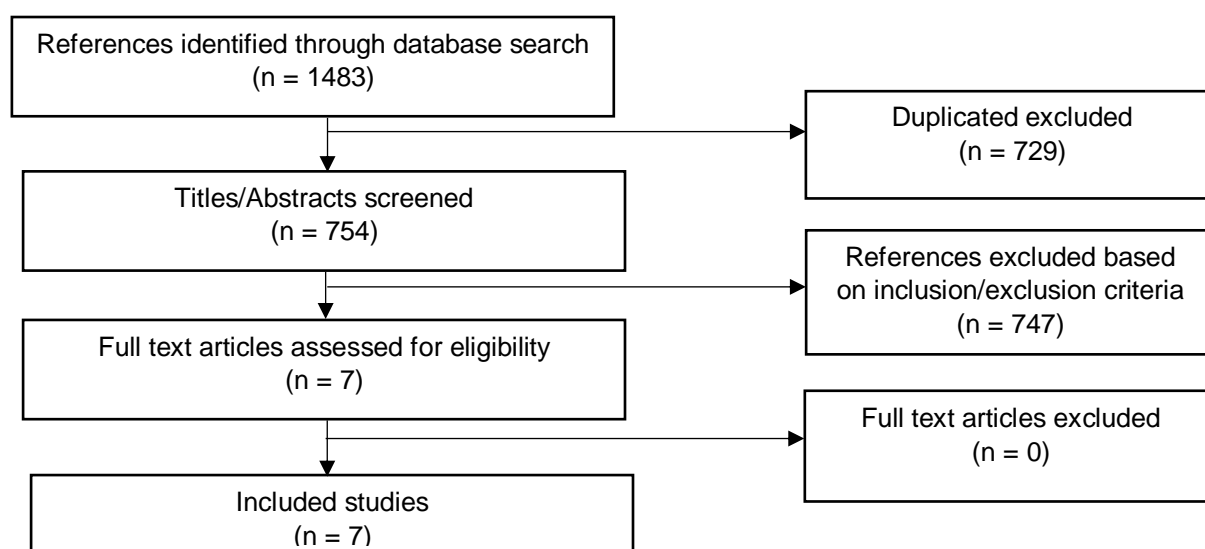
Based on the PRISMA Statement guidelines (Moher *et al.*, 2009).

Studies were mainly excluded based on either not being conducted in care settings located in England, or being highly specialised in their focus, such as support staff approaches to food choices, and end-of-life care. Some specialist studies were included in this review as they investigated support worker views about their role more broadly which was potentially relatable to this study, particularly given the low number of studies identified that explored staff perceptions about their role across their work. In reporting the results of this systematic review I examined specific findings that identified the views and experiences of support workers about their work. Results that focused on specialist areas of support were not described in this review. The reference list of each of the seven included studies and

citations of these studies were reviewed for additional relevant sources but no articles meeting the search criteria were identified.

4.2.2 Included studies

Table 4.2 summarises the seven full text articles identified for inclusion in the systematic review. The seven studies identified were published between 2010 and 2019. Two of the studies adopted quantitative approaches, five described qualitative designs. Four of the qualitative studies incorporated data obtained through semi-structured interviews, one of which also included observation. One study incorporated data through focus groups. Due to the heterogeneity of studies, I used a descriptive approach for the data analysis, including the results of each study. The studies are discussed in further detail in Section 4.3.

Table 4.2. Full text articles included

Author	Year	Title	Method	Results
Windley, D, and Chapman, M	2010	Support workers within learning/intellectual disability services perception of their role, training and support needs.	This study explores the perceptions of support workers working with adults with learning/intellectual disabilities, training and support needs. Data was collected by focus group (n = 3) and semi-structured interviews (n = 5).	Participants saw their key role as maximising quality of life, identified 'trial and error' as the main mode of skill development for new staff, and experienced stress as a result of conflict between their beliefs and demands of the service. Participants recognised their responsibility to model good and challenge poor practice; however, poor communication and assertiveness skills affected their ability to do this. A preference for more on site supervision to provide leadership was indicated.
Dunn, M. C, Clare, I. C. H, and Holland A. J	2010	Living 'a life like ours': support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities	This study examines substitute decision-making by residential care staff relating to the welfare of adults who lack the capacity to make one or more autonomous decisions about their care and support. The paper reports a qualitative, grounded theory analysis of 21 interviews with support workers working in residential care homes for adults with intellectual disabilities, and observations of care practices.	In contrast to the narrow legal responsibilities placed upon them, support workers interpreted substitute decision-making within a broad moral account of their care role, orientating their support towards helping residents to live 'a life like ours'. Support workers described how they drew on their own values and life experiences to shape the substitute decisions that they made on behalf of residents. Support workers' accounts revealed clear discrepancies between the legal regulation of substitute decision-making and the ways that these support workers made sense of their work.

Golding, N. S, and Rose, J	2014	Exploring the attitudes and knowledge of support workers towards individuals with intellectual disabilities	The study explored support workers' attitudes and knowledge towards individuals with intellectual disabilities to see whether a new attitude scale was needed. Twenty support workers from a charitable organisation located in the West Midlands participated in one of four focus groups. Thematic analysis was then conducted which identified the emergent themes from the focus groups.	Five themes emerged from the analysis of support worker attitudes: discrimination of people with intellectual disabilities, attitude change, impacts of integration, their role as carer, and the impact of training. The results suggested that existing attitude scales did not accurately measure the attitudes of support workers.
Smyth, E, Healy, O, and Lydon, S	2014	An analysis of stress, burnout, and work commitment among disability support staff in the UK	A sample of disability support workers across 18 residential care homes with a single care provider in the UK (n = 138) reported their levels of perceived stress, burnout, and commitment to their work against a series of quantifiable measures. The relationship between the frequency and severity of aggressive/destructive behaviours to which they were exposed, and these three measures were examined.	The results revealed an association between challenging behaviours experienced and participants' perceived stress and emotional exhaustion. Perceived stress and burnout were also associated with participants' commitment to their work. A series of regression analyses identified a number of predictors of emotional exhaustion, depersonalisation, and personal accomplishment among disability support workers.
Hutchison, A, and Kroese, B.S	2016	Making sense of varying standards of care: the experiences of staff working in residential care	To find out why standards of care might vary in residential homes for adults with learning disabilities, this study explored the experiences of six care workers in residential homes. Each care worker took part in a semi-structured interview	Research evidence revealed that adults with learning disabilities who live in residential care facilities are exposed to considerable variation in the standards of care they receive. Three superordinate themes were identified as being central to participants' experiences of their work roles: degree of positive

		environments for adults with learning disabilities	where they were asked to talk about their jobs in detail. Data were analysed using Interpretive Phenomenological Analysis.	relationship reciprocity; value congruence and intrinsic motivation; and experiences of environmental and organisational constraints.
Collins, K, Gratton, C, Heneage, C, and Dagnan. D	2017	Employed carers' empathy towards people with intellectual disabilities: the development of a new measure and some initial theory	This study aimed to develop a self-report measure of paid caregivers' empathy towards people with intellectual disabilities. 194 staff working in services for people with intellectual disabilities completed self-report questionnaires.	Two key processes in empathising were identified: experiencing commonality between one's own and people with intellectual disabilities' psychological experiences, and efforts to attune to their internal worlds. Empathising with people with intellectual disabilities may be different from empathy in other contexts. The study identified a need for investigation into whether carers find it challenging to empathise.
Clifford, A, Standen, PJ, and Jones, J	2018	"I don't want to take any risks even If it's gonna mean this service-user is gonna be happier": a thematic analysis of community support staff perspectives on delivering transforming care	The aims of this research was to learn the views of a small but diverse sample of community staff employed in direct support roles for people who have moved to their service as part of *Transforming Care*. Managers and support staff (n = 13), working in specialist community placements, were interviewed about perceived barriers and facilitators to implementing Transforming Care.	Participants identified difficulties balancing people's rights, safety and quality of life needs, and felt the system's expectations of them are hard to deliver within the resources, legislation, values and support models provided them. Multidisciplinary expertise was highly valued for both emotional and practical support, but was least valued when perceived as overly blaming or inspectorial. Specialist health input was seen to withdraw prematurely for this particular client group.

4.2.3 Study quality assessment

In assessing the quality of the studies included in this systematic review I have drawn on the work of Sale and Brazil (2004), and Hutchison and Kroese (2015). Sale and Brazil published a criteria for critically appraising quantitative and qualitative studies based on their systematic review of the literature on the subject. Their criteria particularly drew on Lincoln and Guba's framework of trustworthiness and rigor (1985, 1986). This framework concerns four measures: truth value, applicability, consistency, and neutrality. These measures are further detailed in Table 4.3. Hutchison and Kroese adapted this criteria in their literature review of studies concerning abuse in adult residential care. They favoured this criteria because it outlines measures for critically appraising different methodologies (i.e. quantitative and qualitative studies), and organises these in such a way that a direct comparison can be made between the different research designs.

Given the range of different empirical studies in this systematic review, and the different methods employed, I considered more general research quality markers, applying the evaluation criteria Hutchison and Kroese adapted by Sale and Brazil, which is more recent, concise, and applied in a social care context. Each study was examined against the specific quality markers as set out in Table 4.3. The aim of the quality assessment was to determine the validity of the results based on the design, methods, analysis and conclusions of each study, and to assess the relative contribution of each study to the review.

All seven of the identified studies failed to report key characteristics or study quality indicators. This was particularly notable with the five qualitative studies. In terms of credibility of the findings, three of the five qualitative studies used different research methods (triangulation). No studies incorporated member checking or negative case analysis to validate results. The credibility of the qualitative findings was enhanced by the fact that all studies grounded their assertions in raw data, and provided clear evidence of this through the use of first-hand accounts using quotations. All qualitative studies clearly stated ethical approval processes, the research purpose, question, and design, and described the research context and data analysis. Only two studies were explicit about consent procedures and communicating participant confidentiality. While three studies described how the setting was selected only one of the five studies clearly justified the sampling strategy. None of the qualitative studies undertook an external audit of their processes, and only one study reflected on researcher assumptions in order to promote consistency and neutrality.

Table 4.3 Quality indicators *(Adapted from Sale and Brazil, 2004 and Hutchison and Kroese, 2015)*

Criteria	Windley & Chapman (2010)	Dunn et al., (2010)	Golding & Rose (2014)	Smyth et al., (2014) *Quant	Hutchison & Kroese (2016)	Collins et al., (2017) *Quant	Clifford et al., (2018)	Total Y
Truth value - Refers to having a high level of confidence in the credibility/validity of the findings. Examples of evidence:								
Qualitative:				N/A		N/A		
Triangulation of sources and methods	Y	Y	Y		N		N	3
Peer debriefing	N	N	N		Y		Y	2
Negative case analysis for disconfirming evidence	N	N	N		N		N	0
Member checks	N	N	N		N		N	0
Use of supportive raw data quotations	Y	Y	Y		Y		Y	5
Ethical review	Y	Y	Y		Y		Y	5
Statement of confidentiality	Y	Y	N		Y		N	3
Consent procedures	N	Y	Y		N		N	2
Quantitative:	N/A	N/A	N/A		N/A		N/A	
Identification and control of extraneous variables				N		N		0
Statement about comparability of control group to intervention group				N		N		0
Systematic analysis of data				Y		Y		2
Ethical review				Y		Y		2
Statement of confidentiality				Y		N		1
Consent procedures				N		N		0
Applicability - Refers to the findings being applicable to other contexts, i.e. is there evidence for generalisability or transferability? Examples of evidence:								
Qualitative:				N/A		N/A		
Clearly stated research purpose and research question	Y	Y	Y		Y		Y	5
Design explicitly stated	Y	Y	Y		Y		Y	5
Description of study context or setting	Y	Y	Y		Y		Y	5
Statement of how setting was selected	N	Y	N		Y		Y	3
Clear description and justification for sampling strategy and participants	N	Y	N		N		N	1
Transparent account of data analysis	Y	Y	Y		Y		Y	5
Quantitative:	N/A	N/A	N/A		N/A		N/A	
Statement of objectives				Y		Y		2
Design stated explicitly				N		Y		1
Clear description of setting or conditions				N		Y		1

Clear description of sampling, recruitment, inclusion/exclusion criteria and participants				N		Y		1
Clear description of data collection instruments and procedures				Y		Y		2
Acknowledgement of statistical and clinical significance				Y		Y		2
Power calculation to assess adequacy of sample size				Y		Y		2

Consistency - Refers to being able to demonstrate that the findings are consistent and could be repeated. Examples of evidence:

Qualitative: External audit of process	N	N	N	N/A	N	N/A	N	0
Quantitative:	N/A	N/A	N/A		N/A		N/A	
Standardisation of tools or observers				Y		Y		2

Neutrality - Refers to a high degree of neutrality or confidence in the extent to which the findings of a study are shaped by respondents and not sources of bias. Examples of evidence:

Qualitative:				N/A		N/A		
Statement of researchers assumptions	N	N	N		Y		N	1
Use of bracketing	N	N	N		N		N	0
Quantitative:	N/A	N/A	N/A					
Assurance of objectivity				Y		Y		2
Total (qual: out of 17; quant: out of 15)	8	11	8	10	10	12	8	

Y: Yes, evidence presented. N: No evidence presented

Of the two quantitative studies included in this systematic review, neither described designs that incorporated a control group or made reference to extraneous variables. Both made explicit reference to ethical approval but neither were explicit about consent or confidentiality procedures. The validity of the studies were enhanced by the fact that they gave clear accounts of the research objective, data collection, and acknowledged the statistical significance of the data. In addition, both studies made reference to statistical power calculations, and incorporated standardised outcome measures.

4.3 Main findings

Only three of the seven studies included in this systematic review examined learning disability support workers' views and experiences about their role. While each of these three studies were motivated by a specific aspect of care (the role of Community Learning Disability Teams, Windley and Chapman, 2010; variations in quality of care, Hutchison and Kroese, 2015; and the Transforming Care agenda, Clifford *et al.*, 2018), they examined the support worker role more broadly. This small number of studies highlights the lack of empirical research examining the role of support workers in supporting adults with a learning disability in England, and the relationship between policy and practice.

The remaining studies included in this systematic review focus on a specific area of care work, such as challenging behaviour, and staff stress. However, I based the decision to include these studies in the review on whether they provide insight to the wider views and experiences of support workers. I was able to determine from the title and abstract whether this was the case as specialist studies were very clear when confined to a niche area. What follows is a summary of the approach and key findings from each study included in this systematic review, followed by a discussion of the implications for this thesis.

4.3.1 Study findings

Windley and Chapman's study (2010) was concerned with how Community Learning Disability Teams best provide support and training to support workers of adults with a learning disability. This includes an examination of how support workers perceive their role, as well as training and support needs. The study involved a small sample of support workers in semi-structured interviews (n = 5), and three focus groups, and was carried out within a joint health and social care service in a large city in England. A key theme to emerge from

the research concerned support staff values, with staff stating they enjoy their work when they feel able to facilitate a good quality of life for the people they support. Staff cited being caring and empathetic as important qualities and expressed concern that the people they support were vulnerable and at risk of abuse. The research identified role conflict with support staff having to decide between keeping a house clean and spending time supporting someone to prepare food for example, or wanting to enable people to go out in the community but not having the resources to do so. Support staff felt managers were out of touch with what was happening in the houses of people they support and were not proactive in engaging with support teams. The research identified potential conflict between enablement and dependency with staff sometimes promoting independence while at other times monitoring and controlling behaviour. Windley and Chapman found that staff developed their skills on the job through trial and error which may result in inconsistent support. The study indicated a need for greater recognition of the potential for stress experienced by support workers and that this can be overlooked when supervisors spend little time on site.

Personal values and the emphasis on positive relationships also came through in research by Hutchison and Kroese (2015). They interviewed a small sample of 6 support workers about their experience of working in care as a way to understand why standards in care vary considerably in residential settings for adults with a learning disability. Three themes were identified as central to support workers' role: the quality of their relationships with others; their levels of motivation for their work; and their feelings about the environments they worked in. It was important to staff to feel valued and empowered, especially by managers and peers but they were also able to obtain intrinsic reward through their interactions with people they support. Intrinsic motivation and personal values aligning with the caring role was found to result in greater enjoyment of work by support workers. Participants in the study were negative about their work if they felt they were isolated and if there was a lack of leadership or clear guidance. Hutchison and Kroese called for further research in this area stating that 'little attention has been paid to understanding support staff experiences of working in residential services and to developing a more theoretical understanding of the role they fulfil' (p. 182).

Against the backdrop of the introduction of the Mental Capacity Act (2005), the research of Dunn *et al.,* (2010) was concerned with substitute decision making by support workers for the people they support, as legislated under the Act. They held semi-structured interviews and observations with 21 support workers in three residential care settings for adults with learning disabilities. The study was of interest to my thesis because the researchers found

that in making such decisions, support workers drew on their own values and life experiences, reflecting on what they would do or like when making decisions for others rather than necessarily following the 'best interest' requirements of the Act. Dunn *et al.*, also found that staff favoured 'active risk-taking' to provide new life experiences for people they support outside of their daily routine and procedures as set out in individual's care plan. However, the researchers questioned whether support workers' accounts directly translated into practice and whether their views were romanticised by giving primacy to their own values and life experiences, with no reference to the realities of relationships and dependency. They thought this was especially the case when supporting people who were profoundly disabled and entirely dependent on those who support them (p. 156).

Golding and Rose (2014) again highlighted the limited research into attitudes of support workers in their study of staff attitudes and knowledge of support workers towards people they support (p. 117). Their research, which involved four focus groups with 20 residential care staff, was specifically concerned with the effectiveness of attitude scales used to measure attitudes towards people with a learning disability. While this study had a particular focus, it was included in this systematic review because the results highlighted five central findings concerning support staff that are relevant to my thesis: staff believed people with a learning disability are discriminated against by society; staff became more positive as they gained time and experience; staff were supportive of social integration; staff saw their role as enabling independence, and empowering people they support but also as protecting them from risk; and staff valued training.

During the systematic review process, certain subjects were more prominent in the search results, in particular staff stress, and supporting people with challenging behaviour. During the initial search of title and abstract, I excluded studies on these subjects as they did not provide wider insight into support worker views and experiences. However, there are two studies I chose to include as they did provide potentially useful insight for my study. The first examined staff stress, and the second staff empathy. Both studies employed a quantitative approach, whereas the rest of the studies in this systematic review adopted a qualitative framework.

Smyth *et al.*, (2014) examined stress and burnout among support workers through questionnaires with 138 support staff working in 18 residential care homes with people with learning disabilities and challenging behaviour. They identified a relationship between the incidence of challenging behaviour and levels of stress, as well as the level of commitment staff had to their work. They found that challenging behaviour was predictive of emotional

exhaustion, depersonalisation, and correlated with perceived stress and work commitment. They argued that these results had implications for the quality of care being provided, such as high rates of absenteeism and staff turnover (p. 297). They suggested that targeting perceived stress and burnout among disability support workers may be an essential means of increasing or sustaining employee commitment (p. 303). This research was limited to a single care provider organisation and considered the relationship between stress and challenging behaviour in isolation from other potential causes of stress that support workers might face in their role. However, these results are of interest to this thesis as challenging behaviour is a feature of the experience of many support staff working in residential care settings (Hensel *et al.*, 2012). This is explored further in Chapter 6.

Collins *et al.*, (2015) again emphasise the importance of relationships and relating to people in their examination of empathy among professional caregivers. They state that few studies have investigated carers' empathy in the context of learning disability services. The researchers administered questionnaires to 194 paid staff in services for people with a learning disability. The study suggests that empathy is associated with paid carers' mental representations of caregiving. Collins *et al.*, highlight the nature of empathy in caregivers as: (i) experiencing an emotion related or similar to that felt by the person with an intellectual disability; (ii) drawing on their own emotions and experiences to understand the person with an intellectual disability's experience; (iii) imagining how they would feel in the person with an intellectual disability's situation (p. 141). They also note that people with a learning disability may evoke nurturance tendencies due to their level of need.

The most recent study included in this systematic review by Clifford *et al.*, (2018) was concerned with the effectiveness of the 'Transforming Care' agenda, and provides useful insight into support worker's views. Transforming Care (DOH, 2012) was a government response to the high profile abuse of adults with a learning disability by staff at the private hospital service Winterbourne View in 2011. Essentially the Government's objective was to relocate adults with a learning disability living in inappropriate settings such as hospitals, to more local, suitable accommodation. However, Clifford *et al.*, highlighted data which showed the failure of Transforming Care in achieving this objective. What is of particular interest to my thesis is that the study highlighted the role of support workers in potentially 'making the greatest difference in the lives of service users but remain largely missing from conversations and decisions about what constitutes safe and effective services' (p. 1210). Clifford *et al.*, held semi-structured interviews with a sample of 13 support staff with a minimum of 1 month's direct support responsibilities towards people living at their service as part of Transforming Care. Participants consisted of staff from three support providers

covering five residential or supported living services. The interview was designed to elicit participants' views on support needs, challenges and opportunities, and their relationships and experiences with different stakeholders and each other. Research findings identified that participants felt conflict and contradictions between the lives staff felt they were supposed to be facilitating with people they support, and the methods and/or values through which they were meant to "deliver" them (p. 1212). This included tension between empowering people and risk-taking versus blame and sanctions if there were negative outcomes, and challenges in providing choice which could overwhelm of confuse people they support. Participants valued external expertise when it was not seen as inspectorial or judgemental and if experts were familiar with the people being supported and engagement was not superficial.

4.4 Discussion and limitations

Support workers play a vital role in the lives of people with a learning disability (Smyth *et al.*, 2014, Disley *et al.*, 2009) yet research continues to highlight the limited insight into support worker attitudes and experiences (Hastings, 2010, Golding and Rose, 2014, Hutchison and Kroese, 2015, Clifford *et al.*, 2018). The aim of this systematic review was to provide a synthesis of existing research evidence of the views and experiences of learning disability support workers about their practice and how this relates to policy. Due to the limited amount of research in this area, the criteria for inclusion was broad to avoid excluding studies that could provide relevant insight. Seven studies were identified as suitable for inclusion in this review, highlighting an important gap in empirical studies in England. None of the seven studies considered the relationship between learning disability policy and support worker practice. However, one study (Dunn *et al.*, 2010) considered substitute decision-making by support workers on behalf of people they support in the context of the Mental Capacity Act. There is a body of work examining specific areas of learning disability support work such as staff stress (Hatton, *et al.*, 1999b), challenging behaviour, (Bromley and Emerson, 1995); staff turnover (Hatton and Emerson, 1998), sexuality (Abbott and Howarth, 2007). However, little attempt has been made to integrate the various strands of research concerning support staff (Hatton *et al.*, 2004). The study sample for the majority of the qualitative studies included in this systematic review were small, and failed to meet key quality criteria for evaluating research, making it difficult to generalise applicability. While bearing this in mind, a common theme in the review was the relational importance that support workers perceived with people they support, which was attributed to their personal values and ability to relate.

4.5 Chapter summary

This systematic review of empirical studies identified several findings that the studies had in common; however, due to the limited number of studies it is not possible to draw robust conclusions from these, or to generalise about the perceptions that learning disability support workers might have of their own work. Authors of studies in this review acknowledge the critical role that support workers play in the lives of people they support, and refer to the lack of insight into support worker attitudes. The limited number and quality of studies identified in this review highlight a need for further research in this area. Without accurate understanding of support workers' views and experiences, learning disability policy cannot credibly meet the needs of the people receiving support. The next sections of this thesis set out the methodology and results of new fieldwork undertaken to solicit the views and experiences of learning disability support workers in residential and supported living settings. The findings from this systematic review and the analysis of policy in Chapter 3 have informed the fieldwork process and will be considered in the discussion of the study findings in Chapter 7.

Chapter 5: Empirical research methodology

5.1 Aims and objectives

The review of policy (Chapter 3), and systematic review of empirical studies (Chapter 4) provided limited insight into the role of support workers in the lives of people with a learning disability. This thesis hypothesises that support workers play a critical role in the lives of people they support, which should be better reflected in policy as they are the conduit to translating policy into practice. To test this hypothesis, this thesis aimed to address the following research question: *What role do support workers play in enacting learning disability policy in England?* The empirical study in Chapter 6 had three objectives: 1) to explore how paid support workers talk about their work; 2) to understand the relationship between what support workers say and what they do; and 3) to examine the relationship between learning disability policy to care practice.

This chapter sets out the methodological approach to the empirical research presented in Chapter 6, which examines the perspectives and practice of learning disability support workers in adults social care settings. First I set out the rationale and use of qualitative methods applied in the research, drawing on academic literature to review different perspectives in conducting qualitative research. I then detail the selection of the study site, participants, and sample size. This is followed by a description of the research methods used in the empirical study (interviews, and observation), and the data analysis process (coding and thematic analysis). The criticisms of each research method and my efforts to address them is presented. Finally, I set out the ethical considerations of the empirical study.

5.2 Qualitative methods: rationale

Qualitative research embraces the complexities of human thought and behaviour.
(Roller and Lavrakas, 2015)

This study employed a qualitative research multi-methodology approach, which was centred on the thoughts and behaviour of paid support workers. A multi-method approach is one which involves two or more methods to investigate a research question; in this case interviews, observation (primary research), documentary analysis, and systematic review (secondary research). The strength of qualitative research is its ability to analyse what

happens in naturally occurring settings (Silverman, 2001), and is suited to researching issues that might be difficult to examine in a more structured quantitative study. It is useful at gaining in-depth insight from harder-to-reach or hidden populations – in this case learning disability support workers based in residential and supported living accommodation. Qualitative research encompasses a wide range of methods such as interviews, observation, focus groups and other visual and written data. These methods can generate rich insight into participants' perspective, experience and behaviour, evaluate how things work, or generate new ideas (Ritchie *et al.*, 2014). Figure 5.1 illustrates the focus of qualitative research.

Figure 5.1: Focus of qualitative research. Copyright holder is E. Humphrys.

A qualitative multiple method approach was selected for this study as it supported the aim of understanding the relationship between participants' perceptions (interviews) and behaviour (observation), and what this means for learning disability policy (thematic analysis). Using different methods helped enrich the study as one method helped inform the other, for example observation work raised questions that could be explored during interviews. This study did not involve any group discussion format in order to respect individual support worker confidentiality and to encourage participants to speak more openly about their work and the people they work with, unencumbered by social pressure or influence from group members.

Silverman (2001), distinguishes between three versions of data: Positivism, which is concerned with 'facts'; Emotionalism, which is concerned with people's lived experience; and

Constructionism, which is concerned with how meaning is mutually constructed by interviewer and interviewee. This study was interested in participants' perspectives and practice, and the narratives that they construct to understand and sustain their lives in the care context. The study does not suggest that the views and experiences participants shared were necessarily authentic representations, but rather a result of their subjective interpretation. However, this research was more concerned with how the participants made sense of things, whether real or perceived, how this facilitated or undermined their behaviour as support workers, and the potential implications for social care policy and practice.

There are a wide range of perspectives on how to approach qualitative research. These different perspectives are focused on the 'paradigm' the researcher brings to a study. Roller and Lavrakas (2015) highlight that discussion centres on the philosophical construct of reality (ontology) and knowledge (epistemology). This is fuelled by different views on there being a single objective reality (postpositivism) or multiple subjective realities (constructivism-interpretivism) and the source of knowledge, for example the role of the researcher in bringing their own values into the research process (p. 3). Many academics separate qualitative research design from discussion about paradigms (Guba and Lincoln, 1994). In examining criteria for evaluating mixed-method studies, Sale and Brazil (2004) discuss the link between research methods and paradigms. They state that quantitative methods are based on the paradigm of positivism whereby 'there is only one truth, an objective reality that exists independent of human perception' (p. 353) and the researcher can conduct a study without influencing or being influenced by it. However 'qualitative methods are based on the paradigm of interpretivism and constructivism, whereby multiple realities exist based on one's construction of reality' (p. 353).

Because of the complexities in studying human behaviour, research design considerations associated with trustworthiness and reliability are frequently examined by researchers (Lincoln and Guba, 1985). Roller and Lavrakas argue for a quality strategy in qualitative research that is: (a) paradigm neutral, (b) flexible, and (c) applicable to all phases of the research process' (2015, p. vi). The qualitative methods applied in this study considered the four components set out in their framework (which they refer to as the Total Quality Framework): credibility; analysability; transparency; and usefulness. Their framework is focused on 'how qualitative work is conducted' and stands apart from the issue of paradigms and whether or not there is an overarching paradigm which encompasses qualitative research (p. 20).

5.2.1 Limitations of qualitative research

Qualitative research requires the researcher to recognise that what people say and what they do are the result of multiple influences. It is therefore challenging to conceptualise and operationalise the complexity of human realities which can in turn present research design issues (Roller and Lavrakas, 2015). Qualitative research requires a flexible approach to discover the more subtle influences on perception and behaviour; at the same time the approach needs to be grounded in a framework that can maximise confidence in the research results.

Qualitative field work studies have been criticised for being anecdotal (Sliverman, 2001) because it can be difficult to determine the representativeness of findings. There is a risk that the researcher selects data to fit particular assertions. 'As the researcher abstracts data from raw materials… the original form of the materials is lost. Therefore it is impossible to entertain alternative interpretations of the same materials' (p. 223). Yin (1981) stresses the main issues occur when researchers use categories that are either too small or too numerous. There is a risk of assuming everything is relevant and trying to categorise too much. Instead, the data should reflect "meaningful" events. Determining what is meaningful requires a sense of the central questions of the study in advance. I have made every effort to address these criticisms in the study by being clear of the research question at the outset, and applying a systematic approach to coding the data (interview transcripts and observation field notes), both manually and using data analysis software. This allowed me to find patterns and themes in the codified data that were representative of the study sample (see Section 5.7 for details on data analysis and coding). While this did not eliminate the risks associated with researcher influence, it provided a degree of consistency with which data was assigned to categories. The data was also triangulated with other findings in the study such as the documentary analysis and systematic review in Chapters 3 and 4.

A further concern for qualitative studies is the generalisability of research based on limited data from a single case. It can be difficult to have confidence that such a sample is representative of the population being studied in order to make broader inferences, in this case of the social care workforce in England. I used purposeful sampling in this study which allowed me to identify a case based on a pre-defined criteria that could illustrate the area of study. I linked 'local' data to wider issues such as workforce challenges, work stress, social care funding, and more generally to social care policy. This approach increased the relevance of the findings beyond the specific setting.

5.3 Setting

5.3.1 Service selection: rationale

The fieldwork in this study was concerned with the views and experience of learning disability support workers in adult social care settings in England. Residential and supported living services were selected as the focus of this study because the most common type of accommodation for people with a learning disability, after living with family or friends (29.6%), is living in a registered care home (16.9%) and supported living (12.7%). Essentially, residential homes consist of group living in single dwellings. Supported living housing is similar to private rented accommodation in that residents are tenants of their own home. The largest component of local authority expenditure on services for people with a learning disability was on residential care placements (£1.55 billion) followed by supported and other accommodation (£483 million) (Emerson, *et al.*, 2011, p. 58). As identified in Chapter 4, there is comparatively little research concerning paid support workers in these settings in England. Unpaid carers, and domiciliary care provision were not included in this study as this type of care provision can vary significantly, and the practicalities (such as participant recruitment, logistics, and cost) would have been prohibitive.

5.3.2 Site selection: criteria and approach

I established the following criteria in order to identify potentially suitable adult care services for the fieldwork: 1) Adult service providing residential and supported living care; 2) The number of staff must be sufficiently high for the researcher to engage at least 20 participants; 3) The location must be logistically convenient to enable the researcher to access by public transport at an affordable cost. No requirements were made of the attributes of potential participants other than that they be permanent staff directly employed by the care provider. I did not include bank staff (employed on zero-hours contracts) or agency-provided support workers due to the inconsistency in their working hours and location, and I would have needed consent from the different agencies that the service provider used.

Having discussed potential care providers with my supervisor, I approached the Chief Executive Officer of a national learning disability care provider by email to establish a potential match with the above research criteria. The CEO agreed for the care provider to participate in the study, and asked me to liaise with the Operations Director to identify

suitable services. The care provider suggested three potential locations. I ruled out two of these locations: the first because it was described as a 'flagship' service which raised concerns that the research findings could be atypical if focused on a best-practice site. The second location was rejected because potential participant numbers were not sufficient for the study. The location that fitted the criteria was anonymised as 'The Lane' in the study.

While this study was conducted with one care provider in one geographical location, it was formed of 15 different services, and the sample included staff who had worked at the site under a previous care provider. Though this does not mean the results from the research could be generalised, it increased confidence that the research findings would be of value and inform future research. The Lane provided the additional benefit of having both residential (group living) and supported living (independent living) services on the same site, allowing for comparison between different types of services.

A description of The Lane, including site map, can be found in the Results section of this study in Chapter 6, Section 6.1.

5.4 Sample size, participant selection and consent

The sample selection and size was informed by decision guidelines set out by Roller and Lavrakas (2015) and the number of permanent staff employed at The Lane (20). These guidelines consider (a) the complexity of the phenomena being studied, (b) the heterogeneity or homogeneity of the population being studied, (c) the level of analysis and interpretation that will be carried out, and (d) the finite resources available to support the study (p. 27). They find there is little guidance on choosing 'the right' sample size. Examining research by a range of academics Roller and Lavrakis found that the figures ranged from 6, for hard to reach groups, to 100 when gaining understanding over time across different settings and locations. The concept of 'saturation' is widely discussed by qualitative researchers. This refers to the point at which additional data does not reveal new insight (Robson, 2011); on this basis the researcher decides they do not need to collect further data. Given the size of this study I did not reach a point at which I felt I need not continue but the level of consistency in the data did not create concerns that a larger sample was required for the purposes of this study. The study does however identify the need for further research, which is discussed in Chapter 7.

This study uses purposive sampling, which is a directed approach that involves the selection

of particular people because of their relationship to the subject under study, in this case paid support workers. Given the possible sample size of 20 study participants, following consultation with my supervisors, and reflecting on sample sizes from studies reviewed in Chapter 4, I invited all permanent staff at The Lane to participate in the study and 20 staff consented. In this study, the care provider, locations and participants' names were anonymised (see Section 6.1 for further details).

Participant recruitment was coordinated through the Registered Manager (RM) at The Lane based on the criteria described in Section 5.3, and on grounds that she had direct contact with support workers onsite. Six weeks prior to commencing the fieldwork, I provided a written information letter and a consent form to the RM which she shared with potential participants. These documents set out the purpose of the research, what the research would entail in practical terms, how participants would be involved, and how any data about participants and the study would be used. It also sought explicit consent from staff to participate in the research, and made clear that participants could withdraw from the study at any time of their choosing. The RM provided printed out copies of the letter to staff and provided me with the signed consent forms prior to beginning the research.

Of the 20 staff who consented to participate in the study, 18 were support workers, and two were managers (the Registered Manager, and Service Manager), both of whom had been support workers at The Lane. The age range of participants was 18-63, with the average age being 41. Five of the twenty participants were male (25%). The length of time that staff had been working in the service ranged from 4 days to 11 years. The staff member who had been at The Lane for 4 days had spent the prior 16 years working in learning disability care services.

On every occasion that I visited The Lane, I reconfirmed verbally that participants had consented to participate in the study, their identity would be confidential and any quotes used in the study would be anonymised, that they were happy to continue to participate, and they were free to withdraw from the study at any point. I also checked that residents were okay with me being present during any observation. All support worker observations involved residents who had mental capacity to express whether they were unhappy with my presence or wanted me to leave. This did not happen during the study.

5.5 Research methods: interview

Interview is central to most qualitative research design (Roller and Lavrakas, 2015).

5.5.1 Approach

Interviews allow the researcher to gain a rich understanding of how attitudes are formed and the thinking that drives behaviour. I undertook 20 face-to-face semi-structured interviews. The interview questions were informed by a topic guide (Appendix 3) which I developed in discussion with my supervisors, and reflecting on the studies reviewed in Chapter 4. The topic guide provided a flexible framework which enabled me to ensure relevant issues were covered but allowed me to adapt the questions as warranted by each interview. A semi-structured interview approach provided a better dynamic between interviewer and interviewee by creating a dialogue which was more conducive to establishing trust, and gaining depth by encouraging the participants to speak openly. The interview process also provided an opportunity for participants to contribute their interpretations of the researcher's observation during the study. A structured interview format was rejected as unsuitable for the purposes of this study as it risked being too formal and intimidating, generating guarded, formal responses. At the same time, as this study is focused on understanding a specific question, a completely unstructured interview would not have been appropriate either as it risked the analysability, credibility and comparability of data. To address the issue identified by Silverman (2001), that what people say in interviews does not have a stable relationship with how they behave in naturally occurring situations, interviews were conducted in parallel to observation work. This allowed the two approaches to inform each other rather than operate as separate processes. Through both processes I was able to consider similarities and explore variations across the participants.

All participants consented to interviews being audio recorded and there were no requests to turn off recordings at any point. The interviews were designed to explore staff perceptions of their work, their perceived relationships with people they support, and awareness of care policy. I started each interview with a general question about how participants came to work in care, and then used open questions inviting people to talk about their views and experiences. Responding to participants' narrative, I adapted how I worked through the topic guide and explored participants' perceptions of their role, how they described what they do, their decision-making and rationalisations of different situations they raised, and how they managed challenges. I also used the interviews as an opportunity to discuss any particular

observations that I identified over the course of the fieldwork. Before the interview was ended I asked each participant if there was anything else they wanted to say or if they had any questions.

Interviews took place in different areas of the residential care and supported living homes, such as the living room, the kitchen, and the garden. I asked participants to choose where they would prefer to speak to me. Interviews lasted between 45-60 minutes. The semi structured, conversational approach enabled participants to feel at ease and to speak more freely. This was evident when I put my pen and paper away after the first two interviews; this had been distracting participants, causing them to pay undue attention to what and when I was writing. This also allowed me to observe non-verbal communication better, to demonstrate active listening, and create rapport. At the end of each visit I dictated observations and reflections on a tape recorder, which were then transcribed as field notes and reviewed with other observation and interview data as part of the data analysis.

5.5.2 Limitations of interviews

Academic literature questions the usefulness of research data that are based on interviews, and raise concerns about reliability, particularly in the context of '(a) recalling experiences, (b) understanding and responding appropriately to open-ended questions, and (c) pleasing the interviewer with responses that they believe the interviewer or others want to hear' (Nonnemacher and Bambara, 2011, p. 329). In addition, the answers of interviewees may reflect a certain amount of relativism (e.g. participants may emphasise intrinsic rewards such as making a difference, in the absence of extrinsic rewards such as remuneration). To mitigate the issues of conflicting views and bias, I drew on the approaches described by Lincoln and Guba (1985) relating to the credibility of qualitative research methods and trustworthiness. These approaches include: repeated observation and triangulation (comparing findings across the participant observation, interviews, documentary analysis, and systematic review); deliberately looking for data that does not fit with researcher suppositions; and the regular review of transcripts.

Many of the strengths of the interview method, such as the interviewer-interviewee relationship can also pose risks. A key issue that can undermine the effectiveness of the interview method is interviewer bias. This can be as a result of personal characteristics such as gender, personal values, or other factors such as making presumptions or misinterpreting the interviewee. The interviewer dynamic with the interviewee can also pose challenges if

there is an imbalance in the relationship. This can take a number of forms such as the interview becoming a one-way process driven by the interviewer, or interviewer behaviour such as showing agreement or disagreement. While it is not possible to avoid these risks, I tried to be conscious of any assumptions I may have, and of my interactions during the interview process, utilising techniques such as building rapport and active listening to encourage the interviewee to speak openly, while being aware of my body language (avoiding nodding, frowning) and verbal cues.

5.6 Research methods: observation

Observation is a core component of qualitative research. *'It allows the researcher to gain a meaningful and nuanced understanding of behaviour, attitudes and values by getting close to the lives of the target population…The reality of the experience contributes highly to the credibility of the data'* (Roller and Lavkaras, 2015, p. 182).

5.6.1 Approach

Observational research is primarily participant-led, which adds to the quality of the outcomes. Unlike interviews, observation avoids the potential issues surrounding participant recall of past events and information. In addition, with onsite observation participants are being observed in a location they are familiar with, doing what they normally do. This reality-based approach enables a more true insight into the participants' lives under study.

There are a number of different observer roles that can be adopted for observational research. These roles fall within the two categories of non-participant and participant observer. Within these categories are different degrees of distance between the researcher and the observed, such as offsite non-participant observer, and onsite complete participant observer, who might be someone who becomes part of the workforce they are observing for example. For this study I chose the role of on-site passive-participant observer as the most appropriate research method to explore day-to-day care practice in a live context. This type of observation allowed me to see how paid support workers engaged with the people they support, their interaction with their peers and managers, and how they reacted in different situations as they went about their work. As a central part of my fieldwork was to compare what support workers say with what they do, I needed to be onsite.

An observation guide was created which set out specific areas of observation (see Appendix 2). As a passive participant my role was primarily as observer, but I occasionally interacted with participants and sometimes asked questions. For example, if a staff member was praising someone they supported such as for finishing a puzzle and asked me what I thought, I was complimentary, and if a staff member was undertaking a complicated paperwork process, I asked clarification questions to understand what they were doing. Observation research can also be covert or overt. I was transparent about my research subject and aims as I did not see any benefit in partial or non-disclosure. I found that support staff welcomed having someone interested in their work and they understood I was not looking at best practice but interested in what they do on a daily basis. I did not note any reluctance to being observed by any of the participants. Any initial efforts staff may have made to demonstrate the positive aspects of their work was balanced over the period of the fieldwork by the realities of their day-to-day demands. For example one support worker I was observing started their shift with great energy and was telling me the good work he was doing but within the same shift, when staff absence created pressures, and resident needs mounted, his focus shifted to having to deal with numerous challenges.

My observations ranged broadly, from daily routines within the home environment to scheduled activities both on-site and off-site (e.g. a music session, church service, work placement). I visited The Lane at different times of day, and on different days including weekends. I did not observe any overnight shifts. I undertook at total of 72 hours of observation over a total of 3 months. Observations were spread out over this timeframe to allow time to write-up and review observations, and to capture a broader time period of activity. This limited being susceptible to time-specific influence such as the manager being on leave therefore impacting the routine of the site under study. When one of the residents passed away, I paused fieldwork for two weeks following agreement with the Service Manager.

I recorded my observations, including personal reflections on a tape recorder, and these were later transcribed for analysis. By regularly reviewing my notes, I was able to use the insight in subsequent observations where previous observations and assertions could be examined. As with the interviews, I initially tried to take written notes but found that this was distracting to participants, and impacted my ability to focus fully on observation.

5.6.2 Limitations of observations

There is a lack of agreement among qualitative researchers on whether to conduct nonparticipant or participant observation, whether observation should be overt or covert, how structured or pre-defined the observation should be, the use of public and private locations, and single or multiple sites (Roller and Lavrakas, 2015). I was conscious of the potential for the Hawthorne effect whereby participants could modify their behaviour as a result of being observed. I was also conscious of the possible influence of my characteristics and traits on participants' behaviour. While in some circumstances this may have worked to my advantage in being accepted and trusted (being of similar age to the average participant, having a professional background in social care, being female in a predominantly female service), it could also interfere with gaining a full, clear, impartial understanding of the study subject. Staff and residents showed interest in my presence and appeared to enjoy having a visitor, often wanting to actively make conversation, and offer me cups of tea for example. I addressed the risks associated with the Hawthorne effect and of my influence through a number of measures: comparing observation findings with interviews; repeating observations with participants; being conscious to maintain the passive-participant observer role and not stray into over-familiarity; and recording observations relating to how staff were engaging with me, such as if they lowered their voice or changed topic if a peer or manager was nearby), which was considered as part of the data analysis.

5.7 Data analysis: coding and thematic analysis

Thematic analysis is a widely used qualitative analytical method and is seen as a foundational method for qualitative analysis. It is a method for identifying, analysing and reporting patterns (themes) within data. Thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data (Braun & Clarke, 2006). Thematic analysis is not wedded to any pre-existing theoretical framework, and therefore it can be used within different theoretical frameworks. According to Braun and Clarke (2006), thematic analysis can be an essentialist method, which reports experiences, meanings and the reality of participants, or it can be a constructionist method, which examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society (p. 81). This study was concerned with reality from the perspective and experience of participants.

Understanding the relationship between how support staff perceive themselves and their work, and their behaviour in practice was central to addressing the research question. Therefore, as part of coding and analysing the data, I applied the twin-track approach described by Silverman (2001), which gives importance to an individual's interpretation and description of something, even if these conflict (i.e. how individuals attribute meaning based on their lived experience). Coding serves as the critical link between data collection and their explanation of meaning (Charmaz, 2001). In line with Fine (2002), I did not subscribe to the naïve realist view of qualitative research whereby the researcher simply gives a voice to the research participants. The research and analysis process involved decision-making by the researcher throughout the process such as identifying evidence, and selecting and editing data to present an argument. As part of the data analysis, I drew on the six phases of analysis provided by Braun and Clarke (2006) as summarised in Table 5.7. They emphasise that these are guidelines not rules and not a linear process but rather recursive, moving between the phases as needed (p. 86).

Table 5.7: Phases of thematic analysis. Copyright holder is V. Braun and V. Clarke.

Audio recordings of my observations (field notes) and interviews were transcribed verbatim in a Microsoft Word document. I then imported the transcripts in to NVivo, a data management software package, in preparation for the analysis. A strength of using NVivo is its ability to manage data and to analyse data in a quick and accurate manner compared to only manual coding and analysis. This can reduce the impact of human error in organising and categorising data, and while it does not completely free the researcher from interpreting coding and meaning, the software provides accountability in a consistent manner which adds to the reliability of the data analysis process.

Data coding and analysis was fundamental to this research study, and served as a key evidence base for examining the research question. A mix of coding methods was applied to the data, as informed by Saldana's work on coding (2016). He advises that the choice of coding depends on the nature of the research question, which in the case of this study is an ontological question concerned with participants' realities, and that coding decisions may happen before, during and/or after an initial review of the data. I identified potential coding methods at the outset of the study on the basis of the research question. As the interviews and observations progressed and I gained clearer insight into participant's views and behaviours I reviewed coding decisions. I opted to apply descriptive coding and In Vivo coding to the data in parallel. Descriptive coding is the foundation for qualitative inquiry (Saldana, 2016) and provided a basic inventory of topics (such as 'work pressures' and 'poor quality of agency staff'). In Vivo coding allowed me to capture more detailed meaning from participants' experience using their words (such as 'making a difference'). It is a particularly useful method in studies involving marginalised voices, such as support workers, and can enhance and deepen understanding of the views in their words.

I undertook a detailed manual thematic analysis from the transcription of the observation field notes, and the *verbatim* interviews. I applied an inductive approach to the data coding, identifying codes that were strongly linked to the data as opposed to a theoretical analysis, as the study was not linked to a specific theoretical interest. As the analysis progressed, I identified, reviewed and refined potential codes, grouping similar codes together, creating new codes, and excluding others that did not reflect the focus of the analysis. The final coding framework, as illustrated in Figure 6.2 contained three main coding groups or *themes*: workforce challenges; staff motivations; and complexities of enablement. Sub-themes were categorised under these three groups with a further level of coding under the sub-themes. The analysis culminated in a review of the themes to identify assertions underlying the research findings. Quotes from participants that supported the assertions were extracted from the data as evidence. Chapter 6 details the descriptions and analysis of the codes.

All data collected during this study was safely stored and password protected. The collection, storage, use and disclosure of data was in line with the Data Protection Act 1998 (replaced by the General Data Protection Regulation, and Data Protection Act in 2018), and as such the data will be held and retained for the purposes of collection and analysis for a period of 2 years and will then be destroyed safely and securely.

5.7.1 Limitations of coding

As with all qualitative methods, there have been criticisms of coding. These are mostly around concerns that the process can be mechanical and reductionist, distancing the researcher from the data (Saldana, 2016). However, coding requires the researcher to reflect deeply on the meaning of the data, and the coding process. The researcher's role is to engage with not only the coding process but to understand the detail, subtleties and nuances within the data and the analysis. Roller and Lavrakas (2015) identify the risk of the researcher identifying relationships in the data that do not exist, and constructing the data to fit a narrative they believe is valid when it is not. 'These traps related to causality and storytelling are fairly easy to fall into unless a systematic and conscientious approach is taken in the analysis and interpretation phases of the content analysis process' (p. 247). However, Saldana (2016) argues that 'objectivity has always been an ideal yet contrived and virtually impossible goal to achieve in qualitative research' (p. 41), as each individual researcher brings their personal experience of the world into the coding process.

Coding software was used in this study to improve reliability of the coding and analysis process but there are mixed views about using such software. Basely and Jackson (2007) refer to a widely held perception that use of a computer helps to ensure rigour in the analysis process… and a more complete set of data for interpretation than might occur when working manually (p. 7). However they identify concerns that using such software can distance the researcher from their data and mechanise the analysis process.

Another disadvantage of using coding is that it can ignore uncategorised data. Saldana (2016) remarks on the partiality of coding, asserting that 'all coding is a judgement call, since we bring our subjectivities, our personalities, our predispositions, and our quirks to the process' (p. 8). Even with the use of data analysis software NVivo, my ability as researcher to interpret the data will still have impacted the research outcomes. While computer software can assistant the researcher in finding patterns in the data, it is only a tool and is susceptible to misuse. The integrity of the research outcomes is threatened if the researcher does not take ownership of the quality of the research design and in making decisions that are incorporated into the software. This is also true with transcription of audio recordings where the reliability of interpretation of transcripts may be 'weakened by a failure to note apparently trivial, but often crucial, pauses, overlaps or body movements' (Sliverman, 2001, p. 33).

Roller and Lavrakas (2015) assert that coding software is a poor substitute for what the human mind can accomplish when trying to apply complex logic and generate meaning from

the content. Further caution comes from Saldana (2016) who states that 'trying to learn the basics of coding and qualitative data analysis simultaneously with the sometimes complex instructions and multiple functions of [software] programs can be overwhelming for some, if not most, researchers. Your mental energies may be more focused on the software than the data' (p. 29). He recommends coding manually first for first-time or small-scale studies, which is the approach I used with this study.

I attempted to mitigate risks associated with coding by following the checklist of criteria for good thematic analysis by Braun and Clarke (2006) as set out in Table 5.7.1, and being informed by other published criteria for assessing quality in qualitative data (Silverman, 2000). I regularly returned to the original data and re-examined coding categories during the analysis process. During observations, interviews, and coding, I noted my reflections on the process, participants, patterns, issues, and possible implications from the study. I also regularly referred back to the systematic review of empirical studies, and policy review in Chapters 3 and 4 to consider points of difference and similarity.

Table 5.7.1: A 15-point checklist of criteria for good thematic analysis. Copyright holder is V. Braun and V. Clarke.

5.8 Ethical considerations

'Ethical issues of varying magnitude arise in virtually every study with human participants'
(Saldana, 2016, p. 50).

Ethical considerations were applicable to this study. In designing the study I consulted my
supervisors, reflected on ethical approaches used by the studies reviewed in Chapter 4, and
participated in University-run training in Qualitative Methods which included components on
ethics. The procedures for this study were approved by the University of Cambridge
Research Ethics Committee (Application Number: PRE.2016.094). I also regularly liaised
with the Registered Manager at The Lane to ensure I was up-to-date on any developments
that might require me to be sensitive or to adapt my research schedule, and she also
proactively informed me of any issues such as if someone was unwell.

In undertaking the study, it was important to consider the sensitive nature of engaging with
participants whose work involved ongoing physical and emotional demands supporting
people with disabilities. This research needed to be mindful of a number of ethical issues. I
discussed these with my supervisor and the Registered Manager at The Lane and agreed
appropriate processes and mitigations in advance. I also raised any concerns as the
fieldwork took place, such as when staff were emotional, reflecting on my handling of
situations. Areas that were of particular ethical consideration are highlighted below.

Allegations, or evidence of poor practice of professional misconduct
I agreed with my academic supervisor and the Registered Manager that should this arise, it
would be reported to the safeguarding lead at The Lane.

**Provocation of negative emotions or memories in participants, or disturbing
participants and the people they support**
I tried to minimise these effects by making every effort to enable people to go about their
daily lives. I tried to be self-aware and responsive if my presence had a noticeable impact,
such as leaving the person's space or modifying my conduct. If staff became emotional
during interviews I checked whether they wanted to continue. I checked with the Service
Manager before each visit if there were any issues I needed to be aware of. I also provided
verbal reminders to each participant that they did not need to answer questions if they did
not want, and that they could ask me questions if they did not understand something, and
request a break or to end an interview or observation at any time.

Tension between remaining an observer and voicing concerns

An example of this issue arose on my first visit to The Lane. I asked a participant if I could say hello to the residents in the house they worked in since they would see me coming and going for a number of months. When the support worker entered one resident's bedroom, I could see from the hallway that she was sitting on a wet mattress and had urinated on it. The support worker commented that the resident would need to be changed but ended her shift before doing or advising another support worker. I was conscious that this resident still had not been attended to, so I flagged this to another member of staff rather than wait and observe when action would be taken. I subsequently reflected on this decision in a meeting with my supervisor who supported my decision to say something.

Ensuring research participants understood the boundaries between researcher and colleague

From the outset of the fieldwork, participants were engaged and interested in the study. They invited me to activities and to events that they thought would be of interest. At times when I was observing staff and as staff familiarity with me increased, I had to remind individuals of my role. This particularly happened when support workers wanted to involve me in providing support to residents, such as escorting them out in the community. In one instance, a member of staff asked me to stand in for her to accompany residents on their minibus to church on my own. These situations were straightforward to manage, such as being clear I was a researcher and observer only but highlighted the blurring of boundaries by some participants.

Responsibility towards study participants

Silverman (2001) highlights that when you are studying people's behaviour or asking them questions, the researcher's responsibility to those being studied have to be faced. The rich and detailed character of qualitative research can mean intimate engagement with the lives of individuals. In this study support workers shared personal insight which included their own family histories, and emotional difficulties. I was always mindful of being respectful towards each person I was interacting with, such as ensuring I was actively listening and interested, not interrupting, and giving people the time they needed to express themselves. At the same time I was conscious of maintaining my professionalism and neutrality as a researcher, despite wanting to provide reassurance or support to participants when hearing challenging personal accounts.

Maintaining residents' right to privacy and dignity

Observations of support workers during the study mostly took place in the homes of residents they supported but in order to respect resident's dignity and right to privacy, I agreed with the care provider that no observations would take place inside any bedrooms or bathrooms. While this meant I was unable to observe certain routines which participants talked about in interviews, such as getting people up in the morning, I agreed with my supervisor and the Registered Manager that it would not be appropriate or critical to the study to access these spaces and this would particularly intrude on people's privacy.

5.9 Chapter summary

This chapter has described the research design and qualitative methods for the fieldwork, considered the strengths and limitations of the research methods and data analysis, and reflected on the ethical implications.

The data and my interpretation cannot be separated fully from the context in which it was obtained. This includes the physical environment, potential participant and researcher bias, the participant-researcher relationship, and the way in which interviews and observations were conducted. The study focused on one care provider in one suburban location in the East of England, and reflects the views and experiences of 20 participants with the same care provider. The responses in this research may have been influenced by, or germane to the care provider's specific organisational culture. I did not have the resources to study and compare different care providers in different geographic regions and cannot claim that the study participants in this research represent the target population of interest to the study. The logistical design of the study was influenced by practical issues such as researcher time and budget.

Furthermore, the open access that I was provided, and the way that I was accepted by the research participants will have resulted in a different experience and insight than if access and participation had been closed or restrained. Observer bias can be a greater threat to the credibility of qualitative research than interview bias because of the role the researcher may take on and the potential affinity the researcher may have with the subject under study. The qualitative method applied to the fieldwork, and the data gathering and analysis will have been shaped by my interpretation. Irrespective of the methods used to minimise bias, I cannot claim that the findings are free of subjectivities. However, I contend that the subjective views and experience of the participants are a critical aspect of understanding the

role of paid support workers. For this reason, I deliberately provide first-person extracts from participants in this research. Through detailed thematic analysis and coding, I have identified common themes that could inform future research, policy, and practice but caution will be needed in generalising the findings from this study. The themes and research findings from my empirical study are explored in the next Chapter.

Chapter 6: Fieldwork results

This study has highlighted a gap in policy and academic research concerning the role of support workers in enacting learning disability policy in England. Chapter 3 identified that government policy is centred on promoting disabled people's right to inclusion, independence, choice, and control but such policy has not reflected the extent of the role that support workers play in the lives of people with a learning disability, or the needs of support workers themselves. Chapter 4 highlighted that the role of support workers in enacting policy in England is also under-represented in academic research. This study therefore sets out to provide new insight through primary research examining the perspectives and practice of learning disability support workers in adults social care settings in England.

This chapter begins with an overview of the care provider service 'The Lane', which was chosen as the location for the fieldwork and is formed of both residential care and supported living services (see Section 5.3.2 on site selection). I then present the findings from the fieldwork at The Lane resulting from 20 staff interviews (average interview length of 45-60 minutes), and 72 hours of observation over a total period of 3 months. The results are presented under three main themes which were identified through data analysis of fieldwork transcripts using manual and computer software coding methods (see Section 5.7 on data analysis). The implications of the fieldwork are discussed in Chapter 7.

6.1 The Lane

The Lane is based in a quiet, suburban town in the East of England (see Figure 6.1 for site map). It was established in 1998 as a site for residential care. The existing care provider took over management of The Lane from a private care provider recorded by Companies House as having been dissolved in 2013. The current care provider converted the residential care site to create a mix of supported living accommodation, and four residential care homes. The Care Quality Commission (CQC), the independent body responsible for monitoring, inspecting and regulating health and social care services (as provided for under Section 60 of the Health and Social Care Act 2008), and awarding a quality rating for services (as provided for under The Care Act 2014), gave The Lane a rating of 'good' as a result of its unannounced inspection which took place on 15th September 2017. The CQC defined good in the report as: 'the service is performing well and meeting our expectations'. The highest achievable rating is 'outstanding' which CQC defines as: 'the service is

performing exceptionally well'. The CQC considered five key areas in its inspection: the extent to which the service is safe, effective, caring, responsive, and well-led. The Lane was rated as 'good' across all five areas. The CQC inspection report commented positively on the support staff, stating that: 'Staff knew the people they cared for well and were kind, caring and compassionate in their approach. People were encouraged and supported to remain as independent as possible. Staff ensured that people were treated with dignity and respect and their privacy was maintained at all times.'

At the time of the present study The Lane had 34 beds on site, 14 of which were within the residential care homes, and 20 within the supported living homes. The Lane used to include a day centre but this was removed to make space for additional accommodation. As well as housing, the site included an outdoor wooden shelter which was used as a smoking area by staff and residents, and a self-contained cabin which was used for group activities such as music and art, and for staff meetings. One of the properties on the site served as the management office where the Registered Manager, Service Manager, and administrative support were based.

Figure 6.1 Site map of The Lane
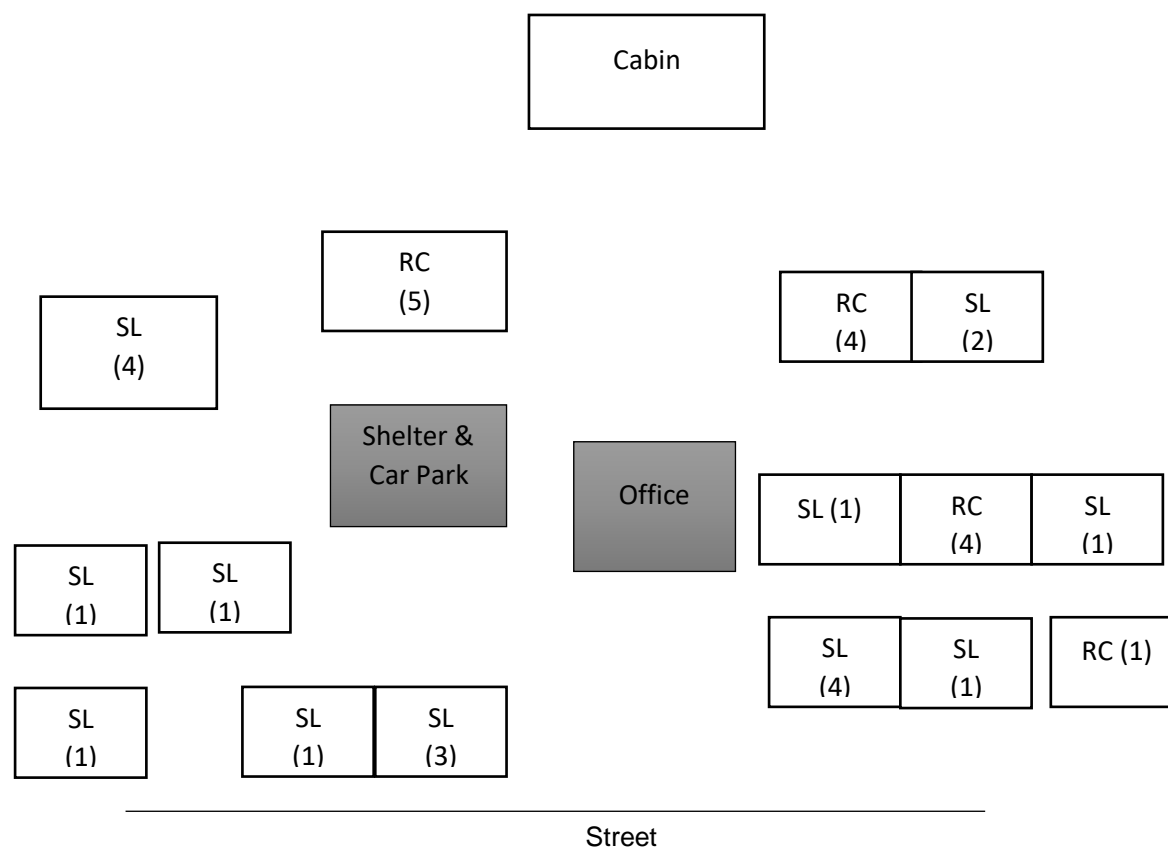
Key: RC: Residential Care, SL: Supported Living

6.1.1 The residents

The age range of residents at The Lane was 38-75 years old. The primary client group was 'adults with a learning disability', although many had additional mental and physical impairments. Residents at The Lane had been living there for between a few months to twenty years. The residential care homes were allocated to people with severe and profound needs (see Table 2.1 for definitions). Three of these buildings were configured for group living with shared facilities, and one building was configured as a single-person dwelling. The three shared residential homes consisted of a private bedroom for each resident, with all other rooms being shared spaces: a kitchen, living room, two toilets and one bathroom, in each building. Eleven of the buildings on The Lane provided supported living housing where residents were tenants of their own home. Supported living services were for people assessed by their local authority as having capacity for independent living. However, the fieldwork identified a lack of clear criteria for people allocated to residential care and supported living services (see Table 6.10(ii)).

6.1.2 The staff

The Lane had an Area Operations Manager who was also the Registered Manager (RM). The RM was the individual registered with the CQC as having the legal responsibility for meeting the requirements of the Health and Social Care Act 2008 and associated Regulations about how the service is run (see pg. 49). The RM was responsible for six services in the geographical area, and reported to a Regional Manager who reported to an Operations Director. The supported living and residential care services had their own permanent staff teams which operated on a rota system. The Lane drew on a bank of support staff to supplement the permanent staff team. Bank staff were employed on a zero-hours contract basis; their working hours depended on the needs of the care provider. The Lane also used agency workers supplied by third party agencies when bank staff were not available. Although support workers were expected to be dedicated to a particular assigned home, they also supported people living in other properties and could cover both supported living and residential care services on the site when there were shortages in permanent staffing. The Registered Manager stated that when a vacancy arose, if a home was running well with an established staff team, efforts were made to keep staff in that home. However, if a particular skill set was needed elsewhere, staff could be moved to another home on the site with little notice.

There were twenty full time staff based at The Lane, of which eight were allocated to the four residential care homes (see Table 6.1 on research participants). On average, six bank staff and five agency workers covered shifts each month due to under-staffing or absence of permanent staff. Staffing hours varied depending on the needs and activities of the residents but typical shifts were between 07:00-14:30, 14:30-22:00, 10:00-18:00 and 10:30-17:30. The hourly rate of pay was £8.06 (National Minimum Wage rate on 1st April 2018 was £7.83). No staff slept at the site. Support staff hours were arranged on a two-week rota system whereby staff worked long and short weeks which involved working a 7-day week with a weekend off, followed by a short week of four days.

Table 6.1 Research participants

Staff	RC/SL*	M/F	Age	Service	Staff	RC/SL	M/F	Age	Service
Registered Manager		F	27	7 years	Carrie	SL	F	58	8 years
Service Manager		F	34	4 years	Mandy	SL	F	27	2 years
Emma	RC	F	30	8 years	Dan	SL	M	58	4 days
Ian	RC	M	30	1 year	Jessie	SL	F	27	2 years
Lucy	RC	F	38	11 years	Jackie	SL	F	39	1 year
Jane	RC	F	50	10 years	Nancy	SL	F	18	7 months
Jenny	RC	F	63	15 years	Rick	SL	M	58	5 years
Mike	RC	M	60	11 years	Rachel	SL	F	61	1 year
Alice	SL	F	22	4 years	Val	SL	F	23	2 months
Charlie	SL	M	51	3 months	Shelly	SL	F	51	1 year

RC: Registered Care support staff; SC: Supported Living support staff

The care provider in this study ascribed to the high-level policy aspirations of choice and inclusion for people with a learning disability (see Chapter 3 for policy review). This was demonstrated by its national advocacy campaigns, which promote the rights of people it supports. At a local level, the care provider made efforts to instil these ambitions in staff through its values, which included qualities such as 'caring', and 'inclusive', and its organisational priorities, which included 'making a difference', 'supporting friendships and relationships', and for people it supports to be better connected to the community. These values and priorities were published around the homes at The Lane, and included in staff induction training. What these aspirations and efforts mean in practice will be examined in this chapter.
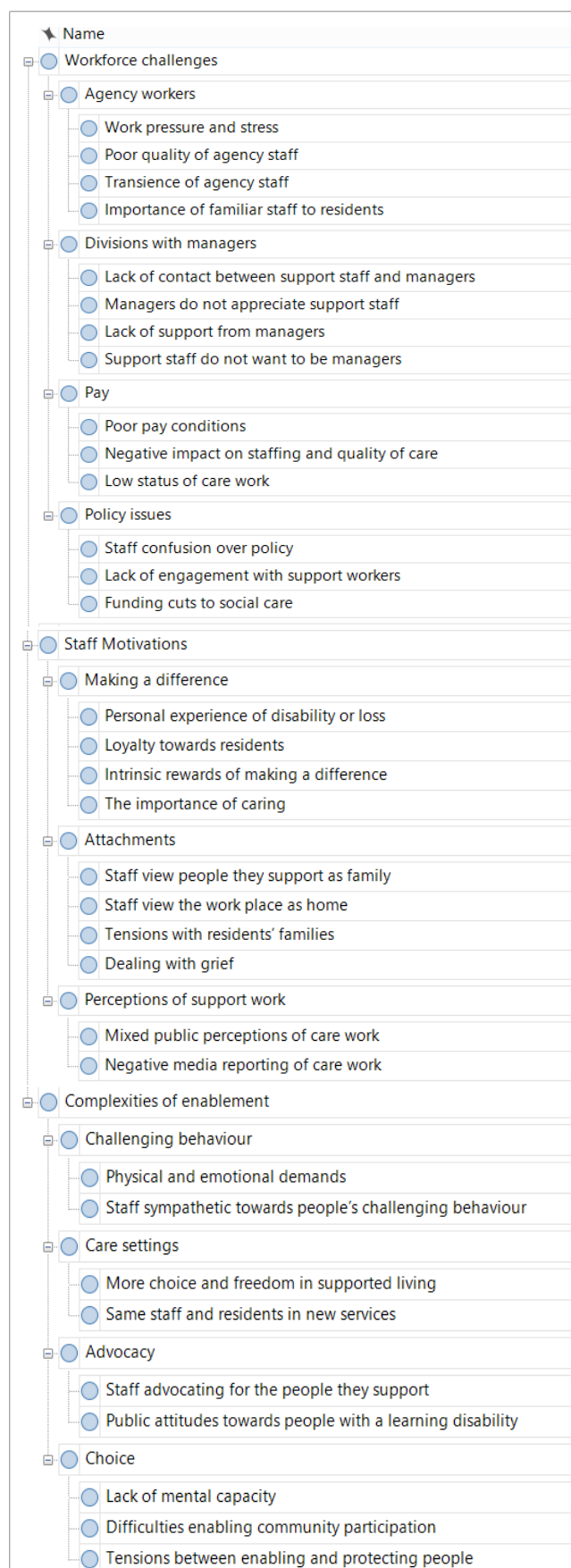
6.2 Research themes

Chapter 5 set out the methodology of coding and analysing the transcripts and field notes from the 20 interviews and observation of staff at The Lane (see Section 5.7). The final coding framework, as illustrated in Figure 6.2, contained three main coding groups or *themes*: The first theme concerned 'workforce challenges', which related to the treatment of the workforce and the impact on the quality of support for people with a learning disability, and the wellbeing of support workers; The second theme concerned 'staff motivations', which provided insight into the rationale for entering and remaining in care work, especially given the issues reported by participants under the first theme; The third theme concerned the 'complexities of enablement' which related to the challenges support workers described in supporting people to experience choice and inclusion. Together, these three themes have important implications for government policy as they impact the consistency and quality of care.

The rest of this chapter will present the research findings under the three themes, and sub-themes, drawing on direct quotations from participant interviews, and extracts from observation field notes. The interviews and observations were conducted in parallel and are reported together in this chapter. In each sub-theme section, participant quotations from interviews are illustrated in a table organised under further categories that emerged from the data (these categories are set in *italics* in the discussion of that sub-theme to help with cross-referencing). For example, in the sub-theme 'Agency workers', the corresponding table presents quotations under four further categories: *work pressures and stress; poor quality of agency staff; transience of agency staff; and importance of familiar staff.* Observations are reported as part of the narrative in this section, along with extracts from field notes.

The findings in this chapter do not claim to represent support workers more widely. However, the implications for policy and future research are discussed in Chapter 7, in the context of the broader insight from this study, and the relevant academic literature.

Figure 6.2 Final coding framework (NVivo)

- ★ Name
- Workforce challenges
  - Agency workers
    - Work pressure and stress
    - Poor quality of agency staff
    - Transience of agency staff
    - Importance of familiar staff to residents
  - Divisions with managers
    - Lack of contact between support staff and managers
    - Managers do not appreciate support staff
    - Lack of support from managers
    - Support staff do not want to be managers
  - Pay
    - Poor pay conditions
    - Negative impact on staffing and quality of care
    - Low status of care work
  - Policy issues
    - Staff confusion over policy
    - Lack of engagement with support workers
    - Funding cuts to social care
- Staff Motivations
  - Making a difference
    - Personal experience of disability or loss
    - Loyalty towards residents
    - Intrinsic rewards of making a difference
    - The importance of caring
  - Attachments
    - Staff view people they support as family
    - Staff view the work place as home
    - Tensions with residents' families
    - Dealing with grief
  - Perceptions of support work
    - Mixed public perceptions of care work
    - Negative media reporting of care work
- Complexities of enablement
  - Challenging behaviour
    - Physical and emotional demands
    - Staff sympathetic towards people's challenging behaviour
  - Care settings
    - More choice and freedom in supported living
    - Same staff and residents in new services
  - Advocacy
    - Staff advocating for the people they support
    - Public attitudes towards people with a learning disability
  - Choice
    - Lack of mental capacity
    - Difficulties enabling community participation
    - Tensions between enabling and protecting people

6.2.1 Theme 1: Workforce challenges

All participants in this study (n=20) reported experiencing workforce challenges related to a lack of permanent staff, exacerbated by use of agency workers, divisions with managers, and low pay. As Chapter 3 highlighted, government policy consistently identifies the workforce as a priority in improving support for disabled people. However, as this section will show, the Government's focus on training and regulation neglects the everyday realities and operational risks affecting support workers. Staff claimed they had little or no understanding of government policy as it relates to their work. The workforce theme is presented under four sub-themes: agency workers; divisions with managers; pay; and policy issues.

Agency workers

See Table 6.2 for supporting quotations

All support worker participants in this study (n=18) said they were concerned by the lack of permanent staff and the resulting reliance on agency workers. This was cited as a major source of *work pressure and stress* for permanent staff, who reported having to regularly work on their own, and being responsible for covering gaps and failings in agency workers' abilities and knowledge. Support staff did not include bank staff in their reported concerns as they were treated as part of the core team, irrespective of their working hours. Staff talked emotionally about the stress and pressure that they experienced in their work. This cut across discussions about support work, whether perceived to be caused by the lack of adequate staffing, or when supporting people with challenging behaviour. Support staff spoke candidly about their own mental health, and that of their colleagues, detailing serious issues including depression and self-harm. Managers (n=2) also reported mental health challenges faced by support staff, highlighting the difficulties of working in the social care sector. (See Table 6.2(i) for staff quotations concerning work pressure and stress).

Support staff reported that a recurring source of pressure was administrative processes, in particular related to medications. This was due to safeguarding resulting from failings in the proper administration of medications. Staff regularly had to manage medications for residents in several different houses in the absence of trained permanent staff. The regulator CQC requires the safe management of medications and can prosecute care providers for harm resulting from unsafe practice. The guidance on safe practice is extensive (National Institute for Health and Care Excellence, Social Care Guidelines SC1) and includes: the

ordering, receiving, storing and disposing of medicines; record-keeping; and supporting residents to take their medicines. The guidelines state: 'Care home providers should ensure that care home staff have protected time to order medicines and check medicines delivered to the home' (1.10.2). During one observation (see Extract 1), support worker Lucy spent her entire shift processing the receipt of medications on her own.

Lucy was sitting at a table on her own all day going through the arrival of medications for residents. This involved a detailed process of checking the labels and contents of each medication to ensure it was correct, noting any inaccuracies, and recording everything by hand. Lucy seemed upset as the medications had arrived late, there were errors, and she had no help. She appeared anxious because she was under pressure to complete the process quickly. Some residents were due to receive their medication that day as their previous supply had run out. Various staff popped in from other houses to check on her progress as they were also becoming anxious about residents receiving their medication on time. This process took the whole of Lucy's shift, during which she was not able to support residents in her service.
(Extract 1 from field notes)

During the field work, every time medications arrived, there was a similar level of stress and fluster as the limited number of qualified permanent staff tried to process medications while trying to meet the needs of people they support. Staff were often running between houses, asking for help with covering residents' support needs so that they could complete the medications process.

Staff described the *poor quality of agency workers* (see Table 6.2(ii)) which centred on practical requirements, for example agency workers not completing tasks such as laundry or taking people to medical appointments; and personal qualities such as not caring. Staff described agency workers as 'not giving a damn', 'terrible' and 'abusing' the homes of the people they support.

Staff reported that problems associated with the use of agency workers were exacerbated by the *transience of agency workers* (see Table 6.2(iii)). Permanent staff said they had to redirect their effort to showing agency workers various aspects of the job, or having to do things agency workers were not qualified or capable of doing, which distracted them from supporting residents. Furthermore, they said they many then never see the agency worker again.

The *importance of familiar staff* who know the personalities, preferences and routines of people they support was regularly raised by support staff (see Table 6.2(iv)). Staff reported

that agency workers caused distress to residents for whom familiarity was important. Building trust over time was described as essential to good support and especially in managing challenging behaviour. Observations confirmed this, with several instances of residents reacting negatively to unfamiliar faces, for example not wanting to come out of their bedroom, or take their medication.

Table 6.2 Descriptions of agency worker issues

Category	Illustrative quotes
(i) Work pressure and stress	'There is a lot of agency, there is a lot of imbalance of staff. So a lot of the time you will get a lot of pressure because you could be the only permanent member of staff on… And a lot of people can't deal with it, because it can be quite stressful.' (ALICE)
	'It can be very draining if it's constant… I think when you see things that aren't being done correctly… 'There's a policy here that basically if your shift isn't covered I would have to stay on… I don't feel you can do a good job that way because you just get burnt-out, you're running on empty… I wouldn't trust myself to be doing a long day and then doing a night shift. I wouldn't trust my decisions, obviously because I've not slept or anything like that. I just feel that it's not fair on them… You could easily make mistakes and stuff if you're burnt-out.' (VAL)
	'If it's not fully staffed, it can be very stressful. Like, sometimes, you have agency, or people that don't know the clients and then, in your head, you're the one that's in charge and you need to make sure everything is done… When I was stressed, I got angry and I got upset, I cried… For me to get like that takes a lot.' (JANE)
	'I used to have really bad mental health, these are all self-harm scars… We've had one girl signed off for two weeks due to stress… I think some days it can be really stressful. I'll come home… I'll get really bad insomnia where I can't sleep, especially because I used to have really bad depression and anxiety and I'll come in and my insomnia will be so bad because I've done a 15 hour shift… We have a helpline we can ring if we feel really low… but obviously if you're working here for a 15 hour shift and you've had that all day, you haven't got five minutes to ring and be like, I feel shit, what can I do?' (NANCY)
	'Now there are so many more people with mental health issues; you're trying to support your staff team as well as you can, as well as them supporting people. It's a really tough balance, I don't think social care is easy.' (RM)

(ii) Poor quality of agency staff	'You do get some that come in that are just not prepared to do it, and they sit there on their phone all day and don't do anything. I had a lady in here last week… I did say to her could you please help to take Emily to the bathroom… because I was up to my eyes in it…. I end up doing it myself… We have agency workers here that work on a weekend, and I come in on a Monday and they don't do any laundry, it's all piled up and it's all left for me today… It's disgusting. It's like you say to them that it's the girls' home, the girls live here, it's their house, don't come in here and abuse it.' (SHELLY)
	'When I'm not here they have to rely on agency, I find jobs aren't being done. I just got off the phone, Phoebe had a physio appointment because she broke her wrist this last summer…but she wasn't taken… She missed two of her appointments because agency hadn't taken her. So if she misses one more appointment, they're going to strike her off their list.' (CARRIE)
	'We have so many agency in that are so terrible, and I can't talk because I used to be agency but they're so terrible and it upsets you to see them treating them like that… like Sharon downstairs has been in bed for two weeks and I'll go down there and I'll get her out of bed and I'll shower her and then I'll come back in, a week, two weeks later and she's still in bed again in the same clothes I put her in two weeks ago….' (NANCY)
	'It's agency not giving a damn, why would they... they still get paid at the end of the day.' (CHARLIE)
(iii) Transience of agency staff	'The thing I find quite difficult is if you have an agency worker who comes in possibly for only one or two shifts and then you never see them again. You spend most of your time trying to look after them and train them and you're never going to see them again, so it's almost like a waste of time unfortunately, lost time.' (RICK)
	'A bad day is when you're short-staffed… you're running round trying to help all different agencies because obviously some agencies come for one day and that's it… So sometimes you can feel a little bit like you're maybe neglecting the people that you're actually meant to be looking after.' (ALICE)
(iv) Importance of familiar staff to residents	'That does have an impact on the people you support, because it's constantly different faces so they can't get used to anyone. That can be a trigger for challenging behaviour as well.' (VAL)
	'I used to work across the road and there is no permanent staff over there and we've watched the residents and one girl started to… she doesn't feel there's anybody in

| | there who cares… I think it's dreadful for them, or any people with learning difficulties, they've got to deal with different faces coming in every day.' (RACHEL)

'I think perhaps as people, we are used to seeing familiar faces and sometimes a bit of a sharp transition from one face to another can be quite frightening, and it might cause a lot of anxiety… I personally don't think it's a good thing to have such a huge change of faces …' (DAN)

'I don't think the people we support like seeing all different faces… Some of them seem to close themselves off, as in would rather be in their room.' (JESSIE)

'Our guys like good, regular and reliable staff. You have to put yourself in these guys position. This is their home. I wouldn't like strangers coming through my house, a different face every day, me having to explain what I want.' (MIKE)

'They're down as being challenging but they're not, not really. Once you get their trust, once you understand them and they trust you, you don't get those behaviours but it's building that relationship up first.' (JACKIE) |

Divisions with managers

See Table 6.3 for supporting quotations

Support staff reported a 'them and us' attitude towards their managers, and described a *lack of contact between support staff and managers* (see Table 6.3(i)). Support staff claimed they wanted more contact, and for managers to be more engaged with the lives of people they support, so that managers would understand 'what really happens'.

Staff claimed that *managers do not appreciate support staff* or value what they do, and simply viewed them as workers (see Table 6.3(ii)). They reported feeling unappreciated, and wanting positive recognition for the work that they do, and that good staff had left due to a lack of appreciation. Staff spoke about being made to feel 'guilty' or obligated by managers to work additional hours due to a lack of permanent staffing, otherwise people would not have support.

As well as a lack of recognition, staff reported a *lack of support from managers* (see Table 6.3(iii)). Support staff were critical of managers for not working as a team, or helping when in

a position to do so, for example in a medical emergency. Support staff used language like 'we're down here' and 'we have to do everything' reflecting a perception of an imbalance in power and responsibility, and claiming that they wanted more teamwork and practical support from managers.

Instead of viewing entering management as a way to address concerns from the inside, *support staff do not want to be managers* (see Table 6.3(iv)). No support staff expressed career aspirations beyond their current level. They claimed career progression would remove them from supporting the residents and that they would end up 'stuck' in an office doing paperwork. The average participant age was 41, which may have influenced this response as some participants commented that they had held management positions prior to entering the care sector and were not interested in returning to management level. Managers said they were not surprised or concerned by this lack of aspiration when asked, and reported this as a positive response as it meant people 'just love being a support worker'.

Table 6.3 Descriptions of management issues

Category	Illustrative quotes
(i) Lack of contact between support staff and managers	'I'd like more contact with my management. I'd like meetings where we actually… the staff talk about what really happens… because weekends can be hell here, absolute hell. I'm often covering medication for four or five services and that's not good.' (RACHEL) 'I would like them to be more aware of the guys' lives, what they do and when they do it. Yes, obviously spend more time with us and then they get a better understanding of what goes on in the actual house itself.' (RICK)
(ii) Managers do not appreciate support staff	'It would be nice if they actually appreciated us, if they actually realised how much a good job that we do sometimes and how much shit we actually put up with… A lot of guilt-tripping goes on here. Oh well, you have to come in. Well, now they're not going to have anyone… we're just workers to them. If we leave, there's someone to fill our spot with agency so they don't care.' (NANCY) 'You've got to be appreciated… If it was better the people wouldn't go. I mean there are so many brilliant staff that have left here that have been here years, and I mean years, and they've just gone… I find that frustrating, and then we're expected to work alone… It is definitely the recognition.' (SHELLY)

(iii) Lack of support from managers	'There was an incident where someone needed meds at eight… there was no-one trained to do it. The manager was obviously trained but she didn't stay on, even though they're meant to; it's policy. She didn't stay on so I just feel… I used to manage pubs and I just thought that I wouldn't ask my staff to do anything that I'm not willing to do.' (VAL)
	'They're there and we're down here. I don't think that's right. We're here running it the best we can… they've got the management that are doing the paperwork and we're in here doing the support and things like that, where really it should be all teamwork… Fair enough, they've got a lot of paperwork to do but these [residents] are more important than paperwork and cigarettes.' (JANE)
	'If you give them an inch they'll take a mile. Here, obviously you have to do all the finances, the medications, you have to try and get them to all their appointments; we have to do the decorating. We have to do everything and you ask for anything and it just gets brushed away.' (SHELLY)
(iv) Support staff do not want to be managers	'I would hate not to be hands-on. I would hate to be stuck behind a desk, seeing everybody else get to do the support and take everybody out and be left to deal with the paperwork. It's not for me. I'm quite happy being a support worker and that's what I like to do.' (JACKIE)
	'I think it's my age… when you get older, you think, no, I don't want all that stress. I don't want all the phone calls. I don't want all the paperwork and I've been in senior… so it's like do I really want that role again? Not really because that will take away from me supporting from the people I support, and the more I'm removed away from the people that I support, perhaps the more unhappy I'd be.' (DAN)
	'You'd be surprised as you'd think people must want to progress on to something else but actually lots of people are just happy doing that role and I think that's a good thing as we need people like that. It's not just about progressing, they just love being a support worker and it is a really different role.' (RM)

Pay

A common concern reported by all participants was *poor pay conditions* (see Table 6.4(i)). Staff described the level of pay compared to the amount of work they do, the breadth of skills required, and the nature of their work. The reference to getting paid more working in 'Tesco' was a common one, with staff reporting the difference they make in people's lives, and the emotional demands and long hours that their work entails. Staff claimed that they had not entered social care for the money and that money could not be a motivation in care work but they stressed the realities of having to pay bills and the challenges of living on a support worker's wage.

Staff talked about low pay as having an *impact on staffing and quality of care* (see Table 6.4(ii)). Both managers and support staff reported that the rate of pay was a fundamental barrier to attracting caring staff to the sector, resulting in poor quality of provision. The Service Manager was outspoken about the financial viability of care work and the future risk of not being able to attract the right people to the sector. Support staff claimed good people had left and that the care provider was 'desperate' to employ anybody as a result of staff shortages due to poor pay.

Support staff reported that pay conditions were a reflection of the *low status of care work* (see Table 6.4(iii)) and that care work was not valued in society. One support worker talked about being 'the working poor' and that care work was seen as low-paid work, while another said it was seen as 'bottom rung of the ladder' if you can't do anything else.

Table 6.4 Descriptions of pay issues

Category	Illustrative quotes
(i) Poor pay conditions	'£8 per hour is disgusting for what we do. Nobody deserves to be on £8 an hour for this sort of work. You go to Tesco and it's £10 odd an hour and they're sitting at a till. For the amount of stuff we do, looking after these guys, making sure they're alright, and when we have the odd one that passes away, we are the ones that have to sit with them while they pass away. We're the ones that are sitting there holding their hands while they're dying… If they gave all support workers a pay rise, something decent, then people would be more supporting.' (SHELLY)

	'We all pay bills… It's great and it's fantastic if you do it for the love but who does it for the love? You've got a British Gas bill, you've got Anglian Water, you've got Council Tax, you've got rent, you've got mortgage – you need to pay for these things and on a support worker's wage, especially the rate they're paid, that's not going to happen.' (CHARLIE) 'I don't know why you would come into this kind of job for the money. That doesn't make sense to me… Personally I don't do it for the money because I can go and do whatever but that's why I feel pay should be better because of how many different skills you actually have to have to be a good support worker, so many.' (JESSIE)
(ii) Negative impact on staffing and quality of care	'It'll get to the point where they won't financially be able to afford to work off this wage, which means that you'll be getting crap in… None of us get paid a lot. All of us are here not because of the money, definitely not. Even as managers not for the money because you could go and earn a lot more money doing something a lot easier. We're here because we all care.' (SM) 'Have you heard the saying, you pay peanuts you get monkeys? It's true…This needs to fundamentally change… They will employ anybody… Because they're desperate because there's a shortage because there's a lack of pay.' (CHARLIE). 'You would get more caring people coming in... A lot of people won't come into it because of the money… We're so short-staffed. You can't expect them to stay.' (SHELLY)
(iii) Low status of care work	'I think support workers should be valued more in society… It's always been said that if you work as a support worker, you don't really do it for the money and you don't get paid very much… but there is this perception that you are a low paid worker… We hear the term working poor quite a bit and I'm not saying we're exactly the working poor but you're near enough' (DAN). 'Unfortunately, I think it's almost sometimes sort of the bottom rung of the ladder, sort of can't do anything else so it's the last chance saloon.' (RICK)

Policy issues

See Table 6.5 for supporting quotations

None of the support staff participants (n=18) could speak about government policy as it relates to social care, learning disability or disability more generally, and there was evident *staff confusion over policy* (see Table 6.5(i)). Some support staff spoke about aspects of law and policy having been included in their induction when they joined the care provider, or as part of other training such as e-learning, but they were unable to recall what this covered, or found this confusing. They did have awareness of the Mental Capacity Act, since they were required to understand the capacity of people they support in decision-making but were unclear about how capacity assessments actually worked.

As support staff were not able to talk about government policy, they were asked to share their thoughts on the role of the Government in creating policies that relate to social care and learning disability. This opened impassioned feedback, with staff reporting a *lack of engagement with support workers* when formulating policies, and the Government's lack of understanding concerning their work, conditions, and the needs of people they support (see Table 6.5(ii)). Once again, as with low pay, participants claimed that this lack of engagement was evidence that what support workers do, and the daily challenges they face, are not sufficiently valued or understood. None of the participants expressed any positive views about government policy and its impact on social care practice.

Discussion of policy centred on *funding cuts to social care* (see Table 6.5(iii))*,* which staff reported impacted support hours for residents and therefore what residents could do. Participants said they were constrained by a lack of financial support, with serious consequences for the quality and continuity of care. They used combative language concerning local authority funding decisions, claiming that they had to 'fight' and 'argue' for the rights of people they support, and they criticised the Government for not recognising the 'human' aspect of care work. The Service Manager questioned the sustainability of support and talked about the detrimental impact on the people being supported if funding cuts were to continue.

Table 6.5 Descriptions of government policymaking

Category	Illustrative quotes
(i) Staff confusion over policy	'Last year I did an NVQ Level 3 Health and Social Care… and there's a lot of things that sometimes contradict each other and it's really quite confusing… You've got all these other acts that are going on and I can just remember thinking which one overrules which one? Which one's the most important one?' (JACKIE) I'm not fully aware of how it all works but they go through the mental capacity… So depending on that, that's how you would decide what decision they can make.' (VAL)
(ii) Lack of engagement with support workers	'They never ask grassroots what the best thing is for anything. They don't, and it's the grassroots workers who are probably the most in a position to say what needs to change… What happens in government is Civil Servants tell the Ministers what they think they want to hear which isn't what actually is happening.' (RACHEL) 'I think they write these policies and not actually think of the person that it's affecting…They should come and actually spend a day on a shift, come and do a shift, come and see what staff have to do, come and see what challenges the guys face on a daily basis.' (SM) 'The Government need to understand that we should be appreciated a lot more than what we are… If there was a politician that had a disabled son or daughter, I would expect that politician to put more money into that area but if it doesn't affect them, then why should they worry?' (CARRIE) 'I think they think that any person could come in off the street and do the job … I don't think the Government understand, I really don't. I think if they saw it for themselves, like I said about the situation in the morning where two people want to get up and they can't because they haven't got people, I think they need a reality check.' (JESSIE)
(iii) Funding cuts to social care	'Here you're looking after someone's life and it's a physical and demanding job… and you can sit at a till and get more money… It can be challenging, it can be stressful. The way that they're cutting everything, it'll get to the point where it'll go back to living in one massive house, no rights, no activity… one lunch, one dinner and no choice… You're not financially going to be able to run.' (SM)

| | 'Funding is a huge issue everywhere. They've tried to cut back hours in as many places as possible and we've really tried to fight that… It's an issue and it will continue to be an issue.' (RM)

'You need the staff and good pay relative to what they do… [The Government] don't understand the role of support workers. Not just that, they don't understand the people we support… They're out of touch… It's about human resources, I don't see a lot of human.' (CHARLIE)

'There's a girl over there, she sits in a chair all day every day. She's non-verbal. I used to look after her. There's a lot you can do with that girl and she sits in a frigging chair watching the TV all day. That's criminal, absolutely criminal… That one is down to Social Services not assessing her for the actual hours she needs on support…' (RACHEL) |
|---|---|

Summary of theme 1

Support staff's perceptions and practices are impacted negatively by how they claim the workforce is treated. Support staff report that their work is undervalued by managers and policy-makers, and find evidence of this in the low remuneration, lack of support and under-recognition of their work. They claim that the quality of care which people receive is compromised by under-staffing and over-reliance on agency workers that often lack the competence and caring values required to meet support needs. Shortfalls in staffing and funding required to provide adequate care reportedly create additional stress, and impact the mental health and wellbeing of support staff. Support staff describe themselves as disengaged from government policy, and report that policy makers are disconnected from what they do and the difference that they make in the lives of people they support. In the context of this theme, the unequivocal message from participants was that they face significant barriers in their day-to-day which have a negative impact on the people they support, and support workers themselves.

6.2.2 Theme 2: Staff motivations

The workforce challenges that participants reported in the previous section raise the question: why do support workers remain in their job? By their own accounts they experience constant pressure, low pay, a lack of support and appreciation for what they do,

and could earn more doing less elsewhere; yet 50% of participants had been in the same role at The Lane for 4 years or more. According to participants, the motivations for staff entering and remaining in care work were driven primarily by the belief that they were making a difference, and the attachments and bonds that staff formed with people they support. While staff reported mixed views about public perceptions of care work, and negative views of media coverage of their work, they said they welcomed feedback that they were doing work that others could not do. Theme 2 is presented under three sub-themes: Making a difference; Attachments; and Perceptions of support work.

Making a difference

See Table 6.6 for supporting quotations

Half of the participants (n=10) reported that they entered care work following a *personal experience of disability or loss* (see Table 6.6(i)). They said this experience had brought out their capacity to care. Participants talked about life-changing moments such as the loss of a parent, or the birth of a disabled child, which they said had led them to move from jobs in finance, or catering, for example, into the care sector where they could make a difference. Staff claimed that their experience of disability and loss gave them a new sense of perspective, making them 're-evaluate things', and a better appreciation of what it means to have a disability.

Participants claimed they were in their jobs because they felt a strong *loyalty towards the residents* they support, despite the negative emotional demands of their work (see Table 6.6(ii)). Staff gave examples of being in tears at work due to stress, but said they remained in their jobs because it would be detrimental to the people they support if they left. Staff said they wanted to 'be there' for the people they support and that they valued being needed by them.

Participants described the *intrinsic rewards of making a difference* (see Table 6.6(iii)). They claimed they felt good about themselves when they had made someone happy or smile, reflecting on this at the end of a working day. Participants spoke with empathy about people they support, asking what it would be like to be in their situation. They claimed that, as support workers, they were changing people's lives.

Staff emphasised the *importance of caring* in their work, and described this as an innate characteristic and not something that could be learned (see Table 6.6(iv)). All participants

described themselves as caring, and many referred to themselves as always having been a caring person. Staff talked about care work in terms of values, and associated 'making a difference' with personal traits rather than professional skills. Paradoxically, staff's focus on innate personal qualities rather than learned professional skills reinforces the lack of recognition of support work as a skilled profession: an issue about which participants voiced concerns (see Tables 6.3 and 6.5).

It is important to note that 'caring' was one of the care provider's official values. The other values were: inclusive, trustworthy, challenging, and positive. In addition, the care provider had five organisational priorities, which included 'making a difference'. The values and priorities were displayed in each of the different services. Although staff talked about the importance of caring, and making a difference in their work, at no point did they reference these as organisational values, or priorities, and instead described these as personal qualities they always had.

Table 6.6 Descriptions of making a difference

Category	Illustrative quotes
(i) Personal experience of disability or loss	'My dad had motor neurone disease. He passed away in March… It was probably about ten years ago that he was diagnosed, so I was quite young, so only 13 and it kind of brought me up to be a caring person. Obviously, I had to do things for him and cook and stuff like that, so I think that's what inspired me the most. It's rewarding as well, I think. If you work in an office, it's just 9-5 and it just gets a bit boring… It's just making a difference really.' (VAL) 'I was working in restaurants and bars and my best friend passed away and I thought why I am serving people who are horrible, daily moaning. I worked in a pretentious restaurant and I thought I just want to do something that's going to make a difference and that you get some satisfaction out of it… The people we look after are so incredible and when they achieve something that's so minor to us and is actually huge to them it makes you re-evaluate things differently.' (RM) 'I started off working in finance… When my eldest son was diagnosed, I put myself on an Autism course to learn about it because I didn't know about it... and I fell in love with it really and I came to The Lane... Learning disability is a big thing, especially if you've got family members.' (SM)

(ii) Loyalty towards residents	'The only reason I stay is because of the guys… There's times when I'll sit outside and I never cry but one time I sat outside crying because I was so stressed… and Stan came out to me and he was like, please don't leave and all of them are like, please don't go. So that's why I stay here. As much shit as you have to deal with from the management and everything, I just think I stay for the boys because I know that if I left, they would not… they would go so downhill.' (NANCY) 'I just find it so rewarding and I just think that the guys need our help… These girls are my life really. As long as they're alright, that's my main concern, isn't it, and I'll always be here for them, as long as I can manage it and cope with it.' (SHELLY)
(iii) Intrinsic rewards of making a difference	'When I worked in a warehouse, I'd go home and I'd just be like all flat, I don't want to talk about my job. Whereas here, because you get the gratitude and you can see that. You've taken them to the zoo and that's made them so happy, you go home and you're feeling good about yourself because you've achieved something for them.' (JACKIE) 'Some people have nobody and I mean nobody, and I look at people and I think there but for the grace of God go I… To be non-verbal and not be able to tell somebody you've got a headache or you are really unwell or you are not happy… It's the only job I think I have ever done, I could be wrong, where you are changing people's lives.' (MIKE) 'It's the moments when you drive home in the car, that's when it makes a difference. You get in the car and you think, oh I'm exhausted, I'm tired, how the hell can I get through another week? But you think, I know what I did today, that was good, that person I supported smiled and it's that simple.' (DAN) 'Putting a smile on somebody's face, I suppose that's one of the most rewarding things of all.' (RICK)
(iv) The importance of caring	'You have to really care about the people you look after and I always put it into situations like my family, like if my sister was in here, how would I want her to be treated? So this is how I'm going to treat the boys.' (NANCY) 'It's just something you have… You can't learn that… I've always been that caring person. I've always been like it, no matter whether I'm here or at home… But that's my personality.' (SHELLY)

	'You can teach somebody the necessary skills they need, but for us it's more about values because… if you're not a nice person you'll never be a nice person. So I think for us, if we can see you genuinely care about others then that's what we're looking for, that you want to make a difference to someone's life.' (RM)

Attachments

See Table 6.7 for supporting quotations

Participants described a strong link between their motivation and their attachments to the people they support. This description went beyond a professional duty of care to a more personal connection. *Staff viewed people they support as family*, and as a part of their lives (see Table 6.7(i)). Whether or not residents had immediate family, staff reported that they spent the most time with people they support which 'naturally' led them to form attachments. They spoke of residents in familial and emotional terms, referring to them as being like their children, and to the love they felt for them; according to staff this emotional involvement gave them the motivation to want the best for people they support.

It follows that *staff viewed the work place as home,* several referring to the amount of time they spend at The Lane, and that coming to The Lane was like coming to their 'second home' (see Table 6.7(ii)). The references to family and home paints a domestic picture of care work, and once again frames care work within a personal rather than professional sphere. Chapter 3 discussed the traditional expectation of women as default domestic caregivers, but it is notable that male support staff at The Lane also described their own work using the same language, in terms of family and home.

The attachments that staff claimed they formed with people they support were further emphasised when staff described the *tensions with residents' families* (see Table 6.7(iii)). Staff spoke about residents having little contact with their own family, or having lost family, leading some staff to describe themselves as 'surrogate' family. Attitudes towards residents' families were mixed, with some support staff expressing understanding, while others, emphasising their own caring qualities, were critical of the lack of engagement or support from families. The role that staff can play in the lives of the people they support was particularly evident in a discussion about 'Circles of Support' (see quote in Table 6.7 (iii)); notwithstanding resident's ability to understand the process, this example highlights the role that residents think support workers play in their lives compared to their immediate family.

Table 6.7 Descriptions of attachments

Category	Illustrative quotes
(i) Staff view people they support as family	'They say that you shouldn't get attachments and things like that but I think naturally, because you are with them for a lot of the time…They kind of become a bit of your life…You do worry when you're at home if you know that they've gone into hospital… I think it's natural, isn't it? You do get attached to them, you do want the best for them and it's a bit like a family.' (ALICE)
	'I literally treat them like my children, like I love all of them. I always say when I leave as well, love you, love you and they're like, love you too.' (NANCY)
	'Obviously some of the guys are lucky, in the fact that they do have family that come and see them. There's people obviously here that don't. But even though they've got family, you're with them still every day and really you're like their immediate family as such.' (VAL)
	'There's always been this question mark about we are not family but often we're the next best thing because if people have got family that have passed away or are not around, we're usually the first port of call really. That's another interesting thing about support work because the people that you support, you can often reassure them and say, hey, you're always going to have someone in your life, there'll always be people around to support you, you needn't worry too much.' (DAN)
	'You play a big part in someone's life… It's weird this is like your family… you can't not be emotionally involved in this job, because that's what makes you want to do the best for people because you really care and if it was my family I would want to know that they are being well looked after by people like that as well.' (RM)
(ii) Staff view the work place as home	'When am I never here? This is like my second home.' (IAN)
	'One girl that I look after, she's very able but actually my relationship with her is quite maternal… This really isn't like coming to work. It is a home from home'. (RACHEL)
	'I know you're not supposed to [get attached] but obviously you do… I know it is your place of work and you've got to be a bit more reserved or whatever but… it's like coming into your second home.' (JENNY)

(iii) Tensions with residents' families	'We massively encourage her to be as independent as possible and it's as if her family want the opposite. So that's really challenging.' (JESSIE) 'A lot of people here, their families have chucked them here and just thought, that's it… That's another reason why I won't leave the boys because they haven't got… They'll all be left here on Christmas Day so you think how can their families just leave them at a special time… it's just another day for them. So it is really sad, really sad.' (NANCY) 'I think families have often a lot of guilt… if they've had a person that's got a learning disability and there's a sense of guilt how they've failed them... I've seen a lot of emotional damage to a family member like the mother or the father or both and it does have an impact.' (DAN) 'The guys [residents] are in the middle, it's their circle… We asked them different things like where would you put mum, where would you put dad, where would you put staff, where would you put your friend Tom from down the road? And what we found, a lot of times, staff were in the centre circle and mum was out there, dad was out there, friends out there because that's what you've got to remember: staff are a massive part of these guys' lives. They're the ones they see day in and day out. We're the ones that support them.' (SM).
(iv) Dealing with grief	'The Christmas before there was a woman that I was looking after who was on palliative care. She actually passed away on the Boxing Day… I wanted to see her still in her bed, just accepting the fact that she'd actually passed because I think I wouldn't have forgiven myself for not seeing her.' (ALICE) 'I was alright and then I got all upset when I came home. I was trying to keep strong for her so that she knew that she had someone strong by the side of her.' (MANDY) 'That's part of life… Sometimes it's grim. Sometimes you have a few tears, you're human but at the same time, you also can bring a sense of accomplishment because you've also helped that person or been part of their life while they're alive, and it's a privilege.' (DAN)

Staff attachment was especially evident in the context of the death of a resident and *dealing with grief* (see Table 6.7(iv)). Staff talked about the loss of a resident as one might talk about the loss of a relative, but also described having to manage their emotions while providing end of life care. Dealing with death was part of the support worker's role at The

Lane, and while support workers talked about their grief and the emotional impact, they also described a positive pragmatism, talking about the difference they had made when someone was alive.

During one observation (see Extract 2), Emma, a support worker became tearful as she tried to support someone who had become seriously ill, feeling helpless but also embarrassed by not being able to contain her emotion.

> Emma, has been supporting a lady at The Lane for over 10 years. She was attending to the lady who is seriously ill, sedated with pain-medication and confined to her bed. As Emma left the lady's bedroom she became emotional. She said the lady was in a lot of pain but the doctor had visited earlier in the week, provided medication, and advised that staff needed to wait to see if the situation changed. Emma started crying; when I asked if she was alright, she responded: 'I'm only human.' She appeared embarrassed to be upset but overwhelmed with a sense of helplessness. She then gathered herself in a private space before returning to the common living room to continue her support work.
>
> *Extract 2 from field notes*

Staff had arrangements in place for older residents, which set out their wishes or best interest in the event of terminal illness or death. One of the residents at The Lane had recently died and his support worker described how this person's end-of-life and funeral wishes had been met. He was Catholic and his requests for a priest had been honoured. In line with his wishes, staff had organised a horse drawn carriage, and as he had loved police cars, the local police force agreed to join the funeral in their cars with their sirens flashing to commemorate him.

Perceptions of support work

See Table 6.8 for supporting quotations

Participants described *mixed public perceptions of care work* (see Table 6.8(i)). A common reaction from the public and acquaintances was said to be 'I wouldn't do your job'. Staff reported two perspectives on this reaction: a) that care work was looked down on, consistent with the perception of this work as low status (see Table 6.4(iii)); and b) that care workers were seen as exceptional, which motivated staff by rewarding their intrinsic desire to make a difference (see Table 6.6(iii)). Even when public reactions were negative staff talked about championing what they do to 'encourage and empower' people they support.

Participants commented on the *negative media reporting of care work* (see Table 6.8(ii)), which they claimed was only interested in reporting 'bad' news, and that the 'good stuff' is never covered. Support staff reported that representations of care work in the media contributed to negative public perceptions and to difficulties in attracting good people to the field.

Participants reported being largely unconcerned with public and media attitudes towards support work but they were more vocal about public attitudes towards the people they support, which is discussed in the next section.

Table 6.8 Descriptions of perceptions of support work

Category	Illustrative quotes
(i) Mixed public perceptions of care work	'I've been told on more than a few occasions, they say: I wouldn't do your job. I say I'm a key worker, my job is to encourage and empower.' (CHARLIE) 'They say that you must be like a special person or not a typical kind of person to be able to do that. That's what I always get, every time, literally every time.' (JESSIE) 'As soon as you say to people I work in care work you get that look as if to say oh, do you have anything bad happen at your place… and you do get a little bit of a frown.' (CARRIE) 'A lot of people I speak to, friends, when we go out, people say what do you do and I say I work for [care provider], and they're a bit like… 'Oh we couldn't do that', or 'I couldn't do that', or 'you're so good for what you do'. It is nice when you get feedback like that from people.' (SHELLY)
(ii) Negative media reporting of care work	'When you see what's been on the TV, all the bad bits have been picked out and publicised. You don't see the good bits on the TV… It's all bad, bad, bad, bad that you hear about and you never hear anything about the good stuff that happens in care homes.' (CARRIE) 'I think the image of care work is actually quite negative. I think this stems from all the programmes that have been on TV, Panorama… They see the bad TV programmes but they're not seeing the good that everybody's doing… I think where we are short-staffed at the moment, it's a struggle to get staff in because they've heard all this negativity.' (JACKIE)

Summary of theme 2

Staff claim their motivation derives from intrinsic rewards. Support staff report that they are innately caring people who want to make a difference. Many have been affected by disability or loss in their personal lives, which they say has motivated them to work in care. Staff describe the people they support as family, and their workplace as home. They use these attachments to justify why they remain in their jobs despite significant emotional challenges. They claim they derive value from the impact they make on people's lives each day, but also from feeling needed by the people they support. Support staff stated that the ability to care and to be empathetic are essential in the effective delivery of care. During the fieldwork, these qualities were identifiable when support staff dealt with poor health and the death of people they support. Support staff claimed that if they left their job the quality of life of people they support would deteriorate, which further reinforced their motivation to remain in their role.

6.2.3 Theme 3: Complexities of enablement

This thesis is concerned with the role of support workers in enacting learning disability policy. Chapter 3 highlighted that a central focus of government policy is the enablement of people to have more choice and control over their lives, and to lead more independent lives. However, support workers report significant challenges in their role, which can be emotionally and physically harmful and impact their wellbeing. Furthermore, staff claim that these challenges can impact their ability to deliver policy aspirations and enable people they support. This section sets out the key challenges reported by participants during the fieldwork and is divided into four sub-themes: Challenging behaviour; Care settings; Advocacy; and Choice. The first three sub-themes provide context for understanding the circumstances and environment in which support staff are expected to facilitate choice and independence. The fourth sub-theme sets out what choice and independence look like in practice. Chapter 7 will discuss the implications of these findings.

Challenging behaviour

See Table 6.9 for supporting quotations

Most staff at The Lane supported people with 'behaviours', exposing staff daily to *physical and emotional demands* (see Table 6.9(i)). These could consist of verbal abuse, shouting,

screaming, self-harm such as head-banging, and physical abuse towards other residents and staff. Staff talked about having a brief 'cry', 'taking a moment' and mentally preparing themselves as part of their coping strategies, rather than seeking support from peers or managers. Staff described being scratched, pinched, bitten, and hit. In this context, how deliverable are policies that promote independence, for example, when people require support to manage self-harm or harming others? This is not to say that such policies are not worthwhile, but success can be interpreted differently at an individual level; for example, supporting a reduction in challenging behaviour can contribute to an individual's ability to achieve a level of independence on their own terms.

Despite the physical and emotional demands of their work, participants did not talk about their own safety or wellbeing when talking about the safety and wellbeing of people with challenging behaviour. Instead staff claimed they were *sympathetic towards people's challenging behaviour* (see Table 6.9(ii)). Staff described trying to understand what someone might be feeling, to relate to people they support, and questioning whether behaviours were challenging or 'normal' given the circumstances of the individual being supported.

Table 6.9 Descriptions of challenging behaviour

Category	Illustrative quotes
(i) Physical and emotional demands	'I walked out for literally a minute… I walked in and he had Jack in a headlock and was punching him in the head… it really shook me up and I put him in his room, shut the door and was like, right, you're staying in here for five minutes to calm down and I just started crying… And when he first hit me as well because he lashes out at staff a lot. He'll bite, he'll hit, he'll scratch… But ever since then, because we're a bit more used to it and we know what to look out for, you kind of mentally prepare yourself.' (NANCY) 'Sometimes I do have to step outside for a minute and just take a five minute breather.' (JACKIE) 'With Luke he goes into behaviour, so he pinches and he can pull you around a lot as well… I remember one of the first two days when I was shadowing, he was in full-blown behaviour and he was banging his head and biting as well actually, and I was thinking, oh god. It didn't even cross my mind that that happens.' (VAL)

(ii) Staff sympathetic towards people's challenging behaviour	'We don't want behaviours. No one wants that, least of all the person you're supporting because it's not nice for them, is it? It's their life, they're trying to communicate to you something. There might be a misunderstanding.' (DAN) 'We all have good days, we all have bad days, we all have days when we don't feel right and you can't pinpoint it. These [the residents] aren't any different but they communicate it in a different way… Why should they be deemed challenging for being normal?' (JACKIE)

Care settings

See Table 6.10 for supporting quotations

The Lane was organised around two types of housing: residential and support living housing (see also Section 6.1). Generally, residential homes consisted of group living in single dwellings: aside from private bedrooms all other spaces (bathrooms, kitchens, etc.) were shared spaces. Supported living housing, on the other hand, was similar to private rented accommodation in that residents were tenants of their own homes. Support staff, most of whom had experience of both types, reported that there was *more choice and freedom in supported living* services (see Table 6.10(i)). Staff claimed residential care was more restrictive, with more guidelines and less opportunity to personalise support. Routines and decisions were determined for the group rather than for the individual. Staff described residential care as 'factory like' and 'like a system' with people receiving their medications all together, for example, or having set meal times and bed times. Support staff reported there was less opportunity to promote independence and choice for people in residential care because of the group living structure. This was confirmed in the course of observations, during which support workers were seen to be responding to the individual wishes and needs of residents in supported living. Though people in residential care had some individual activities, staff tended to consider logistics and planning in the context of all residents, such as meals and outings.

Staff claimed that people with challenging behaviour had benefited from moving to supported living, as it had provided them with more privacy in 'their own space'. During the fieldwork, staff referred to an individual in residential care who had 'episodes' whereby he became anxious and angry towards residents and staff. This individual wanted to move to a supported living service at The Lane and was supported to do so. After just a few months his

staff reported a reduction in challenging behaviour, and that he was much happier because he was able to do more of the things that he enjoys.

Residential care services at The Lane were allocated to people with severe and profound intellectual disabilities while supported living was provided for people with more independent living skills. The example above, however, suggests in principle, at least, that supported living is better positioned to deliver policies relating to personalisation and choice than residential care. Staff reported concern that the care provider was converting its residential care services at The Lane into supported living but with the *same staff and residents in the new services* (see Table 6.10(ii)). Staff questioned how people 'classed as residential' with high support needs were suddenly now in supported living services, and with the same staff in place, when different services required a different approach.

Table 6.10 Descriptions of care settings

Category	Illustrative quotes
(i) More choice and freedom in supported living	'Residential you tend to have more guidelines, whereas here [supported living] you are more free… They have set mealtimes, set times when they get up, set times when they go to bed. I know they try to make it a lot freer nowadays where it's not institutionalised… but here, for example, if Paula wanted to go to bed now, she could. If she wants to have her dinner an hour early, she can. You can't tend to do that in a residential home so you're more restricted.' (CARRIE)

'They used to have all their meds altogether in a kitchen and it was like a system, I don't like it. But now they have them in their rooms so just little things like that so they're an individual, it's not like a group going for their meds at that time.' (JESSIE)

'With residential, I found it almost factory like: Breakfast was at 8.00, lunch was at 12.00, tea was at 5.00, everybody had to be in bed by such a time. You and I don't live like that, why should they live like that?' (JACKIE)

'I've seen a lot of movement from shared accommodation to separate flats… and I've seen almost a reduction in what we used to call challenging behaviour because people suddenly have their own area, their own kitchen, their own space. They're not sharing it with other people where the smallest thing becomes a big thing. It's not always possible, it's not always feasible but I've seen people become happier.' (DAN) |

(ii) Same staff and residents in new services	'My understanding when I came into this job is you've got residential and supported living and I suspected that the residential would be with people with higher demands but, with the switching that's going on at the moment, we've now got three buildings and two have already moved over to supported living, and one's just about to, as far as I know… I'd like somebody to tell me how those people suddenly, classed as residential, are now supported living. Yet when I look at some of those people, they can do next to nothing for themselves.' (RICK) 'Because there's people who've been in care for many, many years they themselves, and the staff become institutionalised because of conditioning.' (CHARLIE)

Advocacy

See Table 6.11 for supporting quotations

Staff at The Lane were responsible for supporting several people that were non-verbal, and who lacked mental capacity to make decisions. This meant that support staff had an important role in *advocating for the people they support* (see Table 6.11(i)). They were responsible for representing their needs and best interest to a wide range of people that impacted residents' quality of life, such as health professionals and social workers, as well as in the community. The advocacy abilities of support staff were often essential in securing access to vital public services, and in shaping the experiences and opportunities of the people they support in society. Staff described themselves as having to 'fight' for the people they support, and the barriers they faced in accessing services. Healthcare, for example, was cited as one area in which people they support did not receive equal treatment because of their learning disability, with staff claiming they had to push for referrals and tests.

During an observation in one of the residential homes, Mike, a support worker appeared distressed about the declining health of someone he supports (see Extract 3). He said he was frustrated that the local authority was not accepting his recommendation concerning the person's diet.

A new resident at The Lane has not been eating and has lost significant weight. Mike was visibly upset, and worried for the person's health. He said he is not getting support from the local authority for this person to receive Complan (a liquid food supplement), which he thinks will help. The local authority has asked the service to first demonstrate that staff have done everything they can to support the resident to eat solid foods. Mike thinks this decision is having a detrimental impact on this individual's life and does not know what he can do to help.

(Extract 3 from field notes)

Staff reported having to speak up for people when out in the community, as illustrated in the church service recorded in Table 6.11(i)). However, while staff claimed to speak up for people they support, I saw mixed evidence of this in practice: in the church example the staff member described themselves confidently speaking up, but on another occasion I observed that residents were seated separately from the rest of the congregation and the support worker essentially acted as a chaperone, making no effort to facilitate engagement between the residents and the rest of the congregation.

As well as claiming to speak up externally, staff described speaking out about poor practice internally. On several occasions I observed staff confronting each other directly. For example, I observed one support worker notice that a resident had not been shaved and was not dressed properly; he immediately raised this with that person's support worker. On another occasion, a support worker was taking someone out and saw that another resident who lacked capacity had been left in their wheelchair on their own in an empty room. He immediately fetched that person's support worker and reprimanded them for leaving the person alone. Support staff talked confidently about speaking up for residents at The Lane with other staff – whether agency workers or permanent staff. In contrast, they did not describe speaking up for themselves, such as in the areas described under 'workforce challenges' in Section 6.2.1.

Staff reported mixed views about *public attitudes towards people with a learning disability* (see Table 6.11(ii)): older, more experienced staff reported that there had been positive progress over the years, with disabled people more visible in the community; younger members of staff who did not have a reference point over time reported current negative attitudes and language, rather than the trend. Staff reported that the people they support remained largely unaware of public reaction, so tended not to react to it.

Staff claimed that public attitudes were attributable to a lack of understanding about learning disability and they talked about their efforts to raise public awareness: Staff reported that the

care provider took it upon themselves to improve community engagement with events such as open days. The care provider had also run education and awareness campaigns at a national level.

Table 6.11 Descriptions of advocacy

Category	Illustrative quotes
(i) Staff advocating for the people they support	'Because they've got a learning disability, they're kind of written off... So sometimes you have to fight for them to listen, to then be able to get referrals done, tests done, have different things done … There's been many times that we've been back and forth to doctors and people are like no, they don't understand.' (ALICE) 'I supported Luke to church and once when I went, I said to Luke 'shall we sit down the front'? And he was like, 'yeah' and so we sat down the front and I remember some little old ladies coming up to me and tapping me on the shoulder and saying that he's not allowed to sit there and I turned round and said 'why'? And she said 'oh they sit over there'… I turned round and said, 'not today… I'm sorry'. Like you're meant to be church people… and you're telling someone to sit behind there, like out the way, I don't think so, love. I'm not having it.' (SM) 'It felt like her night staff were literally leaving her… She's got a monitor screen and they're meant to pop down and check and change her pad, give her a drink and things like that and you can see that they haven't… I reported it straight away because it's not right for her.' (JESSIE)
(ii) Public attitudes towards people with a learning disability	'It has changed... In the past if you took people with a learning disability out to a café, you'd be in there and ten minutes later you'd look around and notice the café would empty because other people didn't understand it. I've been to swimming pools and the same effect. People have gone in and you've had a lane dedicated in a swimming pool and I've seen people get out of the swimming pool and go and complain and say, what are these people doing in here?' (DAN) 'It's made me realise how much other people are prejudiced… When I take Andy out people will just stare and give him dirty looks. And it is more the older generation that does it but you'll have little kids laughing at him and it's horrible, it is really, really horrible. I think even though they say that everyone's perceptions has come such a long way, I don't think it has. People still use the word retard. People still use the word spastic and people say it so off the cuff and so blatant, like so without any thought.' (NANCY)

'I think that people still lack understanding of learning disability and I think a lot of people are scared of it because it's unknown, it's different… We're always raising awareness because I think if people actually took the time and actually spoke to someone or asked someone about learning disability or just looked up on it, you'd actually be surprised that they're still the same. I think a lot of people see them as different.' (SM)

Choice

See Table 6.12 for supporting quotations

Government policy emphasises choice and control in their own lives for people with a learning disability. However, while policy tends to focus on top-level areas such as education and employment, fieldwork observations and interviews highlighted that, in practice, the facilitation of choice was centred on everyday routines and activities. Staff often emphasised that seemingly small achievements made a big difference to the people they support. Staff were regularly seen celebrating people's every day achievements, as illustrated in Extract 4.

Support staff gathered around a resident who is an electric wheelchair user and has high support needs. They started cheering for him as he carefully passed a squeeze ball from one hand to another. As he did this staff whooped, clapped, and shouted praise and encouragement. In response he smiled and laughed and continued to pass the ball between his hands. The staff had been given ball exercises to do with this resident by his physiotherapist. One of the staff informed me that this was the first time he had been able to complete this exercise. There appeared to be a strong sense of pride and celebration among staff.

Extract 4 from field notes

The needs of residents at The Lane varied greatly. Some residents required minimum support, while others were almost completely dependent on support staff. Each day consisted of a mix of scheduled and unscheduled activities. For people with profound intellectual disabilities (see Table 2.1 for definitions), staff focused on basic health and wellbeing, such as supporting individuals when they wake up, with personal care, meals, attending medical appointments or district nurse visits, and activities in the home such as watching television, and making puzzles. For residents that were unable to move from their bed, staff interacted with them in their rooms or, on occasion, supported them to come into communal spaces (e.g. the garden). More-able residents had set activities that included work placements, arts, and social activities in the community such as going to a restaurant,

or cinema. During the day, a range of external professionals visited The Lane to provide services and support to residents, such as physiotherapy, speech and language therapy, and manicures.

It was evident during observations that effective facilitation skills among support staff were critical in enabling people to do the things that they enjoy. This was especially vital for residents with severe and profound intellectual disabilities and there were positive examples of this: for instance, one resident's weekly horse riding session on a mechanical horse. Longer-serving staff appeared more competent at enabling people, as they were more familiar with residents. However, staff frequently commented on the challenges in supporting choice for people who *lack mental capacity* to make decisions (see Table 6.12(i)). Staff spoke about people that were non-verbal and had other serious health issues such as dementia, who were not able to make a choice. They reported that some people would 'just stand there', and not understand how to make a decision. Staff claimed that despite trying everything this could be 'impossible', so they had to make decisions for some people. During the fieldwork observations, staff struggled to provide genuine choice for people who lacked capacity, instead providing superficial, pre-selected options such as choosing between two breakfast cereals or two shirts.

Staff described trying to establish what people might choose and enjoy through a process of trial and error that brought its own challenges and risks. This was especially the case with external activities, during which staff reported *difficulties enabling community participation* (see Table 6.12(ii)). Staff claimed that residents were sometimes unable to cope with certain activities that they had wanted to engage in, or that staff thought they would like, such as having a job or going for a swim, despite repeated efforts. This is illustrated in the example of a resident who started work in a nursery but had to leave after hitting a child. Staff also reported having to step in when people they support became anxious in certain situations, such as having difficulty with handling money in a supermarket. Resources again featured in discussion. A lot of residents enjoyed going out in the community but staff claimed that if there was not enough staff on shift, residents could not go out. Staff reported being frustrated by shortfalls in resource, which they said restricted their ability to support people to do the things they wanted. Staff claimed that residents did not understand why they could not go out when they wanted to and thought they were being punished by staff.

Another challenge staff reported in promoting choice and independence, was a *tension between empowering and protecting people* they support (see Table 6.12(iii)). The right to choose meant the right to make questionable or potentially harmful choices. During

observations one resident chose to watch the same musical DVD seven times in one day, another resident remained in her nightdress chain-smoking all day, while another was diabetic but loved cake. Staff stated that if people had the capacity to understand the potential consequences of their decisions, they had the right to make those decisions. Equally staff reported that if people lacked capacity and wanted to make potentially harmful choices, staff may need to make decisions on their behalf.

Table 6.12 Descriptions of challenges in enabling choice

Category	Illustrative quotes
(i) Lack of mental capacity	'They can't make a choice. I can't get Sophie in here and say, oh Sophie what do you want for lunch? She wouldn't know. I could go in the cupboard and I could be like, right, Sophie what do you want for lunch, that, that or that? She would just stand there. She can't physically say to you, I'd like that or point to it… It's very hard with… especially when they're non-verbal… We have to make the choice for her. We go through the parents and we do the proper routine, but sometimes the parents are not here and we have to make that choice for them.' (SHELLY)
	'You have to work out what decisions they can make, because they could find it really hard to just pick… Luke he doesn't understand.' (VAL)
	'We've got a lot of people with high needs and we've tried everything possible to try and get them to have their choice out there… I don't know if you've met Sharon… we've tried everything with her which is things like technology; didn't work for her… So sometimes you will try everything and it may not work… We have a few of the guys here and it's just impossible.' (ALICE)
	'There's Jack who's got dementia, he's got dysphagia and epilepsy as well, which is why he's had a seizure today. He is completely non-verbal, he only says Sam, will just walk around Sam, Sam, Sam and clap his hands. He's got really bad sight as well and with his dementia, he's forgetting how to swallow. So he takes up a lot of time to look after and he doesn't understand anything we're saying either so it's difficult to get things through to him.' (NANCY)
(ii) Difficulties enabling community participation	'We wanted something for her to do, to get really involved in something… She had a job in a nursery… She's a lot better now but Elizabeth used to have her moments, shall we say, and hit a child, hit a two-year-old, had smacked her. And she just couldn't work there anymore, basically.' (JENNY)

	'You've got to have a lot of patience when you go out somewhere and, say they're doing their shopping and they take ages to get their money out of their purse or they get a bit muddled with their money… You tend to see if they start to get a bit anxious and a bit stress-y and then you think right, okay then, this isn't fun anymore for them, I need to step in now and help them.' (CARRIE)

'When she first went, she didn't mind it but then she obviously didn't like it because she used to get so distressed and she used to defecate in the pool and that was a big problem because it was a public pool and all the pool had to be shut and then she did it every single time… So we stopped taking her for a while. Then we took her again, the same thing happened. Took her again, the same thing happened.' (JENNY)

'It's staffing. Mark has his own car. We would like to have got him out but we can't get him out because we're not… You always have to have two members of staff so it's juggling things about.' (MIKE)

'You try to say to Luke you're not going out today because you haven't got the hours. He doesn't know about that, he thinks that I'm punishing him… He doesn't see it that it's the rules and regulations behind it and that's what makes it so frustrating, is when you know that you can help them but you can't.' (JACKIE) |
| (iii) Tensions between enabling and protecting people | 'You would ask has that lady got the capacity to smoke, to understand the dangers, to understand what could happen? And she does and it's just reflected in her support plan. All the paperwork in best interests is all done. So she understands what smoking is. She can tell you what that can do to her and it's her choice to smoke, like any one of us.' (SM)

'She loves her cake, she loves her chocolate biscuits, she loves all the bad stuff but she's a diabetic. So she's got a Mental Capacity Act form in place because she doesn't have capacity, she doesn't understand eating all those foods is going to have a negative effect on her body and her diabetes. So when we're out and she wants something like a big slice of chocolate cake and we're having to say to her, no… you've got members of the public looking at us like, how dare you say no to her but she doesn't understand.' (JACKIE) |

At The Lane decisions around choice and control were not just about capacity, but also ability. The emphasis in government policy is on enabling individuals to do things for themselves, but this risks minimising genuine individual needs and dependencies. The fieldwork highlighted the dilemmas that staff faced between doing things for people and

respecting their efforts to do things for themselves, even if those efforts caused distress. I observed one resident struggling to transfer from her armchair into her wheelchair while a support worker stood nearby. She kept trying to stand, and falling back into the armchair. She was struggling and in discomfort, shouting 'it hurts' referring to one of her legs. She was finally able to move independently from her armchair to her wheelchair without staff assistance. The tension between choice and control and care and support was evident in the day-to-day support that staff provided.

The care provider was active in its efforts to engage the views of people it supports. However, the fieldwork highlighted a regular gap between the well-meaning intention to include people with a learning disability and their actual ability to engage. This could result in engagement being tokenistic, or support workers taking their best guess about the views of people they support. An example of this arose during a workshop that the care provider ran for people they support, seeking their views about healthcare. The workshop was led by staff from the head office who took the group through a series of activities intended to capture their views for a national campaign. Support staff were there to assist people to participate. Issues around capacity and people's ability to contribute in a meaningful way was apparent from the outset as this example illustrates: residents were seated in different groups and each group was asked to suggest a name for the campaign. They were then asked to vote on the name they liked most by raising their hand. They were allowed to vote for their group's name. One of the groups voted for another group's name but had wanted their own name to be chosen. They did not understand that this meant they should not raise their hand for another group. After the first vote took place and the facilitator realised the confusion, the process was explained again and the participants all said they understood. However, when the voting took place again, the group became confused and again raised their hands for another group. When another group's name was finally chosen, they became angry and upset and did not understand that they had also voted for the winning group. They had been raising their hands when they saw everyone else raise their hands. Later in the workshop people were asked to write down their views on particular topics. This was largely led by support staff who made efforts to ask people questions but in the absence of lucid responses wrote views that they felt represented the people they support.

Summary of theme 3

Government policy advocates that people with a learning disability should have choice and control over their lives. However, policy does not sufficiently recognise or address the complexities that support workers experience in enabling choice and control for people they support. Staff report that they struggle to empower people they support for a variety of reasons, including: challenging behaviour; the lack of mental capacity to make decisions about one's life; under-resourcing; and the care setting itself (residential care, for instance, can prioritise the needs of the group over the needs of the individual). Support staff state that they often have to balance their duty to keep individuals safe with the ambition to empower them to live the lives they choose; people sometimes make questionable decisions that may impact their lives negatively, but if they have mental capacity then staff say they must respect these choices. However, where individuals lack capacity, staff often make choices for them without certainty that these choices reflect the person's preferences. There is also a grey area in the case of people with limited capacity but who are unable to make decisions without support: support staff have to interpret intentions, and sometimes construct choices arbitrarily. When it comes to choice and control, the definition of success also varies in practice: while policy promotes ambitious goals such as employment, support staff celebrate small but reportedly significant outcomes, such as completing a puzzle. These tensions and differences reflect a significant gap between policy and practice.

6.3 Chapter summary

The fieldwork identified a consensus among staff about challenges in the workplace, and the impact this has on the quality of support for people with a learning disability, as well as on staff wellbeing. This has significant implications for government policy, which has not grappled with the extent of these issues. In contrast to well-meaning government policy intended to promote rights, people with a learning disability at The Lane were limited by a lack of resource (permanent staff) and quality of support (reliance on agency workers, low pay). Supporting people with challenging behaviour, and people with different levels of capacity, added further complexity to staff's ability to empower people to have choice and control over their lives. While staff were passionate in communicating their loyalty towards the people they support and 'making a difference', the levels of stress and pressure they reported raise serious concerns over their mental health and wellbeing, and therefore how well-positioned they are to promote the wellbeing of people they support. Staff talked about not being valued, but there was no indication that they valued themselves enough, or felt

able to prioritise their own needs. Support staff referred to having many different roles and responsibilities: cook, cleaner, advocate, administrator, driver, medications expert, and companion to name just a few. However they highlighted qualities such as caring – which they claimed were inherent, rather than professional skills when talking about what makes a good support worker. Depending on the capabilities and dependencies of people they support, staff abilities significantly influenced the quality of life of people with a learning disability at The Lane. Staff cited numerous examples of people not being supported with basic needs, never mind the higher aspirations of government policies of which they reported being broadly unaware. Addressing poor support within The Lane, and equal treatment outside of it, often depended on the ability and willingness of support staff to speak up. This chapter has illustrated the extensive role that support workers play in the lives of people with a learning disability, and raises important questions about government policy and care practice. The final chapter will discuss the implications of the findings in this study.

Chapter 7: Discussion

This study set out to investigate the research question: *What role do support workers play in enacting learning disability policy in England*? I hypothesised that support workers are critical in enabling those they support to achieve the aspirations of recent government policy, yet this is poorly understood and largely ignored in successive policies, from the Mental Health Act in 1959 which established community-based services for people with mental health needs, to the 2014 Care Act which the Government promoted as the most significant reform of care and support in more than 60 years. Furthermore, the role of support workers in enacting policy in England is under-represented in academic research. This study sought to give voice to support workers' views and experience, to understand how they are represented in government policy, and to explore the relationship between learning disability policy and practice.

To investigate the research question several research methods were employed: documentary analysis of care policy, to establish the representation of support workers (Chapter 3); systematic review of empirical studies that examine the role of support workers in adult care settings (Chapter 4); and observations and interviews of 20 residential and supported living services staff to establish their views and experience of support work (Chapter 6). Each aspect of this study sought to present different perspectives, and new insight in understanding the role that support workers play in enacting learning disability policy in England.

I preface this chapter by reflecting on the fieldwork data presented in Chapter 6, and its interpretation. I will then present the strengths and limitations of the study, and discuss the principal findings, drawing on existing literature for context. Finally this chapter will formulate recommendations for policy and practice, and further research.

7.1 Reflections

If social care was being designed today, would that model rely on frontline support staff lacking in skills and professional qualifications, and who are paid little more than minimum wage; who experience high levels of stress, and exhibit low expectations for themselves and for the people they support; who are disconnected from the very policies that they are expected to put into practice for the benefit of the people they support; and who, nonetheless, are expected to support individuals with highly variable levels of capacity and

capability to lead their lives to the full?

When reviewing this study's findings, in particular those from the fieldwork, it is important to consider the motivations that support staff might have had in presenting themselves and their work in the manner that they did. The many concerns and complaints reported by support staff were most often directed at others and at outside factors (e.g. agency workers, poor management, funding cuts, etc.); in challenging situations, or when things went wrong, support staff rarely reflected on their own shortcomings. Support staff described themselves as special and altruistic, but they were also defeatist, presenting themselves as victims of a care system which does not value them. If such low morale is to be taken at face value, can support staff be sufficiently ambitious on behalf of people they support to deliver highly ambitious policy? This is difficult to assess; when staff quote seemingly small outcomes as big achievements, like completing a puzzle, or passing a ball from one hand to the other, is this an example of low ambition, or of empathetic insight into the personal circumstances of individuals with severely limited capacity? Are staff motivated and capable of supporting people to achieve more? Are the limitations they report in others in fact masking their own limitations?

Such questions are not intended to undermine the views and experiences of support workers; one aim of this study was to give a voice to support workers, whose views and experiences are under-represented in policy and research. But it would be remiss not to critique these views. Notwithstanding the issues surrounding participant bias (see Section 5.5.2), I contend that the views and experiences reported by support workers have some basis in fact: the vacancy rate in the adult social care sector is 8.0% (110,000 vacancies), compared to a vacancy rate in the education sector of 1.9% (Office for National Statistics, 2019); according to Skills for Care (2019, p. 8), the average rate of staff turnover was 30.8% (440,000 leavers in 12 months), and 24% of the workforce were employed on zero-hour contracts (370,000 jobs); average pay for care workers in England was £8.10 per hour, an improvement from £7.48 in 2012 following the introduction of the national living wage (ibid., p. 11) but below the basic rate paid in most UK supermarkets (The King's Fund, 2019). The Kingsmill Review (2014) which examined working conditions in the care sector, stated that 'Care work is in crisis. People who may be vulnerable are not being treated with the care and attention they deserve. All too often, their only source of support, Care Workers, are exhausted … and unable to spend enough quality time with the person in receipt of care ... This workforce of 1.8 million people in England is almost invisible … The low status of care work and poor treatment of workers has led to a vicious downward spiral into one of the most difficult sectors for workers, with widespread exploitation' (p. 3). This and other reports

give credence to the views and experience described by support workers in the present study. Government policy must recognise the contribution of support workers, and address their working conditions if it is to deliver a care system that empowers disabled people and those who support them.

7.2 Strengths and limitations

The pervious chapters have provided a critique of specific topics and methods. In this section I summarise the main strengths and limitations of the fieldwork. This thesis raises a number of questions which could not be addressed within the scope of this study but are identified as areas for further research in Section 7.5.

This research applied a qualitative multi-methodology approach, examining what learning disability staff say and do, in order to understand what this means for policy and practice. The study was limited to one care provider, albeit a site with 4 residential care services and 11 supported living services, in a suburban location in the East of England. This meant that I was not able to compare findings, participant demographics and differences in service structure and culture.

A significant strength of this thesis is that it successfully recruited the target of 20 participants for the fieldwork (Chapter 6). There were no requests from participants to withdraw nor for the researcher to stop any fieldwork interview or observation at any time. Participants appeared to engage with the researcher openly. As a mature student with professional experience in the sector, I was able to gain the trust and acceptance of the participants quickly and to understand terminology. While there was a risk of unconsciously drawing personal experience and knowledge into the study, I applied a number of methods, which are detailed in Chapter 5, to ensure this did not influence my integrity or impartiality. For example, as part of the verification process when analysing my results, I regularly consulted my academic supervisors who assisted in reviewing my findings and challenging interpretations.

To mitigate the impact of context and bias in the research findings, I applied several controls: the fieldwork was informed by topic guides (Appendix 2 and 3); I compared findings across different data sources such as interview and observation; and referred back to the policy review and systematic review in Chapters 3 and 4 (triangulation). The use of triangulation (Lincoln and Guba, 1985), whereby findings from the different sources of data are compared,

enabled me to evaluate the validity of the research findings and to identify any contradictory information.

Computer software NVivo was used to assist with the analysis of fieldwork data. While computer software can help the researcher find patterns in the data, it is only a tool, and susceptible to the introduction of bias and error (Roller and Lavrakas, 2015). During both the manual and computer phase of the data coding and analysis, I regularly returned to the original data and re-examined coding categories and compared findings across the data to establish consistency. Overall, the conclusions from my fieldwork may derive additional reliability from the fact that there was considerable consistency between support workers' views and behaviour.

My original thesis proposal set out to also include interviews and observations of people with a learning disability. However, following initial scoping of the research question, and discussion with my academic supervisors, it was clear that greater depth and contribution to new knowledge could be achieved by focusing exclusively on support workers. Having now completed this study, I do believe that, by focusing fully on the role of the support worker in enacting government policy in England, I have been able to undertake a more detailed study of an important and neglected area of research, resulting in a richer understanding of the culture of learning disability support work.

7.3 Findings

This section presents the findings and conclusions made across the study. They should be considered in the context of the reflections made in Section 7.1, which identifies issues associated with interpretation but contends that the evidence from this study provides important, valid insight. Because the findings are interconnected, they are not presented in any order of priority. First I provide an overview of these findings.

The issues raised in this study are critical in understanding the relationship between learning disability policy and practice in England, yet the role of support workers in turning policy into practice is neglected by policymakers and academic researchers. The structure and provision of care has changed significantly over time. Local authorities are now largely social care commissioners rather than employers, working with third sector and private providers but the approach to managing care is still rooted in a public sector model, and a one-size-fits-all approach. Learning disability affects individuals differently and can be accompanied

by other impairments. This complicates attempts by policymakers to define and to cater to learning disability. As a result, policy aspirations are set out in more general terms, with learning disability contextualised around concepts of normality and fitting into a non-disabled society. Discussing disability in terms of quality of life is problematic as this is difficult to define for people with such different needs, and subject to individual interpretation. Support workers seemingly rationalise work challenges through a narrative of care, claiming that they are motivated chiefly by the difference that they make in the lives of people they support. Yet, support workers report daily tensions between enabling and protecting people, especially when supporting individuals who lack capacity for decision-making. Government policy in England fails to fully recognise the role that support workers play in the lives of people they support, undermining the credibility of policy aspirations. In order to craft meaningful, effective legislation, policymakers must recognise the value of a caring relationship between support workers and people they support, and the needs of support workers themselves.

A more detailed examination of each of the ten key findings now follows.

The complexity and diversity of learning disability is problematic to define and to legislate

'Given the multiple and contradictory ways in which both disability and intellectual disability are understood, any discussion of the rights of persons with disabilities is going to be highly problematic' (Redley, 2018, p. 72). The definition and diagnosis of learning disability is critical in informing the development and implementation of policy, and can restrict or enhance the prospects of adults living with a learning disability. However, there are big differences in levels of intellectual impairment, and these often combine with other impairments, health conditions, and economic needs. Moreover, the purpose of identifying learning disability often varies from one government service to another, each with a different threshold: for instance, it can inform interventions in medicine, determine access to special needs services in education, or eligibility for state benefits in social care. This all poses a challenge for policy, which is typically framed in more generalised terms, with high-level language and aspirations that do not address the concrete complexities that are a function of individual circumstances.

The fluid, changing definition and classification of learning disability was explored in Chapter 2. As recently as 2015, the American Psychiatric Association updated its definition of

learning disability, to include replacing the term 'mental retardation' with intellectual disability. There have also been significant changes in how learning disability is understood, with greater recognition of the social factors affecting the quality of life of disabled people (the social model of disability), and of the medical factors. Such changes have influenced attitudes and approaches to clinical and non-clinical interventions.

Government policy does not reflect this wide variation in the definition, diagnosis and day-to-day reality of disability. Instead, policy reflects a high-level approach that is most relevant to the most able. While policy has changed over time to broadly reflect changing professional and social attitudes (i.e. shifting from institutionalised, paternalistic care to community-based support that champions choice and independence), it has not engaged with the detail and difficulties of people's varying needs and abilities. This failure to appreciate the full complexity of learning disability has resulted in policy that does not address the needs of *all* people with a learning disability. As illustrated in Chapter 6, a critical gap in policy is the lack of understanding of the role of the support worker and their needs, resulting in support workers being left to interpret policy as they see fit, or who are completely disengaged from policy and set their own goals for people they support.

Policy aspirations are situated in a homogenous non-disabled society

Government aspirations are based on conceptions of 'normal' and 'ordinary life' as benchmarked against a non-disabled society (Swain, 2003). Sutherland (1981) asserts that a more radical approach is needed: 'we must demolish the false dividing line between 'normal' and 'disabled'… We have to recognise that disablement is not merely the physical state of a small minority of people. It is the normal condition of humanity' (p. 18).

It is important to recognise that people with a learning disability may experience choice, inclusion and independence in ways that are meaningful to them but that might not accord with conventional norms and policy expectations. Ravaud and Striker (2001) observed that inclusion often means assimilating with common social norms and ignoring difference. They discuss the phenomenon of exclusion within a society, and the tension between recognising difference, and promoting universality of human rights (p. 508). Even when trying to accommodate difference through positive discrimination in the workplace, the emphasis is on fitting-in to mainstream, 'ordinary' life. The fieldwork of the present study found evidence of this, too, when residents from The Lane were present but not included in the community, for example when attending a local church service (see Section 6.2.3).

Almost 50 years since the Government's white paper 'Better Services for the Mentally Handicapped' (Department of Health, 1971), which called for improvements based on principles of 'normalisation' that promote autonomy (see Section 2.6), people with a learning disability continue to be marginalised (Jingree, 2014). Policy is rooted in the view that people with a learning disability can be valued members of society when they adopt the roles and behaviours of the dominant group. But what happens if they do not adhere to social norms or are unable to do so? Policymakers and commissioners must be ambitious when drafting policy on behalf of people with learning disabilities but they must also recognise people's very real impediments, particularities and dependencies (Barnes 2001; Williams, 2001).

The assumption that an independent life equates to a better life, is reflected in the continual policy focus on mainstream outcomes such as participation in education and employment (e.g. Valuing People, 2001). This focus has been subject to criticism (Finlay *et al.,* 2008b), and Bunting (2006) has even argued that independence has been promoted not for the benefit of the individual but instead to make funding cuts to social care politically palatable. The fieldwork at The Lane showed that support staff used different benchmarks to measure improvements in quality of life: they recognised relatively small but significant achievements by residents, such as someone with a profound intellectual disability being able to pass a ball from one hand to the other for the first time (see Section 6.2.3). This gap raises the question: is the focus on mainstream ambitions, like employment, diminishing the value of more prosaic, everyday achievements of people with a learning disability that actually contribute to their individual sense of wellbeing?

Quality of life is subjective and therefore difficult to define in policy

Policy aspirations around choice, independence and inclusion are rooted in notions of quality of life. Even if we accept that these aspirations are achievable and empowering for all people with a learning disability, how do you define 'quality of life' for people with such different needs and impairments? There is extensive literature on definitions of quality of life (Cummins, 1998, Schalock, 2004) but there remains much debate about the extent to which quality of life measures have informed and improved policy and practice. Reinders (2002) argues that people seek to live 'a good life' according to their own ideals and have their own conceptions of 'good', and that no public authority should prescribe what people should think, believe or value. The subjectivity of assessing quality of life poses challenges for policymakers because perception of one's life varies with individuals' social and psychological situation (Hensel, 2001). A particular concern is that people with a learning

disability may have been socialised into having low levels of expectation; they may rate their quality of life as positive simply because they do not expect it to be otherwise (Northway and Jenkins, 2003, p. 61). This may also be true of support workers' expectations and ambitions for the people they support.

Support workers at The Lane had firm views about the capabilities of the people they support and what 'a good day' looked like for them, such as being able to have a cigarette or watching their favourite DVD all day. Staff did not express any high aspirations or long-term plans for people they support. Their focus centred-around every day needs, such as people's health, and activities they enjoyed, rather than the ambitions set out by government that are supposed to contribute to quality of life. Was this because support staff were realistic about what was achievable or because they had limited horizons, possibly motivated by a lack of resource, experience, or ambition for people they support? These questions illustrate just a few of the complexities in using quality of life as a basis for policy or measuring outcomes for people with a learning disability.

Learning disability policy must fully recognise the role of support workers

There is a significant gap between government policy and practice concerning people with a learning disability (Harris 2003; Antaki *et al.*, 2008; Mansell 2011). The present study argues that this gap is partly a consequence of not fully recognising role of support workers, who are under-represented in policy. Where they are represented, the focus is disproportionately on regulation, training and managing risk, rather than also recognising their role in providing emotional support, and enabling people. Ultimately this has a negative impact on the intended beneficiaries of government policy. As Hastings (2010) argued, the quality of work that staff delivers directly impacts the overall care standards and the quality of life of the people being supported. However, the analysis of government policy in Chapter 3 found little engagement with, or recognition of support staff's positive impact in the lives of people they support.

Government policy fails to address the deep structural, economic, and social barriers that exist in care work, yet addressing these barriers is fundamental to realising policy ambitions for people with a learning disability. Instead, government solutions to complex issues affecting the social care workforce have largely focused on training and regulation. Even when government policy recognises the needs of unpaid carers (as in The Care Act, 2014), the needs of support workers remain absent. There is very little collaboration between the people defining and commissioning care and the people actually delivering that care and

support. As a result, in the case of The Lane, support workers are disengaged from policies which they claim do not relate to their day-to-day reality. Without meaningful engagement and recognition of support workers, policy risks being little more than an aspiration.

Relationships between support workers and the people they support are critical

The relationship between support workers and the people they support is critical (Hutchison and Kroese (2015), yet policymakers give little attention to the relationships through which support is provided (Barnes, 2011). If the interactions between support staff and people they support is seen to be merely transactional, as nothing more than so many tasks and chores, the dignity of both can be compromised. Fine (2005) refers to 'a future of McDonaldised care', with low-paid, low-skilled workers who, working for providers without commitment to their conditions and wellbeing, will in turn have less commitment to the people for whose conditions and wellbeing they are responsible. This view is shared by Redley (2009) who talks about the commodification of services, and the failure to recognise that services are relational. He argues that services are about relationships as much as they are about people with learning disabilities pursuing their own interests, and that individuals with a learning disability require services that build and sustain positive relationships (2009, p. 501).

Support workers at The Lane described their relationships with people they support as the most rewarding aspect of their work, but reported being frustrated by staffing pressures which prevented them from spending quality time with people. Relationships suffer when there are staff shortages and staff have to shift to a functional (getting things done) rather than relational (helping people to do things) approach. Policy that does not recognise the critical relationship between the support worker and people they support is inherently disempowering; such policy serves neither the ambitions of policymakers nor the wellbeing of support staff, or of the people they support. At its worst, such policy can reduce the quality of life of both the support worker and the supported individual, and lead to the vulnerable supporting the vulnerable. (Duffy *et al.*, 2015). This was highlighted at The Lane, when staff described the stress and mental health challenges that they experienced, and the negative impact they said this had on residents (see Table 6.2).

Staff at The Lane claimed that when caring relationships were not established, the wellbeing of people being supported suffered. Moreover, positive relationships have also been associated with greater choice and autonomy (Nonnemacher and Bambara, 2011; Petner-

Arrey and Copeland, 2015). The difference in the quality of care when someone is task-focused rather than people-focused is highlighted by Gawande (2014); reflecting on the act of helping someone to dress he remarks: 'unless supporting people's capabilities is made a priority, the staff end up dressing people like they're rag dolls. Gradually that's how everything begins to go. The tasks come to matter more than the people' (p. 105). Staff at The Lane described clear differences between agency workers' task-based approach compared to their own reported care, which they claimed was informed by their relationships with the people they support.

While support workers at The Lane claimed that emotional attachment was necessary to do their work well, Johnson (2015) found that support workers faced difficulties when trying to detach themselves from the care-giving role. Support workers at The Lane emphasised their interactions with people they support, stating that their relationships were even more important when the immediate family of a person supported was absent (see Table 6.7). While recognising that building and sustaining relationships are at the heart of a good life, Johnson, *et al.*, (2010) question the capability of support staff to achieve this without essential resources. Examining data relating to the routine activities of the social care workforce at large, the authors noted that these were overwhelmingly task-based (such as serving food, personal care) rather than nurturing relationships.

Support staff at The Lane were quick to emphasise the risks associated with support that is not compassionate or caring, particularly in reference to agency staff: for example, they spoke of neglect and of an increase in challenging behaviour (see Table 6.2). These claims are supported by others studies: Hutchison and Kroese (2015) commented that the absence of a caring relationship between support worker and supported individual 'greatly increases the likelihood of abuse or neglect' (p. 217); Griffith, *et al.*, (2013) highlighted the positive impact on the wellbeing of people with challenging behaviour when they have a good relationship with support staff, which included feeling that the staff genuinely care about them.

The importance that staff, people with a learning disability and their families place on caring relationships is not reflected in policy. When there are failings in social care provision, the response by government and regulators is to focus on formal structures and processes. For example, the UK Government commissioned the Cavendish Review (2013) following a series of high profile failings in hospitals and care homes. The review's recommendations focused largely on formal training, codes of conduct, and on process, including 'minimum standards of competence' in the form of a Certificate of Fundamental Care, and of a code of

conduct for employers. This reflects policy makers' tendency to formalise the delivery of care through structures rather than by engaging with the relationships, interactions and interdependencies that enable quality and consistency of care and support.

The treatment of support workers is paramount to their wellbeing and of the people they support

The fieldwork in Chapter 6 found that support workers presented themselves as undervalued and over-worked. They reported high levels of stress and pressure; expressed frustration with the reliance on agency staff who they claimed delivered poor quality of care, and asserted that the low pay and the lack of recognition reflected a lack of respect for care work. Support workers are vocal about the emotional demands and physical challenges they face every day (Hatton *et al.*, 1999; Disley *et al.*, 2012). Their emotional investment in the people they support can result in great strains being placed on their mental health and wellbeing. Staff at The Lane described distress when people they supported were in pain or treated poorly, and yet their own emotional needs and wellbeing were left unsupported, and they took little or no action to address their own needs. Staffing pressures only exacerbate such strains. 45% of those working with people with challenging behaviours may be suffering from mental health problems (Raczka 2005).

Supporting people with learning disabilities who have limited functional skills, and the personal emotional impact of working with people with learning disabilities are significant stressors (Halliday *et al.*, 1992). Among staff, high stress and poor morale are widespread in services for people with a learning disability. UK surveys found approximately one-third of staff reported high levels of stress indicative of mental health problems (Hatton *et al.*, 1995; Hatton *et al.*, 1998), twice as high as the UK adult population (16%; Bennett *et al.*, 1995). The academic literature is consistent with findings from The Lane: both at the managerial level and at the support staff level, mental health was cited as a concern (see Table 6.2). However, support staff claimed that little support was available to them and they were expected to just get on with their job.

Staff wellbeing must be central to developing high-quality services for people with a learning disability. Can support staff be expected to care adequately for the wellbeing of others when their own wellbeing is disregarded? Poor mental health may lead them to make poor decisions, for themselves and for those who depend on them. Staff provide the interface through which policies are translated into practical action directly affecting the lives of people

they support. Kittay (2001) argues that if we want to improve conditions for people with a learning disability, 'we can begin by treating their caregivers as if their work mattered (because it does) and as if they mattered (because they do)… When care is not adequately supported, either the cost of care is borne by the caregiver alone or the charge fails to receive adequate care - or both suffer' (p. 575).

The frequent management and mitigation of emotion required of support workers can impact their sense of wellbeing. 'The bond that can form between caregiver and care recipient is at once meaningful, personally rewarding, exhausting – and – at times – exploitative' (Duffy, *et al.*, 2015, p. 9). Commenting on the often-overlooked vulnerability of care workers, Duffy *et al.*, said: 'as they care for the bodies and minds of others, care workers regularly put their own physical and psychological health at risk' (p. 79). These risks are exacerbated by underinvestment in social care that leads to care providers having to do more with less.

Staff perceptions of their circumstance play an important role, together with their coping strategies, in determining levels of staff stress. Hatton *et al.*, (1999) observed that different staff members will experience different levels of stress in response to the same set of circumstances: 'Clearly, to understand staff stress in services for people with intellectual disabilities, it is important to discern not only the objective working conditions of staff, but also staff perceptions of their working conditions' (p. 271). Staff at The Lane described serious challenges in their own personal backgrounds, such as physical abuse, divorce, disability and death; however, they claimed that these challenges made them more caring and empathetic towards people they support (see Table 6.6). They reported that the stress they felt stemmed primarily from organisational factors, such as understaffing, not from their relationships with people they support – even when supporting people with challenging behaviour who could cause them physical harm. This perceived emotional strength is contrary to the high levels of mental health problems reported in the studies quoted above, and may belie other factors which impact support workers' opportunities: several policy documents (e.g. Valuing People, 2001, Our Health, Our Care, Our Say, 2006), for example, have highlighted low levels of formal education and qualifications among the care workforce, which limit employment opportunities; moreover, support workers at The Lane were mostly older and chose to work at The Lane because of its locality.

Support workers rationalise work challenges through a narrative of care

Given the challenges, why do support workers remain in care work? The way that support workers describe themselves, their work and the people that they support, provides a valuable insight into the culture of care work. Collins *et al.*, (2015) identified the nurturing tendencies in staff towards people they support and their ability to empathise (see Chapter 4) which is consistent with findings from The Lane. Support workers at The Lane appeared to blur personal and professional life: they emphasised personal qualities rather than professional qualifications; making a difference rather than duty of care; and talked of 'family' rather than of service users or clients (see Section 6.2.2). Could such characterisation form part of a rationale used to mitigate the challenges and pressures that support staff experience in their work? Or does this reflect an unwillingness in staff to recognise the importance of professional skills and respect professional boundaries in supporting people with a learning disability? The use of language such as 'home and 'family' fits with ideas of paid care work as an extension of (or intersecting with) unpaid family care responsibilities (Armenia *et al.,* 2015).

Disley *et al.*, (2012) examined what qualities staff in services for people with a learning disability thought that they brought to the job; they found that being helpful, and their own personal characteristics (such as being caring) were cited most often. When asked what they felt they got from their job, staff cited feeling rewarded for making the lives of people they support better. The emphasis that support workers put on personal rather than professional abilities is reinforced by the views of people with a learning disability and their families. Mansell (2010) analysed feedback from family members of people with a learning disability about what characteristics were important to them, and found that: 'the key attribute was that staff should have a warm, respectful and caring relationship with the person. This was viewed as much more important than the particular background or training that staff had' (p. 4), yet this is not reflected in government policy. Similarly, Clarkson *et al.*, (2009) examined the views of people with a learning disability, who also valued the individual attributes of support staff.

The empirical research in this study suggests that support staff typically cope with the challenges of care work by adopting a personal narrative in which they view themselves as innately caring individuals who are making a difference. They believe they are exceptional because they are doing work that most people say they could not do. But in a sector characterised by chronically low pay, poor career progression, and skills shortages, do support workers place such high value on intrinsic qualities and altruistic rewards to

substitute for elusive material benefits? Duffy *et al* (2015) observed that care workers find the personal aspects of their work to be the most rewarding, but this is also the aspect that is most vulnerable when a drive for efficiency takes centre stage. 'The structural realities of understaffing leave many care workers fighting against the clock, a reality that has deleterious consequences not only for those workers but for those in their care…[This] is exacerbated by cultural preconceptions that render many aspects of caring labour invisible, unaccounted for in job descriptions and work schedules' (p. 289). Staff at The Lane spoke about regularly working longer hours due to understaffing, and feeling responsible for what might happen to people they support if they leave. Staff said they called in from home to check on people and grieved when people they supported died, and yet they were not entitled to personal benefits such as compassionate leave in such circumstances.

The blurring of the boundaries between work and personal life can be challenging for support workers. It can affect how they understand their work, their ability to avoid exploitation, and their ability to advocate for themselves. Duffy *et al.,* (2015) give the example that if a support worker is asked to stay a few hours longer by someone they support because they don't want to be alone, 'the carer may feel conflicted about whether the rules of work or family/friendship apply' (p. 9). Stacey (2005) also examined what he called 'dirty work' which describes work that is emotionally and physically demanding, stigmatising, and offers few material rewards. He, too, concluded that care workers derive a sense of enhanced dignity and self-worth from caring for dependent adults, and argued that the rhetoric of the family-style bond in care work, and the blurring of the line between formal and informal labour, can mask the inequality and exploitation of care workers (p. 839). Stacey's research highlights that conventional approaches to organising workers according to their material interests is inadequate for a workforce that finds meaning in the non-material aspects of their work. This is not to say that the material needs of care work is not important, but the significance of the emotional, intrinsic needs of support work must be recognised.

There are risks associated with defining care primarily in emotional terms: this could undermine efforts to enhance the professional status of care work, and reinforce views of care work as an extension of domestic work, primarily undertaken by women (Ellis 2004). The well-intentioned cultivation of the narrative that support workers are naturally caring may hinder the ability to recruit the right people if there is a belief that caring is an intrinsic quality rather than a professional skill. It could also cause staff to feel that any failure in their work is due to personal rather than professional issues. If, as this study suggests, good care relies on good relationships built-up over time between the support worker and people they

support, then pressures on staff resource will undermine the quality of care. Evidence from The Lane found residents unwilling to accept unfamiliar staff, and permanent staff remarked on mistakes and neglect by agency workers. The casualisation of the workforce is not in the interests of people with learning disabilities (Simpson and Price, 2010).

The motivation of support workers is open to interpretation. While much of the literature focuses on staff being innately caring and motivated by wanting to make a difference, the empirical research in the present study suggests that support workers have different reasons for working in care. Three reasons can be deduced from the fieldwork: 1) some individuals work in care because they derive value from caring for people; 2) some individuals work in this unskilled, low paid, low status sector because they have no other options, and/or low ambition for themselves; and 3) some individuals work in care work because it is convenient or temporary. While it may be true that some support staff frame their work within a caring narrative, if staff are in care work because they have no other option, or because it is convenient or temporary, this is likely to have an impact on the quality and consistency of care they provide, and on their motivation to engage with or deliver ambitious policy objectives to support people to live their lives to the full.

Policy advocating choice and inclusion is complex in practice

There is a clear gap between policy aspirations relating to choice and inclusion for people with a learning disability, and their implementation by support workers (Forbat, 2006, Jingree and Finlay 2008b, Dunn *et al.*, 2010). Evidence shows that despite ambitions, talk of empowerment can be superficial, at best (Antaki *et al.*, 2007). Support workers' ability or willingness to promote autonomy may be constricted by daily challenges that they face, such as stress, lack of support, inadequate knowledge, and low wages – all issues raised by staff at The Lane (see Chapter 6). Support workers reported other significant barriers to enabling choice, including challenging behaviour, the group living structure of residential care services, and a lack of resource (see Section 6.2.3). If, for example, someone with a learning disability at The Lane expressed a choice to go outside but staff was not available to support them, then they simply could not go out. Their right to choose was overridden by a lack of resource.

Similarly, organisational culture towards risk also influences how proactively support staff promote choice and independence. For example, the fear of safeguarding orders and the

resulting desire to minimise risk can conflict with policy to enable. Staff at The Lane were especially attentive to medication protocols, for example, due to previous safeguarding (see Section 6.2.1). Combined with staff shortages this resulted in people's support needs taking second place to processing paperwork. Reflecting on this issue, Ellis (1992) observed that the ability of people with a learning disability to make decisions is compromised when institutional fear of risk means that they are not supported to experience autonomy.

It is important to ask whether the policy emphasis on choice is appropriate and achievable in practice. Government policy paints an idealised picture of people with a disability being more independent, but this does not reflect the real challenges that people with a learning disability may experience (Burton and Kagan, 2006). Enabling meaningful choice and inclusion for people with severe and profound intellectual disabilities entails considerable complexity. Redley states that 'the impact of cognitive deficits on a person's ability to function, raises the question whether all people living with an intellectual impairment are able to make autonomous decisions, even when support is provided' (2018, p. 73). Support staff at The Lane claimed that for some people they support, choice could be confusing, overwhelming, and 'impossible' (see Table 6.12). In other cases, staff reported that promoting choice was secondary to more critical issues such as supporting immediate, and often serious health needs.

Government policy assumes that individuals with a learning disability severe enough to require residential care can conceive what options are available to them, choose between these options, and then express choice in a manner intelligible to a support worker without them introducing personal bias. However, people in residential care often do not have agency due to the severity of their impairments, and providing meaningful, wide-ranging choice can be challenging (Nonnemacher and Bambara, 2011). Furthermore, the mere placement of a person with a learning disability in a residential setting can lead to assumptions among support staff that this person lacks competence (Ellis 1992). Staff at The Lane distinguished residential care services from supported living services on the basis of support needs, with the former group assumed to have diminished capacity. In the absence of a clear definition of what choice means in everyday practice, people are often presented with pre-determined choices by support staff. For example, a person may be free to choose activities at their day centre, but they may have limited control when deciding whether to attend the service in the first place (Hollomotz, 2014). Is choice genuinely enacted when staff construct options based on what they *think* they know about people (Antaki *et al.*, 2006)? And to what extent are support workers qualified and enabled to make

decisions on behalf of the people that they support?

Staff who support the same individual for many years are in a better position to engage in effective 'surrogate decision-making' as a result of the knowledge and experience they acquire of that person over time (Dunn *et al.*, 2010). Indeed, long-serving staff at The Lane were better able than agency staff to interpret the non-verbal communication of people they support, and could understand the meaning of subtle nuances in people's behaviours, such as variations in vocal sounds or facial expressions. However, support staff reported challenges negotiating between their duty to protect and the aspiration to empower, as in the case of the resident with diabetes who wanted to eat cake (see Table 6.12). The tension between empowering and protecting was also identified by Windley and Chapman (2010), and Clifford *et al.*, (2018) whose research was included in the systematic review (see Chapter 4). Staff at The Lane claimed they also struggled to find meaningful ways to engage people with severe communication impairments as demonstrated by the trial and error approach of staff with some residents (see Table 6.11). And yet, despite such communication challenges, support staff were unambiguous in their assessment of the capabilities of people they support, stating that choice was an unrealistic goal, or a low priority for some people.

Government policy may emphasise choice and inclusion but, in practice, serious resource pressures, big differences in individual support needs, and staff ability to enable choice all undermine the credibility of achieving meaningful choice for all people with a learning disability. Given such an evident gap, is this policy assumption a reasonable expectation or simply a well-intentioned bulwark against outdated authoritarian, paternalistic practice? Given the history and negative public profile of the treatment of people with a learning disability, it could be argued that policy has a role in setting out values and principles, alongside governance of social care. However, these values can quickly be seen as disingenuous if policymakers do not provide the means to put policy into action.

The public sector model of care does not reflect the changing market

The changing sector for care has had an impact on the way care and support is delivered. While local authorities used to represent the largest employers in the social care sector, the proportion of the workforce located in the public sector is declining. Among the 1.52 million workers in the adult social care sector, 78% are employed in the independent sector, and

only 7% are employed directly by a Local Authority (Skills for Care, 2019b). The role of local authorities has shifted from that of direct providers to commissioners of social care, yet the models of care provision and workforce development are framed in terms of the public sector (Rainbird *et al.*, 2011), and a one-size-fits-all approach. Redley (2009) argues that the increasing accountability of care providers to local authorities and regulators, and competitive pressures to be efficient have resulted in disempowering service users, and the people that support them. Staff at The Lane gave many examples of having to 'fight' local authorities over funding cuts that affected how many support hours people received and limited what they could do (see Table 6.5).

Learning disability policy needs to reflect the variety and fragmentation of the care market. Without addressing differences in the market, homogenous regulation and policy is left for care providers and individual staff to interpret. In the case of The Lane, staff reported low awareness of policy, and a generic understanding of legal requirements such as the Mental Capacity Act, but did not have the ability to contextualise even this for people they support. The diversity of the sector, the large numbers of small businesses, the extensive use of agency workers, and the way support workers are managed, all impact the delivery of competent, consistent quality of care (Rainbird *et al.*, 2011). While there is recognition in policy of the importance of a 'qualified' workforce, this may be difficult to achieve without significant reforms as it is well publicised that staff working in residential services are in receipt of very low wages (Pennycook 2013). Specifically, to attract a high proportion of intrinsically motivated staff, care work may need to become a more financially viable career option. Staff at The Lane were vocal about the low pay that made care work 'unaffordable' for people and the impact this had on the ability to recruit and retain good staff (see Table 6.4).

The changes in how care is commissioned and provided has also created ambiguities for support staff, who are unclear about what these changes mean in practice. Commenting on learning disability policy, Mansell and Beadle-Brown (2010) state that the move from large residential institutions to community-based small-scale services has probably been the most significant policy development in the post-war period. However, they question implementation and whether supported housing replicates institutional features and should themselves be reformed. This thinking accords with staff views at The Lane who talked about the conversion of residential care services to supported living, but with the same residents and staff remaining in place (see Table 6.10). Mansell, Beadle-Brown, (2010) stress that the way staff provide support is a key determinant of outcomes for the people they support. Therefore 'the shift from institutional care to living in the community is a

necessary but not sufficient condition for better outcomes for all residents. In addition to the change of accommodation, it is necessary to change the kind of staff support that is provided' (p. 107). It is critical that government policy address institutionalised practice and how people work, and not just structural change in the commissioning, design and delivery of care and support. Without a whole system change, and real engagement with the people involved in all parts of the social care system, policy and practice will remain divided. This serves neither the interest of policymakers nor the people that policy seeks to support.

Support workers' role in enacting policy in England is neglected in academic research

Duffy *et al.*, (2015) observed that 'a deep exploration of the cultural meanings of paid care work and the subjective experiences of care workers is crucial to achieving an understanding of the care sector' (p. 127). Furthermore, despite the recognition that support worker perspectives are under-represented in academic research, and the recognition of the value of such perspectives (Hastings 2010, Nonnemacher and Bambara 2011, Hutchison and Kroese, 2015), there is an absence of academic research examining the relationship between government policy and support worker practice in England. Instead, research has been concentrated in other countries, or/and typically focused on specific areas of support work, such as challenging behaviour (Griffith *et al.*, 2013) and stress (Hatton *et al.*, 1999), neglecting the broader, fundamental aspects of the support worker role. Does the lack of academic interest reflect a lack of recognition of the support worker's role in operationalising policy? Certainly support workers themselves have reported feeling under-engaged and under-appreciated (e.g. 'managers do not appreciate support staff'; 'low status of support work'; 'lack of government engagement with support staff'; 'negative media reporting of care work'; see Chapter 6).

7.4 Recommendations for policy and practice

'Despite 12 green and white papers and five independent commissions over the last 20 years, successive governments have ducked the challenge of social care reform' (Thorlby *et al.*, 2018, p. 3).

This section formulates recommendations for social care policy and practice in England in residential and supported living services for adults with a learning disability. These recommendations will focus on the issues concerning frontline support staff, as identified in this thesis; specifically, the barriers impacting support workers' ability to deliver consistent

quality of care. The field of social care research has produced many studies that advocate reform in the social care sector; the case for reform is well rehearsed. The specific issues relating to reform are complex, manifold, and beyond the scope of this thesis. However, such studies raise several points that are germane to addressing the gap between learning disability policy and practice; these will be discussed in the recommendations below. I start with policy recommendations that require action at a national and local government level, followed by practice recommendations for care providers. It is important to consider the recommendations in the context of the limitations set out in Section 7.2, and the implications for future research in Section 7.5.

Political will is required to address the funding crisis in the social care sector
Recommendation: Tackling the challenge of social care reform requires an appropriate funding settlement.

Funding is the single most important factor impacting the quality and sustainability of the care sector. While it was not the main focus of this thesis, funding was clearly raised by participants interviewed in Chapter 6. For more than 20 years, concerns have been raised about the system of publicly funded social care in England. The sector is in crisis, but despite several government proposals and commitments to address this crisis, the political drive to effect lasting change has been lacking: 'As a former senior civil servant, I've had a ringside seat for every effort to reform social care funding in the past decade. I've drafted Green Papers and White Papers and even got legislation passed, but not one reform has ever been implemented' (Warren, 2019).

Compared to NHS workers, social care workers have largely been invisible unless brought into the media spotlight by reports of abuse. Public recognition of healthcare is linked to the NHS 'brand' and most people will know their local hospital, whereas the same cannot be said of social care, which is made up of many independent entities. Furthermore, the health profession has a history of advocacy through established professional bodies, which is not the case for social care. In 2018, when the NHS celebrated its 70th anniversary, Thorlby *et al*. noted: 'The social care system is 70 years old this year but unlike the NHS, its anniversary will pass largely unnoticed. The fault line established 70 years ago between health care which is free at the point of use and social care which is means-tested, remains a fundamental source of inequity and unfairness today' (p. 3). These inequalities are reflected in the under-funding of social care, which is detrimental to the working conditions of care staff, to the quality of care provision, and to the viability of care providers.

The Competition and Markets Authority (2017) found that many care homes, particularly those that are most reliant on local authority-funded residents, are not currently in a sustainable position (p. 13). Four-fifths of local authorities are paying fees to providers that are below the benchmark costs of care (National Audit Office, 2018a). Social care is facing high growth in demand, projected to rise by around £12 billion by 2030/31 (Bottery *et al.*, 2018). Despite this, local authorities have seen a 49.1% real-terms reduction in government funding between 2010/11 and 2017/18, resulting in a 28% reduction in their spending power after council tax adjustments are taken into account (National Audit Office, 2018b). Alderwick *et al.,* (2019) report that 'simply meeting demand pressures for social care under current eligibility would require £2.7bn additional government investment by 2023/24. Boosting staff pay (to grow at the same rate as the NHS) to improve recruitment and retention means this figure would grow to £4.4bn in 2023/24' (p. 7).

Despite this evidence, and despite repeated government promises, the crisis in funding remains unresolved. In December 2019, The Queen's Speech stated the Government's commitment to 'urgently seek a cross-party consensus in order to bring forward the necessary proposals and legislation for long-term social care reform in England' (p. 37). Consecutive governments have acknowledged the need for social care reform, with proposals largely focusing on different forms of taxation (Bottery *et al.*, 2018; Thorlby *et al.*, 2018). Yet there persists a lack of political will to implement increased funding. Without the political leadership to see this through, the sector will remain in crisis. The remaining recommendations in this section are all impacted by this lack of adequate funding.

Improve working conditions of frontline carers
Recommendation: The material and mental health needs of the care workforce must be addressed through national legislation and local, accountable implementation.

This thesis has reported the challenges characterising the working conditions of frontline support workers, including low pay, zero-hour contracts, long hours, high stress, low ambition, poor prospects, and low recognition. These are not conditions under which safe, high-quality care can be delivered and sustained. Beech *et al.*, (2019) highlight the better pay and conditions typically available to NHS workers, and that social care staff are being lost to the NHS. Beech *et al.,* estimate that 'the social care workforce would need around £1.7 billion of investment to match the recent NHS pay deal' (p. 120). At a minimum, the pay and conditions of frontline social care workers must equal those of the NHS, and zero-hour contracts must be banned, along with harmful long working hours. This is difficult to achieve uniformly, however, because care workers are employed by 18,500 independent

organisations (Skills for Care, 2019) and, unlike the NHS, do not have national pay rates and terms and conditions. Nor can all care providers afford to pay their staff more, since the fees they receive from local authorities have been held down (Bottery, 2019b). Nevertheless, these changes cannot be ignored: they are necessary to improving the wellbeing of staff and the quality of care provided. In addition, care providers should be contractually required by care commissioners to have an up-to-date staff wellbeing strategy that supports mental and physical health. More importantly, providers should be required by local authorities to demonstrate adherence to meeting standards in staff health and wellbeing as part of their contractual reporting and evaluation.

Improvements to working conditions are fundamentally tied to funding and, again, to political will. Skills for Care is the body charged by the Department of Health and Social Care (DHSC) with delivering workforce development in the care sector, but this body has negligible influence over the central workforce challenge: the adequacy of government funding for care, pay and progression. The Care Act (2014) guidance states that local authorities should encourage the training and development of care staff, but providers are not formally required to offer such development opportunities to staff. In most contracts, local authorities include obligations to ensure that a provider has an adequate number of suitably qualified staff and that the provider will develop its workforce. However, the National Audit Office (2018a) reported that 'local authorities told us that, given the pressures facing providers and the negative consequences if a provider left the local authority funded market, they were cautious about challenging providers over their investment in workforce development' (p. 45).

The Government's track record in following through on plans to improve working conditions is poor. The logical mechanism to tackling poor working conditions would be to task the lead government department, i.e. the DHSC, with developing a national workforce strategy in collaboration with key stakeholders which addresses the specific workforce issues, and sets out a clear implementation plan with identified roles and responsibilities, and accountability measures. However, the National Audit Office (2018a) reported on the DHSC's oversight of the adult social care workforce and identified several concerns, including that 'the Department does not have an up-to-date care workforce strategy: the last workforce strategy… was published in 2009 … and gives responsibility to some organisations that no longer exist' (p. 9). The report notes that despite changes within the sector since 2009, for example the Care Act 2014, the Department has not refreshed the strategy; in the absence of a national strategy, local and regional bodies and partnerships are not taking the lead on workforce planning.

Tackling the poor working conditions of frontline care workers requires a collaborative approach between the central and local government bodies that legislate and commission care, and the care providers whose workforce conditions are largely defined by the care they are commissioned to deliver – including funding levels. The National Audit Office (2018c) has warned that 'social care cannot continue as a Cinderella service – without a valued and rewarded workforce, adult social care cannot fulfil its crucial role of supporting older and vulnerable people in society'. Existing workforce conditions are detrimental to the quality and safety of care, and must be remedied with the appropriate level of investment, political will and accountability.

Re-evaluate the role of the frontline care worker and the relevance of policy to people with a learning disability

Recommendation: Policymakers should review and restructure the paid care role. This must be informed by the care workforce itself, and include insight into the care worker role (what they do), motivations (why they do it), and challenges in realising policy (what isn't working).

There is a gap between learning disability policy and its practice. This thesis suggests that this is due in part to policymakers not engaging sufficiently with frontline care workers. Government policy does not consider the role, motivations and challenges of the care workforce, and care workers lack awareness of social care policy. It is untenable to advocate for people with a disability while neglecting the voice and value of those who support them. Policy expectations of care provision are high, while value for those providing the care is low.

This thesis did not identify any government policy documents that had been directly informed by frontline care workers (see Chapter 3). As a consequence, government expectations of the care workforce are unrealistic and, as this thesis has argued, government policy is not translating into practice. The care worker role is a complex combination of low-skilled, manual labour (like the provision of intimate personal care) and highly skilled professional work, including advocacy and enablement for some of the most vulnerable people in society. In the context of this broad range of skills and requirements, the crafting of effective government policy concerning learning disability cannot exclude the paid workers who deliver this care. An exhaustive consultation must be undertaken, with the care workforce and the people they support, to inform a reconsideration and restructuring of the care worker role. This restructuring must consider: a) what is possible within an existing, under-funded sector, and with an unqualified, minimum-wage workforce; and b) what support would actually look like if resources matched needs. If the status quo is maintained, if there is no political will for change, then policymakers, commissioners and care providers must redefine

expectations of standards and outcomes. This point is especially relevant when considering the changing demographics of people with a learning disability who are, for example living longer and with increasingly complex conditions (National Audit Office, 2017, p. 14).

I suggest that the care worker role encapsulates several roles with considerably different skill sets (e.g. low-skilled manual labour v. high-skilled advocacy). Consequently, policymakers and care providers should review whether a new or different professional role should be created that requires the skills and competence to proactively advocate and oversee the needs and potential of individuals in their care. The national care provider in this study previously included a 'senior support worker' role but this level was removed due to funding pressures. Whether the care worker role requires a different structure, or a new specialist role is created, the existing model must be reviewed to address the multiple functions currently served by the single care worker role. Ideally, this review would make provisions for a career development structure that rewards experience. Bottery (2019a) highlights that care workers with five or more years' experience are paid on average £0.15 an hour more than new entrants, down from 37p more in 2013. Without a structure that meets the needs and enables the potential of both care workers and those they support, recruitment and retention will remain a serious challenge (National Audit Office, 2018a).

When reviewing the care worker role in order to close the gap between policy and practice, it is equally important to revise the policy assumption that independence leads to a better life. Existing policy stigmatises dependency by idealising independence and promoting independence as the gateway to a better 'normal' life for people with a disability. This undermines the value of disabled people with severe and profound disabilities that require support, and the value of those who support them. Dependency is not a failure and care policy should not be divisive in segregating disabled people into those who can and those who cannot. Policies relating to choice and self-determination must either be redefined to be meaningful for all people with a learning disability, or new, relevant and achievable aspirations need to be formulated. In either case, when it comes to individuals with severe and profound disabilities, there must be clear guidance at the national level, and support at the local level, on putting policy into practice; in particular, this guidance must address the grey areas when policies of enablement conflict with safeguarding duties. Such guidance and support must be appropriate to the capacity and capability of the care workforce responsible for implementing policy.

Care commissioning must abandon short-termism and invest in long-term relationships with quality providers

Recommendation: Train and evaluate local authority care commissioners based on standards that advance empathetic, relational care and address poor commissioning practice.

Local authority care commissioners should receive mandatory training that includes time shadowing frontline care workers and the people they support. Shadowing should be extended to all policymakers involved in drafting policy that impacts the provision of learning disability care. The gap between policy and its implementation requires genuine engagement with the practice of care on the ground, beyond the simple visit, interview, or questionnaire.

A lack of genuine engagement with the experience of care, and of the requirements of quality care, have translated into poorly-informed attempts by local authorities to limit their expenditures on services; this has resulted in an increasing number of providers going out of business or handing back contracts (Bottery, 2019b). In April 2019, Four Seasons Health Care Group, the UK's second largest care home provider, with 340 care homes, announced that it had entered administration. Care market analysts LaingBuisson noted in July 2018 that the Group had a "high exposure to public pay", which had negatively impacted its profitability as a result of 'government austerity and downward pressure on council paid fee rates' (Jarrett, 2019, p. 3). Under the Care Act (2014), local authorities have a duty to shape the market for care; yet, in 2017, the Competitions and Markets Authority (CMA) reviewed 20 market position statements of local authorities (i.e. the published market shaping reports) and found that none included estimates of future additional capacity needs. The CMA concluded that 'this reflects the current pressures on local authorities and their lack of long-term certainty on future funding patterns and levels' (p. 15). The CMA called for 'greater accountability for local authorities in delivering on their care obligations, and their planning and commissioning' (p. 17).

The detrimental impact of funding pressures on the provision and quality of care is clearly recognised by the Association of Directors of Adults Social Services (ADASS). In their 2019 Budget Survey, ADASS state: 'The problems councils and providers face have got progressively worse… Local government is struggling to balance the books and Directors know that adults of all ages with disabilities are not getting all the care they need. Directors are increasingly saying they can't meet their legal responsibilities to the public' (p. 5). 'The market is fragile and failing in some parts of the country… Directors' biggest concern about the impact of savings made or planned is the prospect of providers facing financial difficulty

and quality challenges. 79% of directors are concerned about their ability to meet the statutory duty to ensure market sustainability within existing budgets' (p. 8).

While national government funding policies have prompted poor commissioning practice, local authorities are ultimately responsible for commissioning care that meets standards in quality and safety. Such standards must distinguish between meeting individual needs to survive and to thrive. A lack of funding cannot be an excuse for poor commissioning that prioritises price over people, and harms the care sector and the people whose interests it is expected to serve. Underfunded local authorities have become focused on short-term thinking, as a result of which they are unable to develop long-term relationships with good-quality care providers. Instead, they are being pushed towards outsourcing models to make short-term savings. Ultimately, this impacts both the people receiving care and those delivering it, who are forced onto low-paid and insecure contracts. To redress this dangerous trend, the Trade Union Congress has proposed that social care should be commissioned to promote social value and employment standards, with a voice for service users and the care workforce (Mackridge, 2019). Local authorities must be supported at a national level to deliver best practice in its duty to care for its most vulnerable citizens. This can only be achieved with the necessary investment to meet the real cost of care, by creating a culture of collaboration rather than contactor and contracted, and holding local authorities to account for poor commissioning practice.

Care providers must take ownership on the ground, irrespective of the funding crisis
Recommendation: Enable effective management, peer support, flexible working, relational care, and demonstrate impact.

The recommendations above have focused on the high-level changes that are necessary to address the fundamental issues raised by this thesis. This final recommendation encompasses operational changes that can be implemented more immediately, at the point of delivery. These are practices that should already be in place but which – as this thesis has reported – are lacking in consistency and quality.

While recognising the very real challenges of operating effectively with the limited resources imposed by the central government's underfunding of the care sector, providers of care nevertheless have a duty to address the serious issues relating to their workforce and, by extension, the people that they support. In addition to the recommendations above, I identify

five areas of action that care providers must own:

1. *Quality of management:* This thesis found that frontline care workers report a lack of support, engagement and recognition from direct management. Staff experience serious physical and emotional demands in their work but little to no pastoral care or contact with direct managers; instead they often work alone, and for long hours. Care providers must ensure that direct managers are responsible and accountable for providing the necessary support and recognition to their staff. This is even more critical given existing pay conditions. Managers must be set measurable performance objectives and receive training/support to prioritise staff needs and to have the emotional intelligence to promote staff wellbeing.

2. *Peer support:* In addition to encouraging support from managers, care providers must create conditions that cultivate collaboration and peer support between care workers, and which minimise staff isolation. The fieldwork in Chapter 6 reported that frontline staff experienced similar challenges but there was little peer-to-peer support or reflective practice. This left staff feeling isolated and stressed. There are several mechanisms through which peer support can be developed, such as peer-to-peer mentoring, shared learning, encouraging informal exchange by creating the space to enable this, structuring roles and schedules that facilitate collaborative working between staff, etc. This should be tailored by care providers and service managers and should form part of staff performance objectives.

3. *Flexible working patterns:* It is unsafe for care staff to work excessive hours, and by extension this practice has negative safety implications for the people they support. Care providers must be transparent with local authorities when bidding for and delivering care services in a manner that compromises its workforce. The model of 'person-centred care' has rightly recognised that support should be designed to meet the needs of the person being supported, rather than fitted around the needs of the service. Similarly, because the welfare of the support worker and of the person being supported are so closely linked, the needs of support workers cannot be disregarded. This thesis has highlighted the individual circumstances of support workers, many of whom also have caring roles and responsibilities outside their work. Care providers must adopt flexible working patterns that meet the needs of people they support *and* the people that support them.

4. *Enable relational care:* The relationship between frontline workers and those they support is critical to the quality of care delivered, and yet care workers report sacrificing

quality of interaction for task-based delivery due to resource pressures (see Chapter 6). This thesis highlighted the importance of staff familiarity to people with a learning disability, and that staff are better able to support people with whom they have built a relationship and understanding. Care providers may well emphasise relationships and personalised support in training and in their organisational values but this needs to be supported in practice. Care providers and managers must match staff to people requiring support based on individual qualities and skills, and must minimise disruption and changes in staffing where care relationships are working well. Task-based and administrative responsibilities that impact the quality of interactions between staff and people they support should be reviewed to minimise that impact through alternate scheduling, systems and responsibilities. A greater emphasis on 'person-centred' relational care will reinforce the intrinsic rewards for staff who will be better-placed to provide meaningful rather than superficial support.

5. *Demonstrate impact:* Care providers must learn to communicate effectively to local authorities the value of relational care, so that local authorities can make meaningful cost analyses when demanding financial value from the provider. This effective valuation of relational care should occur both at the provider level, and collaboratively across the sector. This means identifying measures that make the case for relational care to local and central government. As a fragmented and under-resourced sector, learning disability care providers face a genuine challenge in advocating with a unified voice, and often lack the resources and competence to influence independently. There must be a deeper, collective engagement between policymakers, commissioners and providers to ensure that the care sector can deliver a high quality, sustainable service that values its workforce and meets the needs of people it supports.

7.5 Implications for future research

This study raises several questions pertaining to the disconnection between learning disability policy and practice, and the views and experiences of paid support workers. These questions could not be investigated fully here, because a study of this nature is limited in size and scope by the necessity of operating within a certain framework (e.g. set timeframe, limited resources, maximum word count). This section recommends areas for future research identified from the study.

The role of support workers in realising government policy

This study was centred on one care provider, in one geographic location and one site with different services. Further work is needed to establish how the findings of this study compare across care providers, in different locations and services. It will be useful to examine variations in support worker demographics and characteristics, perceptions and practice, and the implications for learning disability policy. The policy analysis in Chapter 3 focused on government legislation and White Papers in England. Analysis of Green Papers and guidelines associated with policy would provide more detailed insight on the thinking behind policy, and the interpretation of policy. The systematic review in Chapter 4 highlighted a paucity of empirical studies in this area, and no studies at all of the relationship between support worker practice and learning disability policy in England. Further research of this type would be valuable in the development of academic knowledge and future policy.

The role of agency workers in learning disability care

Given the reported grievances relating to agency workers, and the apparent negative impact on people with a learning disability, valuable insight could be gained from an analysis of the perceptions, motivations and practices of agency staff compared to permanent staff, and what bearing this has on the quality of care and relationships with people they support.

Views of people with a learning disability

This study was concerned with the views and experiences of support workers, which government neglects to reflect accurately in policymaking. Establishing whether the perceptions and practices of support workers accurately reflect the experiences and wishes of people they support will test the validity of what support workers say and do.

Relationship between competence care and recruitment

This study recognises the importance of the care relationship, but does not minimise the importance of skill and competence. Policymakers undervalue the sheer breadth of skills and abilities required of support workers to realise its ambitions. Further research is needed to understand the dynamic between competence and care, the expectations placed on a largely unskilled, low-paid, low status workforce, and whether these expectations are realistic, or whether the support worker role is in fact a composite of different roles that

require different skills.

The empirical evidence in Chapter 6 identified a strong focus on personal qualities over professional skills among staff. Research into recruitment processes, and the weight that is given to aptitude and attitude will help better understand the strengths and gaps in social care recruiting. The motivation of support staff, and working conditions have implications for recruitment and retention and require a deeper understanding. It is equally important to establish to what extent policy reflects the lives and aspirations of *all* people with a learning disability, so that it can recruit and retain a workforce with the appropriate skills and qualities.

Comparison of findings with other care categories and services

This research raises a number of questions which have implications beyond learning disability and social care. Demographic changes and forecasts, particularly those relating to increased life expectancy and chronic health conditions suggest that the distinction between social care and healthcare will become increasingly blurred, and care practitioners will require a greater ability to support people with multiple needs in different settings. Comparing the results of this study with other categories of care service users (such as older people, people with dementia, people with physical disabilities), other service settings (such as hospitals, hospices), and other care roles (such as nursing, personal assistants), will improve understanding of differences and similarities between different services, service users and support professionals.

Given the feedback from support workers that supported living services enable greater independence that residential care homes, a detailed comparison of the culture and practices in these different settings would help improve clarity of the impact of the type of service provision on quality of care and support.

Testing the validity of choice and control as means to a better life

Much has been written about learning disability policy in relation to choice and control. This research questions the validity of the prevailing policy position that these concepts are the gateway to a better life. Further research is needed to understand the true value of choice to people with severe and profound disabilities who lack mental capacity, and whether the choice and control that they experience is genuine or manufactured by the people who support them. Is quality of life for people who lack capacity dependent on the pursuit and

fulfilment of choice, or do other things matter to them more? Should quality of life be redefined from the perspective of the individual, rather than from the perspective of the policymaker, even if this does not fit with mainstream concepts? What role does limited horizons play in people's expectations of themselves or by the people who support them? Understanding the answers to such questions is critical in devising policy that is meaningful and realisable.

Views of commissioners and policymakers

Given the gap between policy and practice identified by this study, valuable insight may be gained by examining the views and understanding of local authority commissioners and policymakers concerning support workers and support work. It will also be useful to understand how these compare with the views and experiences of the support workers that they are reliant upon. In particular, it would be interesting to examine and compare views about the purpose of support work, the motivations and challenges of support workers, the relationship between support workers and people they support, and the role that support workers play in implementing policy.

Understanding the relationship between different public services and their influence on care provision

This research has focused on learning disability support within social care but what is the impact of policy-practice failings in other public services, such as healthcare, education, housing, and local government? Is it reasonable, for example to expect a support worker to be responsible for promoting the health of an individual when there are challenges accessing healthcare and receiving equal treatment? Can they be expected to support people's social inclusion when local government contracts are financially restrictive? Do such failings place an additional burden on frontline support workers when they attempt to enable choice and independence for the people they support? If public services were more collaborative and engaged, could support work then become more specialised and professionalised, and focus on those with the greatest need? Much of the policy explored in Chapter 3 promoted the integration of health and social care but failings in healthcare provision for people with a learning disability are well reported (Mencap, 2007). Understanding the relationship between the different, vital public services and social care will provide a more coordinated understanding of the challenges experienced by people with a learning disability in trying to

live lives they choose – or are supported to choose.

7.6 Chapter summary

The scope of this thesis was focused on the role of the support worker in enacting learning disability policy in England. But, in the process, this work has highlighted the complex relationships and interdependencies that influence social care outcomes. Furthermore, this thesis raises questions about the ethics of a Society that values ability and autonomy and devalues disability and dependence, fostering a low-pay and low-recognition environment for frontline support workers. Does the complexity of the relationship between the support worker, the supported individual and the State reflect some of the paradoxes of modern life?

In this thesis I have examined government policy and previous research in England concerning learning disability support workers, and integrated insights gained from that examination with new research to provide further perspectives on the relationship between policy and practice. Throughout my research I have used an evidence-based, systematic approach to develop and examine each stage of the research. I found parallels between aspects of my research and existing literature, but I have also generated new insights pertaining to the gap between learning disability policy and practice – a gap resulting from a failure to fully recognise the role of learning disability support workers in the lives of people they support. I hope that my research will encourage other researchers and policymakers to consider the views and experiences of support workers in any efforts to understand, support, and enable people with a learning disability.

References

1. Abbott, D. and Howarth, J. (2007). Still off-limits? Staff views on supporting gay, lesbian and bisexual people with intellectual disabilities to develop sexual and intimate relationships. *Journal of Applied Research in Intellectual Disabilities*, 20, pp. 116-126. https://doi.org/10.1111/j.1468-3148.2006.00312.x

2. Alderwick, H. Tallack, C. and Watt, T. (2019). *What should be done to fix the crisis in social care?* The Health Foundation. [pdf] Available at: https://www.health.org.uk/sites/default/files/2019-08/20190410-What-should-be-done-to-fix-the-crisis-in-social-care.pdf [Accessed 30 April 2020].

3. Alexander, M. and Hegarty, J. (2000). Measuring staff burnout in a community home. *The British Journal of Development Disabilities*, 46, pp. 51-62. https://doi.org/10.1179/096979500799155810

4. Alghrani, A. Case, P. and Fanning, J. (2016). The Mental Capacity Act 2005 - ten years on. *Medical Law Review*, Volume 24(3), August, pp. 311-317. https://doi.org/10.1093/medlaw/fww032

5. Alldridge, P. (2019). On being able to walk twenty metres: The introduction of Personal Independence Payments. *Journal of Law and Society*, 46(3), pp. 448-75.

6. American Association on Intellectual and Developmental Disabilities. (2010). *Intellectual disability: definition, classification, and systems of support*. Washington D.C.

7. American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders*, Fourth Edition. Washington, DC.

8. American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders*, Fifth Edition. Washington, D.C.

9. Anastasiou, D. and Kauffman, J. M. (2013). The social model of disability: Dichotomy between impairment and disability. *Journal of Medicine and Philosophy*, 38(4), pp. 441-59.

10. Antaki, C. Young, N. and Finlay, M. (2002). Shaping clients' answers: Departures from neutrality in care-staff interviews with people with a learning disability. *Disability and Society*, [e-journal] 17(4), pp. 435–455. http://doi.org/10.1080/09687590220140368

11. Antaki, C. Finaly, W. M. L. Sheridan, E. Jingree, T. and Walton, C. (2006). Producing decisions in service-user groups for people with an intellectual disability: Two contrasting facilitator styles. *Mental Retardation*, 44, pp. 322-343. https://doi.org/10.1352/0047-6765(2006)44[322:PDISGF]2.0.CO;2

12. Antaki, C. Finlay, W. M. L. and Walton, C. (2007). The staff are your friends: Intellectually disabled identities in official discourse and interactional practice. *British Journal of Social Psychology*, [e-journal] 46(1), pp. 1–18. http://doi.org/10.1348/014466606X94437

13. Antaki, C. Finlay, W. Walton, C. and Pate, L. (2008). Offering choices to people with intellectual disabilities: An interactional study. *Journal of Intellectual Disability Research*, [e-journal] 52(12), pp. 1165–1175. http://doi.org/10.1111/j.1365-2788.2008.01101.x.

14. Antaki, C. Finaly, W. and Walton, C. (2008b). Saying no to the staff: an analysis of refusal in a care home for people with intellectual disabilities. *Sociology of Health and Illness,* 30, pp. 55-75. https://doi.org/10.1111/j.1467-9566.2007.01028.x

15. Antaki, C. Finlay, W. M. L. and Walton, C. (2009). Choices for people with intellectual disabilities: Official discourse and everyday practice. *Journal of Policy and Practice in Intellectual Disabilities*, [e-journal] 6(4), pp. 260–266. http://doi.org/10.1111/j.1741-1130.2009.00230.x.

16. Ashforth, B. E. and Kreiner, G. E. (1999). How can you do it?: Dirty work and the challenge of constructing a positive identity. *The Academy of Management Review,* 50(1), pp. 413-434.

17. Ashforth, B. E. Kreiner, G. E. Clark, M. A. Fugate, M. (2007). Normalising dirty work: Managerial tactics for countering occupational taint. *The Academy of Management Journal,* 50(1), pp. 149-174.

18. Association of Directors of Adults Social Services (2019). *Budget Survey 2019*. [pdf] Available at: https://www.adass.org.uk/media/7295/adass-budget-survey-report-2019_final.pdf [Accessed on 5 May 2020].

19. Association of Directors of Adult Social Services, Local Government Association, and NHS England, (2015). *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.* [pdf] Available at: https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf [Accessed 1 September 2016].

20. Audit Commission (1996). *Making a reality of community care*. London: HMSO.

21. Banton, M. (1983). *Racial and ethnic competition.* Cambridge: Cambridge University Press.

22. Barnes, C. (1991). *Disabled people in Britain and discrimination*. London: Hurst and Co.

23. Barnes, C. (1999). Disability studies: New or not so new directions? *Disability and Society*, 14, pp. 577–80.

24. Barnes, M. (2006). *Caring and Social Justice*. Basingstoke: Palgrave.

25. Barnes, M. (2011). Abandoning care? A critical perspective on personalisation from an ethic of care. *Ethics and Social Welfare*, [e-journal] 5(2), pp. 153–167. http://doi.org/10.1080/17496535.2010.484265.

26. Baston, C. D, Early, S. and Salvarani, G. (1997). Perspective taking: imagining how another feels versus imagining how you would feel. *Personality and Social Psychology Bulletin*, 23, pp. 751-758.

27. Beadle-Brown, J. Hutchinson, A. and Whelton, B. (2012). Person-centred active support-increasing choice, promoting independence, and reducing challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, 25, pp. 291-307.

28. Beadle-Brown, J. Leigh, J. Whelton, B. Richardson, L. Beecham, J. Baumker, T. and Bradshaw, J. (2016). Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, [e-journal] 29(5), pp. 409–421. http://doi.org/10.1111/jar.12200.

29. Beart, S. Hardy, G. and Buchan, L. (2004). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities,* 18(1), pp. 47-56.

30. Beckett, A. E. and Campbell, T. (2015). The social model of disability as an oppositional device. *Disability and Society*, 30(2), pp. 270-283. https://doi.org/10.1080/09687599.2014.999912

31. Beech, J. Bottery, S. Charlesworth, A. Evans, H. Gershlick, B. Hemmings, N. Imison, C. Kahtan, P. McKenna, H. Murray, R. and Palmer, B. (2019). *Closing the gap: Key areas for action on the health and care workforce.* The Health Foundation, The King's Fund, The Nuffield Trust. Available at: https://www.kingsfund.org.uk/publications/closing-gap-health-care-workforce [Accessed on 3 May 2020].

32. Bennet, N. Dodd, T. Flattley, J. Freeth, S. Bolling, K. (1995). *Health survey for England 1993*. London: HMSO.

33. Bigby, C. Clement, T. Mansell, J. and Beadle-Brown, J. (2009). 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research,* 53(4), pp. 363-76. https://doi-org.ezp.lib.cam.ac.uk/10.1111/j.1365-2788.2009.01154.x

34. Bigby, C. and Atkinson, D. (2010). Written out of history: Invisible women in intellectual disability social work. *Australian Social Work,* 63(1) pp. 4–17. https://doi-org.ezp.lib.cam.ac.uk/10.1080/03124070903482949

35. Bigby, C. Knox, M. Beadle-Brown, J. Clement, T. and Mansell, J. (2012) Uncovering dimensions of culture in underperforming group homes for people with severe intellectual disability. *Intellectual and Developmental Disabilities*, 50(6), pp. 452-467 https://doi.org/10.1352/1934-9556-50.06.452

36. Bigby, C. Knox, M. Beadle-Brown, J. and Clement, T. (2015). 'We just call them people': Positive regard as a dimension of culture in group homes for people with severe intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, [e-journal] 28(4), pp. 283–295. http://doi.org/10.1111/jar.12128

37. Boat, T. F. and Wu, J. T. (2015). Mental disorders and disabilities among low-income children. *National Academies of Sciences. Engineering, and Medicine*. Washington, DC: The National Academies Press.

38. Bottery, S. (2019a). *Why you're better off being a cleaner than a care worker?* The King's Fund. Available at: https://www.kingsfund.org.uk/blog/2019/10/cleaners-paid-more-than-care-workers [Accessed 2 May 2020].

39. Bottery, S. (2019b). *What's your problem, social care?* The King's Fund. Available at: https://www.kingsfund.org.uk/publications/whats-your-problem-social-care [Accessed 30 April 2020].

40. Bottery, S. Varrow, M. Thorlby, R. and Wellings, D. (2018). *A fork in the road: Next steps for social care funding reform.* London: The Health Foundation. Available at:
https://www.kingsfund.org.uk/publications/fork-road-social-care-funding-reform
[Accessed 30 April 2020].

41. Bowen, G. (2009). *Document analysis as a qualitative research method. Qualitative Research Journal*, 9. pp. 27-40. https://doi.org/10.3316/QRJ0902027.

42. Braun, V. and Clarke. V. (2006). 'Using thematic analysis in psychology.' *Qualitative Research in Psychology*, 3(2), pp. 77-101.

43. Bromley, J. and Emerson, E. (1995). Beliefs and emotional reactions of care staff working with people with challenging behaviour. *Journal of Intellectual Disability Research*, 29, pp. 341-252. https://doi.org/10.1111/j.1365-2788.1995.tb00526.x

44. Brown, I. Hatton, C. Emerson, E. (2013). Quality of life indicators for individuals with intellectual disabilities: Extending current practice. *Intellectual and Developmental Disabilities*, 51(5), pp. 316–332.

45. Bunting, M. (2016). 'Who cares: The emotional labour of an undervalued, underpaid workforce'. *Guardian,* 15 March. Available at:
https://www.theguardian.com/society/2016/mar/15/care-workers-undervalued-underpaid-radio-3 [Accessed 10 May 2016].

46. Burton, M. and Kagan, C. (2006). Decoding Valuing People. *Disability and Society*, [e-journal] 21(4), pp. 299–313. http://doi.org/10.1080/09687590600679899.

47. Büttner, G. and Hasselhorn, M. (2011). Learning disabilities: Debates on definitions, causes, subtypes, and responses. *International Journal of Disability, Development and Education,* 58(1), pp. 75-87. https://doi.org/10.1080/1034912X.2011.548476

48. *Care Act 2014.* Chapter 23, London: The Stationery Office.

49. Care Quality Commission (2017). *Local system reviews: Interim report.* [pdf] Available at: https://www.cqc.org.uk/sites/default/files/20171219_local_system_review_interim_report.pdf [Accessed on 2 May 2020].

50. *Care Standards Act, 2000.* Available at: http://www.legislation.gov.uk/ukpga/2000/14/contents [Accessed 28 October 2019].

51. Carulla, L. D. Reed G. M. Vaez-Azizi, L. M. Cooper, S. Leal, R. M. Bertelli, M. Adnams, C. Cooray, S. Deb, S. Dirani, L. A. Grimaji, S. C. Katz, G. Kwok, H. Luckasson, R. Simeonsson, R. Walsh, C. Munir, K. and Saxena, S. (2011). Intellectual developmental disorders: Towards a new name, definition and framework for 'mental retardation/intellectual disability' in ICD-11. *World Psychiatry,* 10(3), pp. 175-180. https://doi.org/10.1002/j.2051-5545.2011.tb00045.x

52. Cavendish, C. (2013). *The Cavendish Review: An independent review into healthcare assistants and support workers in the NHS and social care settings.* Department of Health. [pdf] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/236212/Cavendish_Review.pdf [Accessed 4 June 2016].

53. Chappell, A. L. (1992). Towards a sociological critique of the normalisation principle. *Disability, Handicap and Society,* 7, pp. 35-51.

54. Chappell, A. L. (1998). Still out in the cold people with learning disabilities and the social model of disability, in Shakespeare, T. (Ed.), *The Disability Reader: Social Science Perspectives*, pp. 211-20. London: Cassell.

55. Charmaz, K. (1983). The Grounded Theory Method: An explication and interpretation. In R. M. Emerson (Ed.), *Contemporary Field Research*, pp. 109–26. Boston: Little, Brown.

56. Charmaz, K. (1996). The search for meanings - Grounded Theory. In J. A. Smith, R. Harre, and L Van Langehove (Eds.), *Rethinking Methods in Psychology*, pp. 27-49. London: Sage Publications.

57. Charmaz, K. (2001). Grounded Theory. In R. M. Emerson (Ed.), *Contemporary Field Research: Perspectives and Formulations,* 2nd ed, pp. 335-52. Prospect Heights, IL: Waveland Press.

58. Charmaz, K. and Mitchell, R. G. (2001). An invitation to Grounded Theory in Ethnography. In P. A. Atkinson, A. Coffey, S. Delamonte, J. Lofland, and L. H. Lofland *Handbook of Ethnography*, pp. 160–174. London: Sage.

59. Charmaz, K. (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis.* London: Sage Publications.

60. Clarkson, R. Murphy, G. H. Coldwell, J. B. and Dawson, D. L. (2009). What characteristics do service users with intellectual disability value in direct support staff within residential forensic services? *Journal of Intellectual and Developmental Disability*, [e-journal] 34(4), pp. 283–289. http://doi.org/10.3109/13668250903285630

61. Clegg, J. (2003). The ideal proxy informant. *Ethics and Intellectual Disability*, [e-journal] 7(2), pp. 1–5.

62. Clifford, A. Standen, P. J. and Jones, J. (2018). 'I don't want to take any risks even If It's gonna mean this service-user is gonna be happier': A thematic analysis of community support staff perspectives on delivering transforming care. *Journal of Applied Research in Intellectual Disabilities,* 31(6), pp. 1209-1218. https://doi.org/10.1111/jar.12495

63. Cluley, V. (2018). From 'Learning disability to intellectual disability' - Perceptions of the increasing use of the term 'intellectual disability' in learning disability policy, research and practice. *British Journal of Learning Disabilities*, 46(1), pp. 24-32.

64. Coles, J. (2001). The social model of disability: What does it mean for practice in services for people with learning difficulties? *Disability & Society,* 16(4), pp. 501–510. http://doi.org/10.1080/09687590120059504

65. Collins, K. Gratton, C. Heneage, C. and Dagnan, D. (2017). 'Employed carers' empathy towards people with intellectual disabilities: The development of a new measure and some initial theory.' *Journal of Applied Research in Intellectual Disabilities*, 30(1), pp. 133-46. https://doi-org.ezp.lib.cam.ac.uk/10.1111/jar.12226

66. Competition and Markets Authority (2017). *Care homes market study final report.* [pdf] Available at: https://assets.publishing.service.gov.uk/media/5a1fdf30e5274a750b82533a/care-homes-market-study-final-report.pdf [Accessed 30 April 2020].

67. Cooke, G. and Muir, R. (2012). *The Relational State.* London: Institute for Public Policy Research.

68. Cooper, V. and Ward, C. (2011). Valuing People Now;/; and people with complex needs. *Tizard Learning Disability Review*, 16(2), pp. 39-43. https://doi.org/10.5042/tldr.2011.0167

69. Cummins, R. (1998). *Quality of life definition and terminology: A discussion document from the International Society for Quality of Life Studies*. The International Society for Quality of Life Studies.

70. Daly, M. and Lewis, J. (2000) 'The concept of social care and the analysis of contemporary welfare states.' *British Journal of Sociology*, 52(2), pp. 281–98. https://doi.org/10.1111/j.1468-4446.2000.00281.x

71. Dawkins, B. (2009). Valuing Tom: Will Valuing People now change the lives of people with profound and multiple learning disabilities? *Tizard Learning Disability Review, 14*(4), pp. 3-12. https://doi.org/10.1108/13595474200900032

72. Department of Health (1998). *Modernising social services: Promoting independence, improving protection, raising standards.* London: HMSO.

73. Department of Health (2001). *Valuing People: A new strategy for learning disability in the twenty-first century*. London: HMSO.

74. Department of Health (2006). *Our Health, Our Care, Our Say: A New Direction for Community Services*. London: HMSO.

75. Department of Health (2008). *Putting People First.* London: HMSO*.*

76. Department of Health (2008a). *Transforming adult social care. Local Authority Circular*. London, Crown.

77. Department of Health (2009). *Valuing People Now*. London HMSO*.*

78. Department of Health (2010). *A Vision for Adult Social Care: Capable communities and active citizens*. London HMSO.

79. Department of Health (2012). *Transforming Care: A national response to Winterbourne View Hospital Department of Health review*: *Final Report*. London, Department of Health.

80. Department of Health (2014). *The Adult Social Care Outcomes Framework 2015/16*. [pdf] Available at: https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-handbook-of-definitions [Accessed 3 March 2016].

81. Department of Health (2015). *Measures from the Adult Social Care Outcomes Framework: England 2014-15, Final Release*. Available at: https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof/archive/measures-from-the-adult-social-care-outcomes-framework-england---2014-15-final-release [Accessed 22 February 2018].

82. Department of Health (2017). *Liberating the NHS: No decision about me, without me - further consultation on proposals to secure shared decision-making.* [pdf] Available at: https://consultations.dh.gov.uk/choice/choice-future-proposals/supporting_documents/Choice%20consultation%20%20No%20decison%20about%20me%20without%20me.pdf [Accessed 18 February 2018].

83. Department of Health and Social Security (1971). *Better services for the mentally handicapped* (Cmnd 4683). London: HMSO.

84. Department for Work and Pensions (2010). *Disability Living Allowance Reform*, CM7984 [pdf] Available at: https://www.gov.uk/government/consultations/disability-living-allowance-reform [Accessed 20 November 2019].

85. Department for Work and Pensions (2012). *Disability Living Allowance Reform, Impact Assessmen*t, May 2012. [pdf] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/220176/dla-reform-wr2011-ia.pdf [Accessed 7 February 2020].

86. Devereux, J. Hastings, R. and Noone, S. (2009). Staff stress and burnout in intellectual disability services: Work stress theory and its application. *Journal of Applied Research in Intellectual Disabilities*, [e-journal] 22(6), pp. 561–573. http://doi.org/10.1111/j.1468-3148.2009.00509.x.

87. *Disability Discrimination Act 1995,* Chapter 50. London: The Stationery Office.

88. Disley, P. Hatton, C. and Dagnan, D. (2009). Applying equity theory to staff working with individuals with intellectual disabilities. *Journal of Intellectual and Developmental Disability*, [e-journal] 34(1), pp. 55–66. http://doi.org/10.1080/13668250802684701

89. Disley, P. Hatton, C. and Dagnan, D. (2012). Inputs and outcomes: What do staff in services for people with intellectual disabilities perceive they bring to and receive from their work-based relationships? *Journal of Intellectual Disabilities*, [e-journal] 16(4), pp. 297–306. http://doi.org/10.1177/1744629512466793.

90. Duffy, M. Armenia, A. Stacey, C. (2015). *Caring on the clock: The complexities and contradictions of paid care work.* New Jersey: Rutgers University Press.

91. Dunne, C. (2001). The place of the litearture review in Grounded Theory research. *International Journal of Social Research Methodology*, 14 (2), pp. 111-124.

92. Dunn, M. C. Clare, I. C. H. and Holland, A. J. (2010). Living 'a life like ours': Support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, [e-journal] 54(2), pp. 144–160. http://doi.org/10.1111/j.1365-2788.2009.01228.x.

93. Dwyer, P. and Wright, S. (2014). Universal Credit, ubiquitous conditionality and its implications for social citizenship. *Journal of Poverty and Social Justice*, 22(1), pp. 27-35. https://doi.org/10.1332/175982714X13875305151043

94. Ellis, J. W. (1992). Decisions by and for people with mental retardation: Balancing considerations of autonomy and protection. *Villanova Law Review,* 37 (6), pp. 1779-809.

95. Ellis, K. (2004). Dependency, justice and the ethics of care. In H. Dean (Ed.), *The ethics of welfare: Human rights, dependency, and responsibility*, pp. 29-48. Bristol: Policy Press

96. Emerson, E. Hatton, C. Robertson, J. Roberts, H. Baines, S. Evison, F. and Glover, G. (2011). People with learning disabilities in England 2011: Services and supports. [pdf] *Learning Disabilities Observatory.* Available at: https://www.improvinghealthandlives.org.uk/securefiles/161101_0608//IHAL2012-04PWLD2011.pdf [Accessed 1 March 2016].

97. *Equality Act, 2010.* c.15. London: The Stationery Office.

98. Fine, M. (2002). *Disruptive voices: The possibilities for feminist research.* University of Michigan Press.

99. Fine, M. (2005). Individualization, risk and the body: Sociology and care. *Journal of Sociology*, [e-journal] 41(3), pp. 247–266. http://doi.org/10.1177/1440783305057077.

100.   Finkelstein, V. (1980). *Attitudes and disabled people*. New York: Word Rehabilitation Fund.

101.   Finlay, W. M. L. Antaki, C. and Walton, C. (2008). Saying no to the staff: An analysis of refusals in a home for people with severe communication difficulties. *Sociology of Health and Illness*, [e-journal] 30(1), pp. 55–75. http://doi.org/10.1111/j.1467-9566.2007.01028.x

102.   Finlay, W. M. L. Walton, C. and Antaki, C. (2008b). Promoting choice and control in residential services for people with learning disabilities. *Disability and Society*, [e-journal] 23(4), pp. 349–360. http://doi.org/10.1080/09687590802038860.

103.   Flick, U. von Kardorff, E. and Steinke, I. (2004). *A companion to qualitative research*. London: Sage.

104.   Forbat, L. (2006). Valuing People: Hopes and dreams for the future. *British Journal of Learning Disabilities*, 34, pp. 20-27.

105.   Fyson, R. and Simons, K. (2003). Strategies for change: Making Valuing People a reality. *British Journal of Learning Disabilities*, 31(4), pp.153-58. https://doi.org/10.1111/j.1468-3156.2003.00251.x

106.   Gates, B. and Mafuba, K. (2016). Use of the term 'learning disabilities' in United Kingdom: Issues for international researchers and practitioners. *Learning Disabilities Contemporary Journal*, 14(2), pp. 9-23.

107.   Gawande, A. (2014). *Being mortal: Medicine and what matters in the end*. New York: Metropolitan Books, Henry Holt and Company.

108.   Geddes, R. J, Andreasen, N. C, and Goodwin, G. M. (2020). *New Oxford Textbook of Psychiatry*, Third Edition. Oxford University Press.

109.   Gill, K. (2019). *The social care system is in crisis. Here's how to fix it.* Trade Union Congress. Available at: https://www.tuc.org.uk/blogs/social-care-system-crisis-heres-how-fix-it [Accessed 30 April 2020].

110.   Gillies, A. Krishna, H. Osborne, S. Paterson, J. Toal, A. and Willis, M. (2017). *Universal Credit: What you need to know*. 4th Rev. ed. London: Child Poverty Action Group, [distributor] Central.

111.   Gillman M. Heyman B. and Swain J. (2000). What's in a name? The implications of diagnosis for people with learning difficulties and their family carers. *Disability and Society*, 15(3), pp. 389–409.

112.   Glaser, B. G. and Strauss, A. (1967). Discovery of Grounded Theory. Chicago, IL: Aldine

113.   Glaser, B. (1992). *Basics of Grounded Theory analysis.* Mill Valley, CA: Sociological Press.

114.   Glaser, B. (2001). Doing Grounded Theory. *Grounded Theory Review,* 2, pp. 1-18.

115.   Goble, C. (1998). 50 years of NHS involvement in the lives of people with learning difficulties: a cause for celebration? *Disability and Society*, 13, pp. 833-835.

116.   Golding, N. S. and Rose, J. (2015). Exploring the attitudes and knowledge of support workers towards individuals with intellectual disabilities. *Journal of Intellectual Disabilities*, 19(2), pp. 116-29.
https://doi-org.ezp.lib.cam.ac.uk/10.1177/1744629514563777

117.   Goodley, D. (2001). 'Learning Difficulties', the Social Model of Disability and Impairment: Challenging epistemologies. *Disability & Society*, 16(2), pp. 207-231
https://doi-org.ezp.lib.cam.ac.uk/10.1080/09687590120035816

118.   Grant, L. (2013). NHS North West, A Disability history timeline, The struggle for equal rights thorugh the ages. [pdf] Available at:
https://www.merseycare.nhs.uk/media/1749/disabiliyt-timeline-2013.pdf [Accessed 31 October 2019].

119.   Gray, P. (2014). An independent review of the Personal Independence Payment Assessment. London: HMSO.

120.   Gray, P. (2017). The Second Independent Review of the Personal Independence Payment Assessment. *Strategy Policy and Analysis Group*. [pdf] Available at:
https:// assets.publishing.service.gov.uk/government/uploads/system/uploads/ attachment_data/file/604097/pip-assessment-second-independent-review. pdf [Accessed 7 July 2019].

121.   Griffith, G. M. Hutchinson, L. and Hastings, R. P. (2013). 'I'm not a patient, I'm a person': The experiences of individuals with intellectual disabilities and challenging behavior – A thematic synthesis of qualitative studies. *Clinical Psychology: Science and Practice*, [e-journal] 20(4), pp. 469–488. http://doi.org/10.1111/cpsp.12053.

122.   Griffiths, R. (1988). *Community care: Agenda for action*. London: HMSO.

123.   Guba, E. G. and Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin and Y. S. Lincoln (Eds.), *Handbook of qualitative research,* pp. 105– 117. Thousand Oaks, CA: Sage.

124.   Guba, E. G. and Lincoln, Y. S. (2005). Paradigmatic controversies, Contradictions, and emerging confluences. In N. K. Denzin and Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research,* pp. 191-215. Thousand Oaks, CA: Sage.

125.   Haegele, J. A. and Hodge, S. (2016). Disability discourse: Overview and critiques of the medical and social models. *Quest*, 68(2), pp. 193-206.
http://doi.org/10.1080/00336297.2016.1143849

126.   Haigh, A. Lee, D. Shaw, C. Hawthorne, M. Chamberlain, S. Newman, D. W. Clarke, Z. and Beail, N. (2013). What things make people with a learning disability happy and satisfied with their lives: An inclusive research project. *Journal of Applied Research in Intellectual Disabilities*, [e-journal] 26(1), pp. 26–33. http://doi.org/10.1111/jar.12012

127.   Hale, J. Alfonso, V. Berninger, V. Bracken, B. Christo, C. Clark, E. Yalof, J. (2010). Critical issues in response-to-intervention, comprehensive evaluation, and specific learning disabilities identification and intervention: An expert white paper consensus. *Learning Disability Quarterly*, 33, pp. 223–236. http://doi.org/10.1177/073194871003300310

128.   Halliday, S. Potts, M. Howard, A. and Wright, J. (1992). Caring for people with severe learning difficulties in ordinary housing. *Journal of the British Institute of Mental Handicap*, (20), pp. 137-43.

129.   Halsey, A. H. and Webb, J. (2000). *Twentieth-Century British Social Trends* (3rd ed.). Basingstoke: Macmillan.

130.   Hammill, D. (1990). On defining learning disabilities: An emerging consensus, *Journal of Learning Disabilities*, 23(2), pp. 74-84. https://doi.org/10.1177/002221949002300201

131.   Harris, J. (2003). Time to make up your mind: Why choosing is difficult. *British Journal of Learning Disabilities*, [e-journal] 31(1), pp. 3–8. http://doi.org/10.1046/j.1468-3156.2003.00181.x.

132.   Harris, J. and White, V. (2013). *A Dictionary of Social Work and Social Care*, First Edition. Oxford University Press.

133.   Harris, J. and White, V. (2018). Deprivation of Liberty Safeguards. *A Dictionary of Social Work and Social Care,* Second Edition. Oxford University Press.

134.   Harris, P. (1995). Who am I? Concepts of disbality and their implications for people with learning difficulties. *Disability and Society*, 10, pp. 341-351.

135.   Hartley, D. (2012). The ethical deficit of the United Kingdom's proposed Universal Credit: Pimping the precariat? Political Quarterly, 83(2), pp. 353-59. https://doi-org.ezp.lib.cam.ac.uk/10.1111/j.1467-923X.2012.02292.x

136.   Hastings, R. and Horne, S. (2004). Positive perceptions held by support staff in community mental retardation services. *American Journal on Mental Retardation*, [e-journal] 109(1), pp. 53. http://doi.org/10.1352/0895-8017(2004)109<53:PPHBSS>2.0.CO;2.

137.   Hastings, R. (2010). Support staff working in intellectual disability services: The importance of relationships and positive experiences. *Journal of Intellectual and Developmental Disability*, [e-journal] 35(3), pp. 207–210. http://doi.org/10.3109/13668250.2010.492710.

138. Hatton, C. Brown, R. Caine, A. and Emerson, E. (1995). Stressors, coping strategies and stress-related outcomes amongst direct-care staff in staffed houses for people with learning difficulties. *Mental Handicap Research*, 8, pp. 252-271.

139. Hatton, C. and Emerson, E. (1998). Brief Report: Organisational predictors of actual staff turnover in a service for people with multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, 11(2) pp. 66-71. https://doi.org/10.1111/j.1468-3148.1998.tb00058.x

140. Hatton, C., Emerson. E, Rivers. M, Mason. H, Mason. L, Swarbrick. R, Kiernan, C. Reeves. D and Alborz, A. (1999). Staff stressors and staff outcomes in services for adults with intellectual disabilities: The staff stressor questionnaire. *Research in Developmental Disabilities*, 20(4), pp. 269–285.

141. Hatton, C. Emerson. E, Rivers. M, Mason. H, Mason. L, Swarbrick. R, Kiernan, C. Reeves. D and Alborz, A. (1999b). Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research*, 43(4), pp. 253-267. http://doi.org/10.1046/j.1365-2788.1999.00208.x

142. *Health and Social Care Act 2012,* Available at: http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted [Accessed 17 February 2018].

143. Hensel, E. (2001). Is satisfaction a valid concept in the assessment of quality of life of people with intellectual disabilities? A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 14(4), pp. 311–326.

144. Hensel, J. M. Lunsky, Y. and Dewa, C. S. (2012). Exposure to client aggression and burnout among community staff who support adults with intellectual disabilities in Ontario, Cana*da. Journal of Intellectual Disability Research*, (56), pp. 910–915.

145. Hollomotz, A. (2004). Are we *valuing people's* choices *now*? Restrictions to mundane choices made by adults with learning difficulties. *The British Journal of Social Work*, 44(2), pp. 234–251, https://doi.org/10.1093/bjsw/bcs119

146. Holstein, J. A. and Gubrium, J. F. (2003). Qualitative interviewing and grounded theory analysis. *Inside interviewing*, pp. 310-330. SAGE. http://doi.org 10.4135/9781412984492.n15

147. Hughes, B. and Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability and Society*, 12, pp. 325–40.

148. Hughes, B. McKie, L. Hopkins, D. and Watson, M. (2005). Love's labours lost? Feminism, the Disabled People's Movement and an ethic of care. *Sociology*, 39, pp. 259-275.

149.   Hughes, R. (2012). The Future (of the future) adult social care workforce – key issues for leaders. *International Journal of Leadership in Public Services*, [e-journal] 8(2), pp. 90–98. http://doi.org/10.1108/17479881211260463

150.   Hughes, R. Redley, M. and Ring, H. (2011). Friendship and adults with profound intellectual and multiple disabilities and English disability policy. *Journal of Policy and Practice in Intellectual Disabilities*, [e-journal] 8(3), pp.197–206. https://doi.org/10.1111/j.1741-1130.2011.00310.x

151.   Humphrys, E. (2018). *Understanding the pathways to oesophageal and stomach cancer diagnosis: a multi-methods approach.* https://doi.org/10.17863/CAM.36645

152.   Hutchison, A. Kroese, S. B. (2015). A review of literature exploring the possible causes of abuse and neglect in residential care. *The Journal of Adult Protection*, 17(4), pp. 216-233.

153.   Hutchison, A. and Kroese. B. S. (2016). Making sense of varying standards of care: The experiences of staff working in residential care environments for adults with learning disabilities. *British Journal of Learning Disabilities*, 44(3), pp. 182-93. https://doi.org/10.1111/bld.12136

154.   Independent Living Strategy Group (2015). *Promoting people's right to choice and control under the Care Act 2014*. Birmingham: In Control.

155.   Ismail, S. Thorlby, R. Holder, H. (2014). *Quality Watch focus on: Social care for older people*. The Health Foundation and Nuffield Trust. [pdf] Available at: https://www.nuffieldtrust.org.uk/files/2018-10/qualitywatch-social-care-older-people.pdf [Accessed 19 March 2018]

156.   Jarrett, T. (2019). *Four Seasons Healthcare Group – financial difficulties and safeguards for clients.* Commons Briefing Papers CBP-8004 (2019). House of Commons Library. Available at: https://commonslibrary.parliament.uk/research-briefings/cbp-8004/ [Accessed 2 May 2020].

157.   Jingree, T. Finlay, W. M. L. and Antaki, C. (2006). Empowering words, disempowering actions: An analysis of interactions between staff members and people with learning disabilities in residents' meetings. *Journal of Intellectual Disability Research*, [e-journal] 50(3), pp. 212–226. http://doi.org/10.1111/j.1365-2788.2005.00771.x.

158.   Jingree, T. and Finlay, W. M. L. (2008). You can't do it… it's theory rather than practice: Staff use of the practice/principle rhetorical device in talk on empowering people with learning disabilities. *Discourse and Society*, 19, pp. 705-726.

159.	Jingree, T. (2015). Duty of care, safety, normalisation and the Mental Capacity Act: A discourse analysis of staff arguments about facilitating choices for people with learning disabilities in UK services. *Journal of Community and Applied Social Psychology*, 25(2), pp. 138-52. https://doi-org.ezp.lib.cam.ac.uk/10.1002/casp.2202

160.	Johnson, E. K. (2015). The business of care: The moral labour of care workers. *Sociology of Health and Illness,* [e-journal] 37(1), pp. 112–126. http://doi.org/10.1111/1467-9566.12184

161.	Johnson, K. Walmsley, J. and Wolfe, M. (2010). People with intellectual disabilities: Towards a good life? Bristol: Policy Press, University of Bristol.

162.	Jones, A. Wilson, W. Jarrett, T. Kenndy, S. Powell, A. (2017). *The UN Inquiry into the Rights of Persons with Disabilities in the UK.* House of Commons Library Briefing Paper no. 736. London: House of Commons Library. Available at: https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7367#fullreport [Accessed 1 October 2019].

163.	Kattari, S. K. Lavery, A. and Hasche, L. (2017). Applying a social model of disability across the life span, *Journal of Human Behavior in the Social Environment*, 27(8), pp. 865-880. http://doi.org/10.1080/10911359.2017.1344175

164.	Kennedy, S. (2011). Disability Living Allowance reform. *Commons Briefing papers* SN05869. House of Commons.

165.	The King's Fund, (2006). *Briefing: Our Health, Our Care, Our Say.*

166.	The King's Fund, (2008). *Briefing: Mental Health Act 2007*

167.	The King's Fund, (2013). *How is the health and social care system performing? Quarterly Monitoring Report,* Feburary. [pdf] Available at: https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/quarterly-monitoring-report-feb2013.pdf [Accessed 11 August 2016].

168.	Kingsmill, D. (2014). *The Kingsmill Review: Taking Care, an independent review into working conditions in the care sector*. [pdf] Available at: https://www.policyforum.labour.org.uk/uploads/editor/files/The_Kingsmill_Review_-_Taking_Care_-_Final_2.pdf [Accessed 21 February 2020].

169.	Kittay, E. (2001). When caring is just and justice is caring: Justice and mental retardation. *Public Culture*, 13(3), pp. 557–579.

170.	Kittay, E. (2005). *At the margins of moral personhood*. I, [e-journal] 116(1), pp. 100–131. http://doi.org/10.1086/454366

171.	Kittay, E. (2011). The ethics of care, dependency, and disability. *Ratio Juris*, [e-journal] 24(1), pp. 49–58. http://doi.org/10.1111/j.1467-9337.2010.00473.x.

172.	Kratz, C. (2013). Research findings. *Nursing Times,* 80(18), pp. 21.

173. Kwok, T. and I. R. Hastie. (1995). Community Care Act. *Postgraduate Medical Journal*, 71(835) pp. 259-60.

174. Levitt, J. M. (2017). Exploring how the social model of disability can be re-invigorated: in response to Mike Oliver. *Disability and Society*, 32(4), pp. 589-594. http://doi.org/ 10.1080/09687599.2017.1300390

175. Lewis-Beck, M. S. Bryman, A. and Futing Liao, T. (2004). *The SAGE encyclopaedia of social science research methods.* Thousand Oaks, CA: Sage Publications, Inc. http://doi.org/10.4135/9781412950589

176. Leyin, A. (2010). Learning disability classification: Time for re-appraisal? *Tizard Learning Disability Review*, 15(2), pp. 33-44.

177. Lincoln, Y. S. and Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills: Sage.

178. Lincoln, Y. S. and Guba, E. (1986), 'But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New directions for program evaluation*, No. 30, pp. 73-84. https://doi.org/10.1002/ev.1427

179. Lord Chancellor (2008). *Deprivation of Liberty Safeguards: Code of practice to supplement the main Mental Capacity Act (2005).* London: HMSO.

180. Machin, R. (2017). Made to measure? An analysis of the transition from Disability Living Allowance to Personal Independence Payment. *Journal of Social Welfare and Family Law*, 39(4), pp. 435-453. https://doi.org/10.1080/09649069.2017.1390291

181. Maguire, M. and Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *The All Ireland Journal of Teaching and Learning in Higher Education*, 9(3), pp. 3351-33514. Available at: https://ojs.aishe.org/index.php/aishe-j/article/view/335 [Accessed 25 July 2019].

182. Mackridge, K. (2019). *Three ways to solve the social care crisis*. Trade Union Congress. Available at: https://www.tuc.org.uk/blogs/three-ways-solve-social-care-crisis [Accessed 1 May 2020].

183. Makowiecki, B. (2015). Great Britain's Welfare Reform Act of 2012 - Implementation overview, preliminary impact, and future Implications. *International Lawyer*, 48(3), pp. 243-269.

184. *Manion*, M. and *Bersani*, H. *(*1987*).* Mental retardation as a western sociological construct: a cross-cultural analysis. Disability, *Handicap and Society*, 2(3), pp. 231-46.

185. Mansell, J. Elliott, T. Beadle-Brown, J. Ashman, B. and Macdonald, S. (2002). Engagement in meaningful activity and 'active support' of people with intellectual disabilities in residential care. *Research in Developmental Disabilities,* 23, pp. 342-352.

186. Mansell, J. (2010). Raising our sights: Services for adults with profound intellectual and multiple disabilities. *Tizard Learning Disability Review*, [e-journal] 15(3), pp. 5–12. http://doi.org/10.5042/tldr.2010.0399.

187.   Mansell, J. and Beadle-Brown, J. (2010). Deinstitutionalisation and community living: Position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *Journal of Intellectual Disability Research,* 54(2) pp. 104-112.

188.   Mansell, J. (2011). Fulfilling the promise of better lives. *Tizard Learning Disability Review*, [e-journal] 16(1), pp. 2–4. http://doi.org/10.5042/tldr.2011.0001.

189.   Meldgaard H. A. (2016). Rehabilitative bodywork: Cleaning up the dirty work of homecare. *Sociology of Health and Illness*, 38(7), pp. 1092–1105.

190.   Mencap (2007). *Death by indifference.* [pdf] Available at: https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf [Accessed 25 February 2020].

191.   Mencap (2012). *Stuck at home*: The impact of day service cuts on people with a learning disability. London: Mencap. [pdf] Available at: https://www.mencap.org.uk/sites/default/files/2016-08/Stuck_at_home.pdf [Accessed 27 February 2018].

192.   *Mental Capacity Act 2005.* Chapter 9, London: The Stationery Office.

193.   Meyer, J. W. and Rowan, B. (1977). Institutionalized organizations: Formal structure as myth and ceremony. *The American Journal of Sociology*, 83(2), pp. 340–363.

194.   Millar, J. and Bennett, F. (2017). Universal Credit: Assumptions, contradictions and virtual reality. *Social Policy and Society*, 16(2), pp. 169-82. https://doi-org.ezp.lib.cam.ac.uk/10.1017/S1474746416000154

195.   Moher, D. Liberati, A. Tetzlaff, J. and Altman, D. G. The PRISMA Group. (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.* PLoS Med, 6(7). http://doi.org/10.1371/journal.pmed.1000097

196.   Mol, A. (2006). *The Logic of care: Health and the problem of patient choice*. London: Routledge.

197.   Morse, J. (2010). Procedures and practice of mixed method design: maintaining control, rigor, and complexity. In Tashakkori, A. and Teddlie, C. *SAGE handbook of mixed methods in social and behavioral research,* pp. 339-352. Thousand Oaks, CA: SAGE. http://doi.org/10.4135/9781506335193

198.   Muir, R. and Parker, I. (2014). Many to many: How the relational state will transform public services. *Institute of Public Policy Research*. [pdf] Available at: http://www.ippr.org/images/media/files/publication/2014/02/Many-to-many_Feb2014_11865.pdf [Accessed 2 March 2016].

199.   National Audit Office. (2013). *Universal Credit: Early progress*, London: HMSO.

200. National Audit Office. (2017). *Health and social care integration.* (HC 1011 2016-17). London: The Stationery Office. [pdf] Available at: https://www.nao.org.uk/wp-content/uploads/2017/02/Health-and-social-care-integration.pdf [Accessed 2 May 2020].

201. National Audit Office. (2018a). *The adult social care workforce in England.* (HC: 714, 2017-19). London: HMSO. Available at: https://www.nao.org.uk/report/the-adult-social-care-workforce-in-england/ [Accessed 1 May 2020].

202. National Audit Office. (2018b). *The financial sustainability of local authorities 2018*. (HC: 834, 2017-190). London: HMSO. Available at: https://www.nao.org.uk/report/financial-sustainability-of-local-authorities-2018/ [Accessed 1 May 2020].

203. National Audit Office. (2018c). *The adult social care workforce in England.* Press Release. Available at: https://www.nao.org.uk/press-release/the-adult-social-care-workforce-in-england/ [Accessed 1 May 2020].

204. *National Health Service and Community Care Act. (1990).* London. HMSO.

205. National Institute for Health and Care Excellence. (2014). *Managing medicines in care homes, Social care guidelines [SC1].* Available at: https://www.nice.org.uk/guidance/sc1/chapter/1-recommendations?utm_medium=(other)&utm_source=socialcare&utm_campaign=tpresource [Accessed 21 February 2020].

206. Nazarko, L. (2001). A new broom: The Care Standards Act. *Nursing Management*, 7(8), pp. 6-9.

207. Needham, C. (2012). *What is happening to day centre services? Voices from frontline staff.* University of Birmingham. [pdf] Available at: https://www.birmingham.ac.uk/Documents/college-social-sciences/social-policy/HSMC/publications/2012/what-is-happening-to-day-centre-services-Unison-report.pdf [Accessed 27 February 2018].

208. Netten, A. (2011). Overview of outcome measurement for adults using social care services and support. *SSCR Methods Review*, 6. London: London School of Economics.

209. Neimeijer, A. and Visse, M. (2016). Challenging standard concepts of 'Humane' care through relational auto-ethnography, *Social Inclusion*, 4(4), pp. 168-175 http://doi.org/10.17645/si.v4i4.704

210. Nirje, B. (1985). The basis and logic of the normalization principle. *Australia and New Zealand Journal of Developmental Disabilities*, 11(2), pp. 65-68. http://doi.org/10.3109/13668258509008747

211.   Nonnemacher, S. L. and Bambara, L. M. (2011). 'I'm supposed to be in charge': Self-advocates' perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities*, [e-journal] 49(5), pp. 327–340. http://doi.org/10.1352/1934-9556-49.5.327

212.   Northway, R. and Jenkins, R. (2003). Quality of life as a concept for developing learning disability nursing practice. *Journal of Clinical Nursing*, [e-journal] 12(1), pp. 57–66. https://doi.org/10.1046/j.1365-2702.2003.00697.x

213.   Nussbaum, M. and Sen, A. (1993). *The quality of life*. Oxford: Oxford University Press.

214.   Office for Disability Issues, HM Government. (2011). *UK Initial Report on the UN Convention on the Rights of Persons with Disabilities.* [pdf] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/345120/uk-initial-report.pdf [Accessed 10 October 2019].

215.   Office for National Statistics. (2019). *What are the vacancy trends in the public sector?* Available at: https://www.ons.gov.uk/economy/governmentpublicsectorandtaxes/publicspending/articles/whatarethevacancytrendsinthepublicsector/2019-08-06#adult-social-care-employee-numbers-and-vacancy-rates-have-both-increased-since-2013 [Accessed on 21 February 2020].

216.   Oliver, M. (1990). *The politics of disablement.* Basingstoke, UK: MacMillan.

217.   Oliver, M. (1996). *Understanding disability: From theory to practice*. Basingstoke, UK: Macmillan.

218.   Oliver, M. (1998). Theories in Health Care and Research: Theories of Disability in Health Practice and Research. *British Medical Journal, 317*(7170), pp. 1446-1449. Available at: www.jstor.org/stable/25181063 [Accessed on 13 June 2020]

219.   Oliver, M. (2013). 'The Social Model of Disability: Thirty Years on.' *Disability and Society*, 28(7), pp. 1024– 1026.

220.   Owens, J. (2015). Exploring the critiques of the social model of disability: The transformative possibility of Arendt's notion of power. *Sociology of Health and Illness*, 37 (3), pp. 385 - 403. https://doi.org/10.1111/1467-9566.12199

221.   P v Cheshire West and Chester Council; P and Q v Surrey County Council [2014] UKSC 19

222.   Parrott, R. (2013). Promoting independence, preventing dependency. *Tizard Learning Disability Review*, [e-journal] 18(4), pp. 161–170. http://doi.org/10.1108/TLDR-02-2013-0017.

223.   Patel, D. R. Apple, R. Kanungo, S. and Akkal, A. (2018). Intellectual disability: definitions, evaluation and principles of treatment. *Paediatric Medicine*, 1(11). http://doi.org/10.21037/pm.2018.12.02

224.   Patrick, R. (2011). The wrong prescription, disabled people and welfare conditionality, *Policy and Politics,* 39(2), pp. 275–91. https://doi-org.ezp.lib.cam.ac.uk/10.1332/147084411X574572

225.   Pennycook, M. (2013). *Does it pay to care? Under-payment of the national minimum wage in the social care sector*. London: Resolution Foundation.

226.   Petner-Arrey, J. and Copeland, S. R. (2015). 'You have to care.' Perceptions of promoting autonomy in support settings for adults with intellectual disability. *British Journal of Learning Disabilities*, [e-journal] 43(1), pp. 38–48. http://doi.org/10.1111/bld.12084

227.   Pybus, K. Pickett, K. Prady, D. Lloyd, C. and Wilkinson, R. (2019). Discrediting experiences: Outcomes of eligibility assessments for claimants with psychiatric compared with non-psychiatric conditions transferring to Personal Independence Payments in England. *BJPsych Open* 5(2): E19.

228.   Raczka, R. (2005). A focus group enquiry into stress experienced by staff working with people with challenging behaviours. *Journal of Intellectual Disabilities*, (9), pp. 167-77.

229.   Rainbird, H. Leeson, W. and Munro, E. (2011). Is regulation good for skill development? Mediating actors and workplace practice in adult social care in England. *The International Journal of Human Resource Management*, 22(18), pp. 3727-3741. http://doi.org/10.1080/09585192.2011.622921

230.   Ravaud, J. and Striker, H. (2001). Inclusion/Exclusion: An analysis of historical and cultural meanings. In Albrecht, G. Sellman, K. and Burry, M. (Eds.), *Handbook of Disability Studies*. London: SAGE.

231.   Redley, M. (2009). Understanding the social exclusion and stalled welfare of citizens with learning disabilities. *Disability and Society*, [e-journal] 24(4), pp. 489–501. http://doi.org/10.1080/09687590902879122.

232.   Redley, M. and Weinberg, D. (2007). Learning disability and the limits of liberal citizenship: Interactional impediments to political empowerment. *Sociology of Health and Illness*, 29, pp. 767–786. https://doi:10.1111/j.1467-9566.2007.01015.x

233.   Redley, M. (2018). Full and Equal Equality. *Tizard Learning Disability Review*, 23(2), pp. 72-77. https://doi.org/10.1108/TLDR-11-2017-0044

234. Reinders, J. S. (2002). The Good life for citizens with intellectual disability. *Journal of Intellectual Disability Research*, 46(1), pp. 1–5. http://doi.org/10.1046/j.1365-2788.2002.00386.x

235. Richards, B. and Williamson, L. (2015). Supporting innovation in the UK: Care Act 2014. *Bioethical Inquiry,* 12: pp. 183-187. https://doi-org.ezp.lib.cam.ac.uk/10.1007/s11673-015-9637-5

236. Ritchie, J. Lewis, J. McNaughton Nicholls, C. Ormston, R. (2014). *Qualitative research practice. A guide for social science students and researchers*: SAGE. pp. 30-37.

237. Robertson, J. Emerson, E. Hatton, C. Elliott, J. McIntosh, B. Swift, P. Krijnen-Kemp, E. Towers, C. Romeo, R. Knapp, M. Sanderson, S. Routledge, M. Oakes, M. and Joyce, T. (2005) *The impact of person centred planning*. Lancaster: Institute for Health Research, Lancaster University.

238. Robson, C. (2011). *Real world research*, Third Edition. West Sussex, UK: Wiley.

239. Roller, M. R. and Lavrakas, P. J. (2015). *Applied qualitative research design : A total quality framework approach*. New York: Guildford Publications.

240. Rose, J. (1999). Stress and staff in residential settings: The move from hospital to community. *Mental Handicap Research*, 6, pp. 312-332.

241. Roulstone, A. (2015). Personal Independence Payments, welfare reform and the shrinking disability category. *Disability and Society*, 30(5), pp. 673-88.

242. Royston, S. (2012). Understanding Universal Credit. *The Journal of Poverty and Social Justice*, 20(1), pp. 69-86. http://doi.org/10.1332/175982712X626789

243. Rubery, J. Grimshaw, D. and Hebson, G. (2013). Exploring the limits to local authority social care commissioning: Competing pressures, variable practices, and unresponsive providers. *Public Administration*, [e-journal] 91(2), pp. 419–437. http://doi.org/10.1111/j.1467-9299.2012.02066.x.

244. Saldana, J. (2009). *The coding manual for qualitative researchers*. London: Sage

245. Sale, J, and Brazil, K. A. (2004). A strategy to identify critical appraisal criteria for primary mixed-method studies. *Quality and Quantity*, 38(4), pp. 351-65. https://doi-org.ezp.lib.cam.ac.uk/10.1023/B:QUQU.0000043126.25329.85

246. Scales, K. Bailey, S. Middleton, J. Schneider, J. (2017). Power, empowerment, and person-centred care: using ethnography to examine the everyday practice of unregistered dementia care staff. *Sociology of Health and Illness*, 39(2), pp. 227–243.

247. Scanlon, D. (2013). Specific learning disability and Its newest definition: Which Is comprehensive? and which Is insufficient? *Journal of Learning Disabilities*, 46(1), pp. 26-33. http://doi.org/10.1177/0022219412464342

248.   Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, [e-journal] 48(3), pp. 203–216. http://doi.org/10.1111/j.1365-2788.2003.00558.x

249.   Scourfield, P. (2005). Implementing the Community Care (Direct Payments) Act: Will the supply of personal assistants meet the demand and at what price? *Journal of Social Policy*, 34 (3), pp. 469–488. Cambridge University Press. http://doi.org/10.1017/S0047279405008871

250.   Scull, A. (1984). *Decarceration: Community treatment and the deviant - a radical view*. Cambridge: Polity Press.

251.   Select Committee on the Mental Capacity Act 2005, House of Lords. (2014). '*Mental Capacity Act 2005: Post-Legislative Scrutiny.*' HL Paper 139. [pdf] Available at: http://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf [Accessed 11 November 2019].

252.   Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.

253.   Shakespeare, T. (2013). *Disability rights and wrongs revisited*. London: Routledge.

254.   Shakespeare, T. and Watson N. (1997). Defending the Social Model. *Disability & Society*, 12(2), pp. 293-300. https://doi.org/10.1080/09687599727380

255.   Shakespeare, T. and Watson N. (2001). The Social model of disability: An outdated ideology? In S. Barnett and B. Altman (Eds.), *Exploring Theories and Expanding Methodologies: where are we and where do we need to go?* Oxford: Elsevier Science.

256.   Siegel, L. (1999). Issues in the definition and diagnosis of learning disabilities: A perspective on Guckenberger v. Boston University. *Journal of Learning Disabilities*, 32(4), pp. 304-319.

257.   Silverman, D (Ed). (2000). *Doing qualitative research: a practical handbook.* London: SAGE.

258.   Silverman, D. (2001). *Interpreting qualitative data*. London: SAGE.

259.   Simpson, G. and Price, V. (2010). From inclusion to exclusion: Some unintended consequences of Valuing People. *British Journal of Learning Disabilities*, 38(3), pp. 180-86. https://doi.org/10.1111/j.1468-3156.2009.00572.x

260.   Skills for Care, (2017). *The state of the adult social care sector and workforce in England.* Skills for Care. [pdf] Available at: http://www.skillsforcare.org.uk/Documents/NMDS-SC-and-intelligence/NMDS-SC/Analysis-pages/State-of-17/State-of-the-adult-social-care-sector-and-workforce-2017.pdf [Accessed 19 March 2018].

261. Skills for Care, (2019). *The state of the adult social care sector and workforce in England.* Skills for Care. [pdf] Available at: https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/State-of-Report-2019.pdf [Accessed 20 February 2020].

262. Skills for Care, (2019b). *The size and structure of the adult social care sector and workforce in England.* Skills for Care. [pdf] Available at: https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/Size-of-the-adult-social-care-sector/Size-and-Structure-2019.pdf [Accessed 20 February 2020].

263. Slack, R. (1999). Modernising social services. *Public Health*, 113, pp. 1.

264. Slasberg, C. and Beresford, P. (2014). Government guidance for the Care Act: Undermining ambitions for change?, *Disability and Society,* 29(10), pp. 1677-1682. https://doi.org /10.1080/09687599.2014.954785

265. Smyth, C. M. and Bell, D. (2006) 'From biscuits to boyfriends: The ramifications of choice for people with learning disabilities.' *British Journal of Learning Disabilities*, 34(4), pp. 227-36. https://doi.org/10.1016/j.ridd.2015.09.023

266. Smyth, E. Healy, O. and Lydon, S. (2015). An analysis of stress, burnout, and work commitment among disability support staff in the UK. *Research in Developmental Disabilities*, 47(C), pp. 297-305.

267. Stacey, C. L. (2005). Finding dignity in dirty work: the constraints and rewards of low-wage home care labour. *Sociology of Health and Illness*, 27(6), pp. 831-854.

268. Steuer, N. and Marks, N. (2008). *Local wellbeing: Can we measure it?* The Young Foundation. [pdf] Available at: https://youngfoundation.org/wp-content/uploads/2013/02/Local-Wellbeing-Can-we-Measure-it-September-2008.pdf [Accessed 3 March 2016].

269. Stirton, R. (2017), The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: A Litany of Fundamental Flaws? *The Modern Law Review*, 80, pp. 299-324. https://doi:10.1111/1468-2230.12255

270. Sunstein, B. S. and Chiseri-Strater, E. (2012). *Fieldworking: reading and writing research*, Fourth Edition. Boston: Bedford/St. Martin's.

271. Sutcliffe, J. and Simons, K. (1993). *Self-advocacy and people with learning difficulties.* Leicester: MACE.

272. Sutherland, A. (1981). *Disabled we stand.* London: Souvenir Press.

273. Swain, J. and Cook, T. (2001). In the name of inclusion: 'We all, at the end of the day, have the needs of children at heart'. *Critical Social Policy*, 21, pp. 185-207.

274. Swain, J. and French, S. (2000). Towards an affirmation model of disability. *Disability and Society*, 15(4), pp. 569-582. https://doi.org/10.1080/09687590050058189

275.   Swain, J. French, S. and Caomeron, C. (2003). *Controvertial issues in an disabling society.* Philadelphia: Open Univeristy Press.

276.   Switzky, H. N. Greenspan, S. (2006). *What is mental retardation? Ideas for an evolving disability in the 21ˢᵗ Century*. Washington: American Association on Intellectual and Developmental Disabilities.

277.   Tannock, R. (2013). Rethinking ADHD and LD in DSM-5: Proposed changes in diagnostic criteria. *Journal of Learning Disabilities*, 46(1), pp. 5–25. https://doi.org/10.1177/0022219412464341

278.   Teddlie, C. and Tashakkori, A. (2010). Overview of contemporary issues in mixed methods research. In Tashakkori, A., and Teddlie, C. *SAGE handbook of mixed methods in social and behavioral research,* pp. 1-42. Thousand Oaks, CA: SAGE. https://doi.org/10.4135/9781506335193

279.   Thane, P. (2009). *Memorandum submitted to the House of Commons' Health Committee Inquiry*: Social Care. October 2009. [pdf] Available at: http://www.historyandpolicy.org/docs/thane_social_care.pdf [Accessed 25 April 2018].

280.   Thomas, C. (1999). *Female forms: Experiencing and understanding disability.* Buckingham: Open University Press.

281.   Thomas, C. (2004). Developing the social relational in the social model of disability: a theoretical agenda. In Barnes, C. and Mercer, G. *Implementing the social model of disability: theory and research*, pp. 32-47. Leeds: The Disability Press.

282.   Thomas, C. and Rose, J. (2010). The relationship between reciprocity and the emotional and behavioural responses of staff. *Journal of Applied Research in Intellectual Disabilities*, [e-journal] 23(2), pp. 167–178. http://doi.org/10.1111/j.1468-3148.2009.00524.x.

283.   Thorlby, R. Starling, A. Broadbent, C. and Watt, T. (2018). *What's the problem with social care, and why do we need to do it better?* The Health Foundation, The Institute for Fiscal Studies, The King's Fund and The Nuffield Trust. [pdf] Available at: https://www.health.org.uk/sites/default/files/NHS-70-What-Can-We-Do-About-Social-Care.pdf [Accessed 30 April 2020].

284.   Thornicroft, G. (1994). The NHS and Community Care Act, 1990: Recent government policy and legislation. Psychiatric Bulletin, 18(1), pp. 13-17. https://doi.org/10.1192/pb.18.1.13

285.   Timmins, N. (2012). *Never Again? The story of the Health and Social Care Act 2012.* London: The King's Fund and the Institute for Government.

286.   Towell, D. (1988). *An ordinary life in practice: Developing comprehensive community-based services for people with learning disabilities*. London: The King's Fund.

287. Toynbee, P. (2015). *'How the care crisis is making old age a nightmare'.* Guardian, 2 September. Available at: https://www.theguardian.com/society/2015/sep/02/how-care-crisis-making-old-age-nightmare [Accessed 30 August 2016].

288. Tracey, P. and Phillips, N. (2016). Managing the consequences of organizational stigmatization: Identity work in a social enterprise. *Academy of Management Journal*, [e-journal] 59(3), pp. 740–765. http://doi.org/10.5465/amj.2013.0483.

289. Tregaskis, C. (2002). Social model theory: The story so far, *Disability and Society*, 17 (4), pp. 457-470. http://doi.org/10.1080/09687590220140377

290. Tronto, J. C. (1994). *Moral boundaries: A political argument for an ethic of care.* London: Routledge Press.

291. Ogston-Tuck, S. Baume, K. Clarke, K. and Ung, S. (2016). Understanding the patient experience through the power of film: A mixed method qualitative research study. *Nurse Education Today*, (46), pp. 69-74. https://doi.org/10.1016/j.nedt.2016.08.025

292. UK Government (2019). *Queen's* Speech, *December 2019.* [pdf] Available At: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/853886/Queen_s_Speech_December_2019_-_background_briefing_notes.pdf [Accessed 2 May 2020].

293. *United Nations Convention on the Rights of Persons with Disabilities.* (2006).

294. *United Nations Committee on the Rights of Persons with Disabilities. Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland.* (2017). Available at: https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhspCUnZhK1jU66fLQJyHIkqMIT3RDaLiqzhH8tVNxhro6S657eVNwuqlzu0xvsQUehREyYEQD%2BldQaLP31QDpRcmG35KYFtgGyAN%2BaB7cyky7 [Accessed 10 October 2019].

295. UPIAS. (1976). *Fundamental Principles of Disability*. Union of the Physically Impaired against Segregation.

296. Vlaskamp, C. (2009). Valuing Tom: Will Valuing People now change the lives of people with profound and multiple learning disabilities? *Tizard Learning Disability Review*, 14(4), pp. 13-16.

297. Wacquant, L. (2009). The body, the ghetto and the penal state. *Qualitative Sociology,* 32, pp. 101-129. https://doi.org/10.1007/s11133-008-9112-2.

298. Walker, D. and Myrick, F. (2006). Grounded Theory: An exploration of process and procedure. *Qualitative Health Research*, 16(4), pp. 547–559.

299.   Wanless, D. (2006). *Securing good care for older people: Taking a long-term view.* The King's Fund. [pdf] Available at: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/securing-good-care-for-older-people-wanless-2006.pdf [Accessed 27 May 2018].

300.   Ward, D. (2019). *Average pay for care workers: Is it a supermarket sweep?* The King's Fund. Available at: https://www.kingsfund.org.uk/blog/2019/08/average-pay-for-care-workers [Accessed 20 February 2020].

301.   Warren, S. (2019). *Social care reform, more haste, less speed*, The King's Fund. Available at: https://www.kingsfund.org.uk/blog/2019/07/social-care-funding-reform [Accessed 30 April 2020].

302.   *Welfare Reform Act (2012). C.5.* London: HMSO

303.   Welshman, J. and Walmsley, J. (2006). *Community care in perpsective: Care, control and citizenship.* Hampshire: Palgrave Macmillan.

304.   Whittington, C. Whittington, M. Quinn, A. and Thomas, J. (2009). *Key Policy and legislation with implications for interprofessional and inter-agency collaboration (IPIAC): A timeline of examples 1968-2008.* Available at: https://www.scie.org.uk/assets/elearning/ipiac/ipiac01/resource/text/content/keyPolicy/keyPolicy.htm [Accessed 31 October 2019].

305.   Williams, F. (2001). In and beyond New Labour: Towards a new political ethics of care. *Critical Social Policy,* 21, pp. 467-493.

306.   Williams, J. (2005). Achieving meaningful inclusion for people with profound and multiple learning disabilities. *Tizard Learning Disability Review,* 10(1), pp. 52–56.

307.   Windley, D. and Chapman, M. (2010). Support workers within learning/intellectual disability services perception of their role, training and support needs. *British Journal of Learning Disabilities,* 38(4), pp. 310-18. https://doi.org/10.1111/j.1468-3156.2010.00610.x

308.   Wolfensberger, W. (1972). *Normalization: The principle of normalization in human services.* Toronto: National Institute of Mental Retardation, Leonard Crainford

309.   World Health Organisation (1980). *International Classification of Impairments, Disabilities and Handicaps.* Geneva.

310.   World Health Organization. (1996). *ICD-10 Guide for Mental Retardation.* Geneva.

311.   World Health Organisation (2001). *International Classification of Functioning, Disability and Health.* Geneva.

312.   World Health Organisation. (2017). *Definition: Intellectual disability:* Available at: http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability [Accessed 2 October 2020].

313. Yin, R. K. (1981). The case study crisis: Some answers. *Administrative Science Quarterly*, *26*(1), pp. 58-65.

314. Yin, R. K. (1981). The case study as a serious research strategy. *Knowledge*, *3*(1), pp. 97-114.

315. Yin, R. K. (2006). Mixed methods research: Are the methods genuinely integrated or merely parallel. *Research in the Schools*, *13*(1), pp. 41-47.

Appendix 1: Ethics Committee approval

Appendix 2: Participant observation framework

1. *Environment:* i.e. physical place and space, sensory observation, furniture, condition
2. *Personal appearance:* i.e. anything particularly striking, similarities, differences
3. *Interactions:* between staff, managers, supported individuals with different mental capacities, anyone else (including: language, tone of voice, facial expressions, non-verbal communication, familiarity)
4. *Hard and soft skills:* what abilities are staff demonstrating (such as communication/advocacy skills, proactive, resilience, problem solving, empowering people they support)?
5. *Emotions:* what emotions do staff display (such as empathy, stress, sadness, pride)?
6. *Reflection:* signs of staff reflecting on what they do/how they do it, consulting others?
7. *Support:* what support do staff have? How do they support others (residents, peers)?
8. *Structure:* how is activity/time structured?
9. *Relationships:* what is the dynamic between support staff and people they support, peers and managers?
10. *Challenges:* what challenges and demands do staff face and how do they deal with them?
11. *Rewards:* i.e. what evidence is there of staff feeling rewarded, valued, satisfied/motivated at work?
12. *Conversation:* what do staff talk about at work?

Appendix 3: Framework for semi-structured interviews

Introduce myself and run through purpose of study and interview. Remind participant of anonymity. Confirm permission to audio record interview. Remind participants they can ask questions if they are unclear on anything, and can ask to pause/stop the interview at any time.

1. Motivations for becoming a paid support worker to people with a learning disability; professional background
2. What do they bring to the job/characteristics and skills of a good support worker?
3. What does a good life looks like to supported individuals, and the role of paid support workers in enabling this?
4. Rewards and challenges/tensions of their work
5. Dealing with challenges/tensions; what support do staff have?
6. What happens when things go wrong; why things go wrong; opportunities for learning/reflection?
7. Language staff use to talk about themselves, their work, people they support, managers, others
8. Ambitions/prospects
9. Relationship between support workers and people they support, peers, managers, others
10. Awareness of wider policy issues. Policy impact on the day-to-day work of paid support workers; understanding and implementation of policy aspirations: choice, independence, inclusion
11. Image and reputation of support work
12. Is there anything else you would like to say?

Appendix 4: Information and consent letter

[Date]

Dear [Potential Participant Name],

Re: Research study looking the role of the support worker in meeting the aspirations of learning disability policy

I am a PhD student at the University of Cambridge undertaking research to understand the relationship between government policy and support worker practice.

I am especially interested in understanding the day-to-day support provided by paid support workers. I would like to explore the routines, relationships, interactions and processes that support workers have with the people they support as well as the risks and challenges that come with the role. In order to do this, I would like to observe support workers with people they support in their daily lives. I would also like to interview support workers so I can hear directly about these areas.

Once my fieldwork research is complete, I will produce a report setting out what my research has found. In the report I publish, unless someone is happy to be mentioned by name, I will not use anyone's real name and will not identify the name of the location I am visiting. Everyone taking part in the research will be asked to sign a consent form confirming they are happy to participate.

The research I am doing is independent and I do not represent any political or other interest group. I am funded by the National Institute for Health Research and Collaboration for Leadership in Applied Research and Care East of England.

I would like to invite you to participate in this research. I attach a consent form asking you if you are happy to participate. The observations will take place for up to two hours twice a week for 4 weeks. The interview will last approximately one hour. Observations and interviews will be arranged with you in advance. You can change your mind about participating at any point during the research.

If you have any questions about my research please contact me on 01223 746001 or email: rc207@cam.ac.uk.

If you have any concerns you can also speak to the Principal Investigator Dr Marcus Redley on 01223 746191 or email: mr382@medschl.cam.ac.uk. Thank you.

Rashmi Becker
PhD Researcher

Consent Form

If you are happy to take part in this research, please read the statements below and circle YES if you agree or NO if you do not.

- I confirm that I have read and understand the Participant Information Sheet

    YES   NO

- I have had the opportunity to ask questions and had them answered

    YES   NO

- I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified

    YES   NO

- I agree that data gathered in this study may be stored anonymously and securely

    YES   NO

- I agree that data gathered in this study may be used for future research (you may still take part in this research if you tick 'NO' to this question)

    YES   NO

- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason

    YES   NO

- I agree to take part in this study

    YES   NO

I am happy for the researcher to contact me by:

Phone (Please write preferred contact number)   …………………………………...
Email (Please write preferred email address)   ………………………………….

Participant Name…………………………………………

Participant Signature………………………………… **Date**……………………………

Please return this form in the freepost envelope provided or you can scan and email it to: rc207@cam.ac.uk