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Social justice and the experiences of people with mild learning difficulties who are looking for paid work

Thesis submitted to the University of Nottingham for the degree of Doctor of Philosophy

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August 2020

ESRC Grant Number ES/J500100/1

Acknowledgements

I am grateful to all of the people with mild learning difficulties who agreed to be interviewed for this research. I would like to thank them for talking to me openly and for trusting me with representing their experiences. Their stories were often painful and distressing for them to relate and for me to hear but were a great source of inspiration for me during the writing up of this thesis and taught me a huge amount. I wish them better times in the future.

I have thoroughly enjoyed discussing the research and this thesis with my two supervisors, Professor Rachel Fyson and Dr Simon Roberts. I thank and respect them for their dedication and for pushing me to question and develop my thinking. I am also grateful to Emeritus Professor Bruce Stafford for his helpful advice and guidance. I would like to acknowledge the help and support of academic and administrative staff in the School of Sociology and Social Policy. I would also like to thank the ESRC and the University of Nottingham Doctoral Research Centre for supporting me financially and making me feel part of a research community. It has been a great privilege to have the opportunity to study at this level and I would not have been able to do so without all of that support.

I count myself lucky to have made some great friends at the University of Nottingham. Their camaraderie has been especially appreciated in the last year and during the Covid-19 lockdown.

Finally, a shout out to my three daughters and my non-PhD friends who have been more than tolerant of my obsession with this research.

Abstract

People with mild learning difficulties who are not eligible for adult social care are largely absent from research about employment and unemployment. Policy discussions about supporting disabled people into employment also tend to overlook people with mild learning difficulties, either assuming that they are not disabled at all or that the barriers they face are the same as for other disabled people. This thesis challenges those assumptions by focusing on the stories of people with mild learning difficulties who were looking for work. These stories were gathered through multiple interviews and observations guided by a narrative research methodology, a social model view of disability and a commitment to social justice.

The research explored the assumptions underpinning government policy towards the employment of disabled people, focusing on the period from 2010 to 2019, and the implications for people with mild learning difficulties. It highlighted how government policy towards promoting the employment of disabled people had been inadequate and unjust, with detrimental effects for people with mild learning difficulties, particularly by miscategorising disability as an individual characteristic and over-individualising responsibility for employability.

The thesis draws on Fraser's social justice concepts of participatory parity, maldistribution and misrecognition (Fraser, 2001) to analyse participants' stories of unemployment and employment, and their relationship to notions of disability. It concludes that people with mild learning difficulties face a range of "structurally-produced injustices" (Fraser, 2012:45) in their relationships with the paid labour market, through inadequate and sometimes counterproductive support, insufficient income and disrespect that too easily slides into exploitation or abuse. The thesis highlights evidence of multi-faceted injustices, arising from the interactions of the participants with the welfare state and the labour market. Aspects of these injustices, which demand to be addressed for their own sake, also have relevance to a much larger section of the population who work in low paid, precarious work and/or claim social security benefits.

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Abbreviations

Social Security

DLA	Disability Living Allowance
ESA	Employment and Support Allowance
JSA	Jobseeker's Allowance
PIP	Personal Independence Payment
UC	Universal Credit
WCA	Work Capability Assessment
WRAG	ESA Work-Related Activity Group

Institutions

DfE	Department for Education
DoH	Department of Health
DWP	Department for Work and Pensions
EHRC	Equality and Human Rights Commission
HMRC	Her Majesty's Revenue and Customs
UN	United Nations

Other

DEG	Disability Employment Gap
SEN	Special Educational Needs

Chapter 1 Introduction

"Bosses should hire disabled people because 'they often work longer hours' and 'they forego quite a lot of holiday because they love the whole idea of being in work', Iain Duncan Smith told a packed meeting at the Tory Conference in Birmingham this month" (Private Eye, 2018)

"Top Labour MP blasted by his own party's welfare chief over claim firms could pay disabled people under minimum wage" (Bloom, 2017)

"There is a group, and I know exactly who you mean, where actually as you say they are not worth the full minimum wage and actually I'm going to go and think about that particular issue, whether there is something we can do nationally without distorting the whole thing, which actually if someone wants to work for £2 an hour [sic]." (Lyons, 2014, reporting David Freud's response to a question about the employment of "mentally damaged individuals")

The above quotes are illustrative of the limited and often pernicious nature of political discussion about the employment of disabled people. The first quote refers to the Secretary of State for Work and Pensions from 2010 to 2016 and the founder of the influential right-wing think tank, the Centre for Social Justice; the second refers to Frank Field MP, the Labour chair of the House of Commons Work and Pensions Select Committee from 2015 to 2018 and a Minister for Welfare Reform in a Labour Government until 1998; and the third is from the Conservative Minister of State for Welfare Reform from 2010 to 2016. Both Freud and Duncan Smith are closely associated with the two major new social security benefits introduced since 2010: Universal Credit (UC) and Personal Independence Payment (PIP) (Millar, 2018; Sainsbury, 2018). The three quotes are built on a complex set of assumptions about the identification, rights and

needs of disabled people relating to income, social relations, work, well-being and happiness.

In 2016 the government issued a Green Paper on work, health and disability, which reported that “just 5.8% of adults with a learning disability known to local authorities are in a job” (DWP & DoH, 2016:34). The subsequent White Paper referred to Labour Force Survey data indicating an employment rate of 24% for “working-age disabled people with a reported main health condition of a learning difficulty” (DWP & DoH, 2017:19). It promised “support for those who need it” (ibid:9) but made no specific commitments that would include adults with mild learning difficulties. Most adults with mild learning difficulties are *not* eligible for adult social care and therefore not included in data that refers to people as ‘known to local authorities’.

This research explores issues of social justice in the lives of people with mild learning difficulties who are looking for paid employment. The research is set in the context of a policy environment which promotes paid work as the main solution to disadvantage and poverty, a labour market which provides increasingly challenging and limited employment opportunities for people with cognitive impairments, and an increasingly conditional and limited social security system.

The research is intended to support the rights of people with learning difficulties to social justice. Examining the assumptions underpinning current policy towards the employment of disabled people, the research questions whether such policy is adequate to address the barriers faced by people with mild learning difficulties who are attempting to participate in the UK labour market. It explores the relationship between how people engage with notions of disability and how they experience work and unemployment. Using concepts of social justice drawn from the work of Nancy Fraser, the research explores the complexities of the experiences of people with mild learning difficulties. It questions the extent to which the barriers they face relate to their learning difficulties rather than systemic or structural aspects of the labour market and the welfare state.

The following two chapters explain how concepts of social justice and learning difficulties are used within the research and explore related research. The

research design is described in detail in Chapter Four. The main research question is:

How do people with mild learning difficulties experience looking for paid work?

There are six subsidiary questions, which are intended to clarify the scope of the research and inform the research design:

1. *What are the tensions and contradictions in government policy towards supporting the employment of people with learning difficulties and promoting social justice?*
2. *How do people with mild learning difficulties relate to concepts of disability and how does that affect their sense of their rights and entitlements?*
3. *What stories do people with mild learning difficulties tell about unemployment, looking for work, and being in work?*
4. *What do these stories reveal about the labour market and the social security benefits system?*
5. *What do the stories of people with mild learning difficulties who are looking for work reveal about the adequacy of the government's policy approach to supporting the employment of disabled people?*
6. *Are concepts of social justice useful to understanding the position of people with mild learning difficulties who are looking for paid work, and if so, how are they useful?*

Following Chapter Four, there are five further chapters that present and discuss the data collected during the research, followed by a concluding chapter. The first data chapter (Chapter Five) explores how governments since 2010 have conceptualised and embedded constructions of disability in general, and learning difficulties in particular, within policy, especially in relation to employment, unemployment and employability. The chapter explores government policy relating to the employment of disabled people, highlighting the narrowness of its focus on the disability employment gap (DEG), the difference in the employment

rates of disabled and non-disabled people, and the lack of policy attention towards the needs of people with learning difficulties. This policy chapter frames the subsequent exploration of the views and experiences of the research participants. It provides a central element of the conclusions of the thesis.

Chapter Six introduces the research participants: a group of 16 people with mild learning difficulties who participated in multiple qualitative interviews. This is followed (Chapter Seven) by an analysis of how participants talked about disability. Participants' experiences of looking for work, being in work and losing work are presented and analysed, using a social justice lens, in Chapters Eight and Nine. Chapter Ten presents the conclusions of the research, considering the adequacy of the policy response and the relevance of the concepts of social justice.

This first chapter begins with a contextual overview of the key characteristics of the labour market and the social security system, focusing on their implications for people with mild learning difficulties. The question of how people with mild learning difficulties experience looking for paid work is considered in the context of two phenomena: the hidden-ness and misrepresentation of people with mild learning difficulties in research, in statistical data and in policy documents (Hatton, 2018); and a policy environment that promotes paid work as a central remedy for social inequality (Patrick, 2017, Roulstone, 2015) and the principle measure of individual worth and contribution (Grover, 2015).

The following discussion largely avoids speculation about the impact of Brexit, due to the high level of uncertainty about its enactment at the time of the research. It also does not take into account the Covid-19 pandemic and its impact on the economy and on employment. However, it is apposite to note here that the response to the pandemic has highlighted that "people with learning disabilities are disproportionately likely to die a Covid-19 related death than other people" but also "people with learning disabilities are in any year much more likely to die at much younger ages due to avoidable causes compared to other people" (Hatton, 2020: unpaginated). Hatton also highlights the failure of Public Health England to include any mention of disabled people in its latest Covid-19 review of disparities in risks and outcomes (ibid).

Labour market context

A host of factors can be identified as affecting the labour market context at the time of this research (2016-2019), including globalisation and changes to trade patterns, de-regulation and the impact of austerity politics, and the impact of technological change (Crouch, 2019; Green, 2019; Gottschall & Dingley, 2016). The research was carried out during a period when headline unemployment figures were falling and the overall employment rate was heralded as “the highest since records began” (Taylor M, 2017:17), although there was also evidence of underemployment (Meager, 2015; Warren, 2015) and hidden unemployment (Barr et al, 2019; Merrick, 2018). Three factors are particularly pertinent to the employability of people with mild learning difficulties in this context: the impact of technological change and automation, especially on semi-routine, routine and low-paid jobs; the expansion of the service sector as the main source of employment; and the rising precariousness and intensification of so-called low-skill jobs. All of these might have potentially negative implications for anyone lacking qualifications and the ‘right’ behaviours, regardless of whether they have learning difficulties or not. Whether there are particular implications for people with learning difficulties, mild or otherwise, is generally under-researched (Hatton, 2018).

The impact of technology on the current and future skills profile of the UK labour market has been highlighted by a number of studies (for example, Deloitte, 2015; Frey & Osborne, 2013; Gallie, 2013; Goos & Manning, 2003). These indicate that computerisation and automation increasingly supplant jobs involving “clearly defined and fixed work routines” (Gallie, 2013:11) while adding value to jobs considered high-skilled (Gallie, 2013). Typically, lower paid jobs have the “highest potential for automation” (Lawrence et al, 2017:3). However, some sectors considered to be low-skilled, such as care work and personal services, where work is “relatively unsystematic”, remain less affected by automation and have the potential to see an increasing concentration of poor quality and poorly paid jobs (Lawrence et al, 2017). Technological change may not only result in a “hollowing out” of middle income jobs (Deloitte, 2015:5-6) but may also increase competition for ‘low-skilled’ jobs, which may have the effect of crowding out people with lower educational qualifications and disabilities (Greve, 2017;

Helsper & Riesdorf, 2016). For people with learning difficulties these trends are exacerbated by rising “academic thresholds” for the general population (Roulstone, 2012:213), and the likelihood that disabled people are “encouraged into less academic routes to educational success” (ibid:213), which further entrench their lack of opportunities for paid employment outside “relatively low-skilled” and low paid work (Woodin, 2015:183; Wistow & Schneider, 2003).

Technology is also increasingly being used to intensify managerial surveillance of employee activity and behaviour (Akhtar & Moore, 2016; Grint & Nixon, 2015). Technology-based monitoring, such as the ‘scan rate’ of supermarket checkout operators, can provide management with real-time information to support performance-related pay, targets and decisions about hiring and firing (Grint & Nixon, 2015). Digital interfaces with consumers can enable the rapid collection and analysis of ‘customer feedback’. Such mechanisms can result in an increase in self-imposed “self-monitoring” by workers, as well as increased surveillance by managers (Grint & Nixon, 2015:316). These developments have the potential to result in “psychosocial violence” by promoting overwork, pressurising workers to reduce break times, and intensifying the speed of work (Akhtar & Moore, 2016:103). Workers with learning difficulties are likely to be particularly at risk here, as discussed further below.

The shift in the labour market towards the service sector has been ongoing since the 1960s or earlier (Grint & Nixon, 2015; Noon et al, 2013) but was particularly marked during the 1980s and has continued since. Service industries have accounted for around 84% of all UK jobs during the last decade, compared to just over half in the early 1970s (House of Commons, 2020; Noon et al, 2013). Workplace surveys suggest that employees in these jobs rate “emotional skills” and “aesthetic skills” as essential to the work, with “literacy, planning and communication” skills also rated highly (Grint & Nixon, 2015:288). Such service work, and their associated skills, have long been associated with women’s work, related to domestic activities and stereotypes of femininity (Grint & Nixon, 2015), often characterised as “very low skilled” and usually offering very low pay (Grint & Nixon, 2015:288). These jobs include catering, retail and cleaning jobs.

Employer demand for “aesthetic labour” is associated with “corporeal capacities and attributes that favourably appeal to customer senses” (Nickson et al,

2012:66) or “embodied performance”, where the service becomes “inseparable from the person providing it” (McDowell, 1997:121). A preference for “employees who ‘look good’ or ‘sound right’” (Nickson et al, 2012:66) and those who can manage their emotions “in ways conducive to the demands of the customer” (Grint & Nixon, 2015:287) may obstruct the participation of disabled people in service sector work. This is evidenced by examples of workers with visible signs of disability being moved away from serving customers (Butcher & Wilton, 2008; Wilton, 2004).

However, these service sector jobs are also the types of job categories for which people with learning difficulties are often “typecast” (Kaehne, 2016:524), despite being less likely to demonstrate the required “social and cognitive skills” (Dowse, 2009:573) or the “image and performativity” (Roulstone, 2012:216) expected for customer-facing work. It seems likely that people with mild learning difficulties, who may not be visibly disabled but who may behave or communicate in ways which affect their “embodied performance” (McDowell, 1997:121), are significantly disadvantaged by these contradictory conditions, but there is a lack of research in this area.

So-called low-skill work itself is also experiencing a “major intensification” (Green et al, 2016:331), including demand for people to work “long hours on flexible contracts” (Hall & Wilton, 2015:222) and at “very high speeds” (Green et al, 2016:331). This coincides with a trend towards employees experiencing a sharp decline in the control they have over the way they work (Green et al, 2018). The combination of intensification and loss of control has been described as a “toxic combination that leads to stress, anxiety and higher risk of cardiac illness” (O’Connor, 2018). Speeding up may present particular problems for people with learning difficulties, with employers often intolerant of those unable to “pick up the pace” (Wilton, 2005:144). Increasing demands from employers for ‘flexibility’ has manifested in the rise of zero-hours contracts and other variable hours arrangements and, within the workplace, in demands for employees to move rapidly “from one set of tasks to another” (Woodin, 2015:186). Such demands can also be particularly problematic for people with learning difficulties who may need more time and additional help to learn specific tasks (Woodin, 2015).

Low paid work has also become increasingly characterised as precarious work and associated with the terms ‘gig economy’ and ‘zero-hours contracts’ (Crouch, 2019). Use of the word ‘gig’, and its association with self-employment, self-realisation, the tech sector and creative industries (Littler, 2018), suggests workers having *more* control over their working conditions. In practice, the opposite effect has been widely documented (Crouch, 2019; Joyce & Xu, 2019). Self-employment and standard employment are also increasingly associated with precariousness, which weakens “workers’ bargaining power at the bottom” (Joyce & Xu, 2019:18). Attempts to restrict access to legal redress, such as the imposition of fees for Employment Tribunals from 2013, further reduced workers’ rights, as evidenced by surge in the numbers of claims relating to disability discrimination after fees were abolished in 2017 (Croft, 2020).

The precariousness of the UK labour market is manifested in the growth of part-time work, including increasing numbers of part-time workers who would prefer to work more hours (Warren, 2015), and the increase in temporary contracts, including agency work (Pettinger, 2019). However, the existence of precarious work practices can have an effect on the conditions of all workers, through expectations and fears (Pettinger, 2019). As a result, workers have seen the “erosion of working conditions” (Littler, 2018:50), such as cuts to sick pay and pension rights.

The growth of precarious working conditions can be connected to the rising influence of neoliberalism over policy since the late 1970s (Crouch, 2011). Neoliberalism is a contested term and is not the central focus of this research. It is used within this research to refer to an ideological outlook that breaks with mid-20th century commitments to reducing inequality through welfare policy and redistribution but is also different from pre-20th century Enlightenment ideas of progress (O’Brien & Penna, 1998:103). In this research, the term neoliberalism is used to refer to a commitment to a combination of ideas about markets, individuals and moral order, including that markets are “the most effective way of allocating scarce resources” (Pettinger, 2019:88) and far more effective than governments (Brown, 2019), that each individual must be “held responsible and accountable for his or her own actions and well-being” (Harvey, 2005:65), and

that “voluntary innovation and individual responsibility are the basis of moral order” (O'Brien & Penna, 1998:104).

De-regulated or ‘flexible’ labour markets “free employers of responsibilities to those who work for them” (Crouch, 2019:6). Neoliberalism’s association with “certain forms of individualism, autonomy, self-reliance and the notion of equal rights” (Gamble, 2019:992) and “competitive individualism” and “meritocracy” (Littler, 2018:69) has underpinned its appeal as a progressive force offering “opportunity and choice” (Gamble, 2019:992), while also promoting a “stripped-down, nonredistributive form of “equality” designed for global consumption...and compatible with continued upward redistribution of resources” (Duggan, 2014). The effect of this appeal to opportunity and choice is to suggest an acceptance that some inequalities are unjust (such as Conservative Prime Minister May referencing “burning injustices” (May, 2016)), while proposing that they can and should be addressed primarily by increased marketisation and individual “responsibilisation” (Littler, 2018:71). These themes are also apparent in the design and workings of the social security system and policy towards unemployed people, as discussed below.

Social security

The UK social security system is highly complex matter involving law, policy and provision and therefore the discussion presented here inevitably only covers certain aspects of it. The focus here is on the provision, or lack of provision, for unemployed people and working-age disabled people, especially with respect to people with mild learning difficulties, since the election of a Conservative-led government in 2010. Social security in this period is characterised by a widening gap between provision and need, underpinned by notions of deservingness and undeservingness. These are illustrated here by reference to four inter-related policy areas:

- austerity and the shrinking of state spending;
- the promotion and implementation of UC, the ‘flagship’ change to the social security system implemented during the period of the research;
- conditionality within work-related and unemployment benefits;
- changes to disability benefits.

Note that this subject matter is rife with acronyms and a full list is available on page viii.

A huge programme of cuts to public spending was heralded as the ‘Age of Austerity’ by the UK Conservative party before it formed the coalition government in 2010 (Cameron, 2009). Austerity was positioned as a response to the increase in national debt arising from the 2008 financial crash and subsequent recession but also as a political response to the previous Labour government’s economic policies. Cuts in spending from 47% to 40% of GDP since 2010 have fallen disproportionately on local government services, social security spending (excluding pensions), education, policing and prisons (Quilter-Pinner & Hochlaf, 2019). These include cuts to state-run crisis provision at a time when “the failings of state-run systems” were “one of the major drivers pushing people into financial crisis” (Sefton et al, 2018:65). The cumulative effect of the austerity programme has been estimated as a reduction of £100bn in the size of the economy in 2018/19 (Stirling, 2019). Many of the more significant cuts to social security spending were introduced through the 2012 Welfare Reform Act (DWP, 2012a) (Millar, 2018). The Conservative government elected in 2015 announced plans to cut “welfare spending” (social security) by £12bn by 2018/19, although the Office for Budgetary Responsibility estimates the outcome was some £4bn lower due to cost over-runs and “policy reversals” associated with UC and disability benefits (OBR, 2019:6). The OBR reports that the “most reliable sources of cuts were those that squeezed average awards” (OBR, 2019:6), in other words, the freeze on benefit levels which remained in place from 2015 to 2020.

In 2018 the EHRC reported that the cumulative effects of changes to taxes, benefits, tax credits and UC announced since 2010 “are regressive, however measured”, with the bottom two deciles losing approximately 10% of net income on average (Portes & Reed, 2018:15). For disabled people, their families were particularly negatively impacted, with disabled lone parents of at least one disabled child facing a cut of around 30% to their net income (Portes & Reed, 2018). The UN Special Rapporteur on extreme poverty and human rights concluded that disabled people had been “some of the hardest hit by austerity measures” (Alston, 2019:17).

UC is a means-tested benefit for people on a low income who are in work or out of work. It is delivered by the Department for Work and Pensions (DWP) and replaces six benefits previously delivered by the DWP (Income-related JSA, Income-related ESA, Income Support), HMRC (Working Tax Credits, Child Tax Credits) and local authorities (Housing Benefit). UC is usually paid monthly in arrears to claimants, based on a monthly assessment period within which earnings and other income are used to calculate means-tested entitlement. Earnings data is collected from HMRC's real-time information system, based on data provided by employers. For most claimants, UC includes a personal element (standard allowance) and a housing element. For claimants with children, UC also includes a child element, although this is limited to two children for those born after April 2017, one of the clearest examples of a new gap within the social security system between provision and need. UC may include a health-related element, known as the Limited Capability for Work-Related Activity (LCWRA) element. UC claimants who are in paid work are entitled to a 'work allowance' and any earnings above this result in a deduction from UC at the rate of 63p for every £1 earned (the 'taper rate').

There are a number of characteristics of UC that make it different from the benefits that it replaces. It is a 'digital by default' system, with most claimants expected to create and manage an on-line account linked to a personal email address and phone number. Putting claimants "in control of accessing and managing their benefit" (DWP, 2013a:7) is promoted as a fundamental and positive aspect of the conditionality embedded in the design of UC. In practice it provides grounds for sanctioning claimants who do not 'manage' to the required extent. When the DWP accepts that a claimant is unable to manage a digital claim, for example due to their health condition or level of literacy, the DWP can create a UC account on the claimant's behalf and the claim is designated as a 'phone claim', with phone-based communications between DWP and the claimant and no access for the claimant to a digital account. However, phone claims disadvantage claimants by excluding them from access to a text-based audit trail, restricting the potential for others to support them in managing their claim. This is part of a wider pattern of "digitalised welfare encounters" that have exclusionary effects on already disadvantaged groups of claimants such as disabled people (Schou & Pors, 2019:473).

DWP staff are expected to identify claimants with ‘complex needs’ (previously referred to within DWP documents as ‘vulnerability’) and have the discretion to offer a range of alternatives to the standard UC arrangements, such as phone-based claims, more frequent payments, direct payments to landlords, home visits and reduced risk of sanctioning. This emphasis on the discretion of street-level bureaucrats (Lipsky, 1980) has a long and dismal history in the DWP (Kaufman, 2020; Patrick, 2017; Fletcher, 2011). Multiple examples of DWP’s failures to identify and support “vulnerable claimants” (Committee of Public Accounts, 2018:13) have been widely documented (Ryan, 2019; Stevens, 2019), with some suggesting that “responsibility for helping ‘harder-to-help’ groups” (Pollard, 2018:14) should be transferred away from the DWP entirely, due to its “institutional resistance” (ibid:8) to reform. The DWP’s poor record on dealing with disability-related discrimination against its own employees has further undermined confidence in its ability to support people with disabilities and health conditions (BBC, 2020).

UC is mostly paid monthly, in arrears, to the claimant, whereas the benefits it replaces were mostly either paid more frequently or paid directly for services (e.g. Housing Benefit). There is a minimum five-week wait between submitting a claim and getting the first full payment, reflecting payment in arrears based on the monthly assessment period. Claimants are offered a loan to cover the five-week wait and this loan is repaid by deductions from an already very low level of benefit, in many cases “exacerbating claimants’ debt and financial difficulties” (NAO, 2020:9). Deductions (which may also relate to previous overpayments or court charges) may be made by the DWP for up to 25% of the standard element of UC without further consent from the claimant. The eligibility rules for UC are more stringent than for legacy benefits in several areas including citizenship status, with claimants compelled to prove their entitlement to claim through an identity check and, for some, a habitual residence test, that has been linked to “the ‘hostile environment’ measures [that] seek to make it as inconvenient and unpleasant as possible for people without documents to live in Britain” (Ghelani, 2018, no pagination).

The aims of UC are described by the DWP as: making the system simpler; making sure claimants are better off financially in paid work; creating a new “two-

way relationship” between claimants and the government; matching payment with “the way most salaries are paid” (that is, monthly in arrears); and responding month-by-month to changes in earnings (DWP, 2013b:2). The business case for UC (DWP, 2018c) indicates that the DWP believed that UC would reduce administrative costs and benefit spending, because claimants would choose to work or to work more, payments would be lower, fraud would be reduced and the system would be cheaper to operate, requiring fewer staff managing a higher caseload (DWP, 2018c). These are fundamental to the current government’s approach to social security, focusing on reducing public spending and on influencing the behaviour of claimants (particularly through conditionality, discussed further, below). In practice, UC has not delivered reductions in public spending and it is “not certain” (NAO,2020:42) that it will be cheaper to administer than the benefits it replaces, due to design and delivery failures.

There are indications that UC claimants experience *higher* levels of complexity compared to claiming legacy benefits, and that the “simplicity” claimed as a feature of UC is merely administrative, achieved by pushing the complexities of social security “onto the shoulders of claimants themselves” (Summers & Young, 2020:14). The recent Court of Appeal judge’s conclusion that UC payment regulations were “perverse” and “irrational” (Lady Justice Rose, quoted at Royal Courts of Justice, 2020) highlights some of the many complexities facing claimants, and the difficulties of making legal challenges to such practices. These design complexities and government resistance to challenges suggest an intention to intimidate claimants and deter claims, consistent with the historic principle of ‘less eligibility’. This principle, dating back to the 19th century Poor Laws (Harris, 2004) and intended to ensure those not in paid work are worse off or more uncomfortable than those in paid work, has been extended under UC to include people in paid work but on a low income.

UK welfare benefits associated with unemployment have never been completely unconditional but there was little emphasis on conditions or disqualifications until the sharp rise in unemployment in the 1980s (Webster, 2019). Since the mid-1980s, job search requirements and penalties for non-compliance have gradually been tightened by successive Conservative and Labour governments, accompanied by “a hardening of public attitudes towards the unemployed”

(Webster, 2019:317). There is widespread recognition of a step-change increase in the stringency of conditions and the severity of punishments for failure to comply since 2010 (Fletcher & Flint, 2018; Welfare Conditionality Project, 2018; Patrick, 2017; Reeves & Loopstra, 2017; Dwyer & Wright, 2014). Until 1986, the maximum penalty for non-compliance with unemployment benefit conditions was a disqualification for benefit (known as a sanction) of six weeks (Flint & Fletcher, 2018).

The reach and extent of sanctions was increased during the 1980s and 1990s to cover more claimants and to be more punitive, but measures included in the 2012 Welfare Reform Act were much more draconian, including extending the maximum sanction to three years (Webster, 2019). This sanctioning system, heralded by the government as “ending the ‘something for nothing’ culture” (DWP, 2013c), has been described as a “huge, secret, parallel penal system” (Webster, 2019:319), involving penalties applied immediately, without a hearing and without reference to the individual’s circumstances. Between 2010 and 2015, 25% of all JSA claimants were sanctioned (Webster, 2019). Sanctions are known to have been applied disproportionately to the most disadvantaged groups, including disabled people, homeless people and prison-leavers (Flint & Fletcher, 2018; Welfare Conditionality Project, 2018). The three-year maximum was reduced to six months in 2019, after a scathing report by the House of Commons Work & Pensions Committee, which confirmed that disabled people, along with care leavers and single parents, were proportionately more likely to be sanctioned and that the application of sanctions was “inconsistent”, “inappropriate” and caused “unjustified and sustained hardship” (WPC, 2018a:4). The report concluded that:

“Of all the evidence we received, none was more compelling than that against the imposition of conditionality and sanctions on people with a disability or health condition. It does not work.” (WPC, 2018a:3).

Conditionality creates a link between eligibility for work-related and unemployment-related social security benefits and the behaviour of individual claimants (Dwyer & Wright, 2014). This is epitomised in the notion of ‘activation’ through ‘welfare-to-work’ (WTW) programmes, which “reinforce individual work incentives” (Finn, 2018:218) by pushing claimants towards activities that are

deemed to “make people (feel) more responsible” (Eleveld et al, 2020:1). WTW in the UK, involving voluntary and mandatory training courses and work placements, has been delivered through a ‘payment by results’ commissioning process involving the DWP-owned Jobcentre Plus and a number of “for-profit prime contractors” (Finn, 2018:227). This was the model for delivery of the Work Programme that ran from 2013 to 2017 and for its much smaller replacement, the Work & Health Programme, introduced in 2018. Conditionality and WTW are primarily defended by policy-makers by reference to “contractual ideology – with its prioritising of individual responsibility and reciprocity” (Welfare Conditionality Project, 2018:9). Receipt of social security is viewed as a bargain between the claimant and the state in which benefits are provided in exchange for behaviours and actions on the part of the claimant, connected to a broader political discourse of “responsibilities and obligations”, represented during the Coalition government by the concept of ‘big society’ and in the subsequent Conservative government by the ‘shared society’(Patrick, 2017:33). The notion of ‘responsibilisation’, in combination with conditionality, places the solution to unemployment firmly on the ‘supply side’, where “the unemployed person is the focus of intervention” and “individuals are expected to provide for themselves” (Eleveld et al, 2020:7).

Conditionality is consistent with the dominant policy idea that people *choose* “how many hours... to work” (DWP, 2018c:7) and that unemployment is largely a product of the attitudes and behaviour of the unemployed (Webster, 2019), rather than a lack of jobs. It is part of a wider programme of applying “psychological models of behaviour change” (Mehta et al, 2020:6) to ‘activate’ claimants and reduce the number of claims, largely based on a belief that social security payments provide a financial disincentive to look for or accept paid work and encourage dependency on the welfare state (Spicker, 2017:17). Conditionality provides a set of coercive practices ranging from the requirement to accept a contract (‘the claimant commitment’, which sets out the obligations of the UC claimant), to the threat of punishment (awareness of sanctions), to actual punishment (application of sanction to stop payment) (Mehta et al, 2020; Webster, 2019). The devastatingly sharp drop in income resulting from a sanction, and the difficulties and delays involved in challenging a sanction

decision, justify the characterisation of conditionality as “parallel penal system” (Webster, 2019).

There is evidence to suggest that, in practice, conditionality related to social security benefits “initiates and sustains a range of *negative* behaviour changes and outcomes” (Welfare Conditionality Project, 2018:4, *italics added*), including increasing poverty, reducing engagement with job seeking, and exacerbating ill-health, especially poor mental health (Dwyer et al, 2020). The Welfare Conditionality Project, a major ESRC-funded study, concluded that “conditionality within the social security system is largely ineffective in facilitating people’s entry into or progression within the paid labour market” (Welfare Conditionality Project, 2018:4). Moreover, the discretion afforded to street-level bureaucrats in the delivery of conditionality (Patrick, 2017), in particular the role of Jobcentre Plus work coaches and staff in related agencies (Kaufman, 2020) in policing the behaviour of UC claimants, and the lack of redress and safeguards available to claimants, can result in “the increased exercise of subtle, indirect *and* authoritarian forms of power over social assistance recipients” (Eleveld et al, 2020:10, *emphasis in original*). This is also evident in the structure and allocation of disability benefits.

Disability benefits

The UK social security system provides two types of benefits for people with disabilities and long-term health conditions: income-replacement benefits, related to employment status, which are now largely provided for new claims through UC; and income-supplement benefits, related to extra or compensatory costs associated with having a disability (Sainsbury, 2018). These highly complex areas are worth examining in some detail because they demonstrate the policy context for this research, including the often obstructive and punitive activities of the DWP.

Both types of benefit are “intrinsically selective” (Spicker, 2017:78), using points-based tests and face-to-face or telephone-based assessments to ration entitlement, even for people with severe, long-term or permanent health conditions (Gedalof, 2018; Spicker, 2017). These tests and assessments have been subject to extensive criticism from a wide range of sources, and their

continued use suggests that they are part of a deliberate policy of restricting entitlement by obstructing the process of claiming (Benstead, 2019; Ryan, 2019; Baumberg Geiger, 2018; Kennedy et al, 2018; Morris, 2017; The British Psychological Society, 2016; Dugan, 2015). Several studies have highlighted the adverse effects of recent disability benefit reforms on the health, particularly the mental health, of claimants (Patrick 2017; Barr et al, 2016; Garthwaite, 2014; Kaye et al, 2012; Wood, 2012). These include the financial and emotional impact of uncertainty, cuts and the withdrawal of benefits, the stigmatising of disability benefit claimants in the media, and the surrounding narrative of fraud, dependency and scrounging.

Such restrictions in principle are not new, but efforts to shrink the “disability category” (Stone, 1984) have become much harsher and more extensive since 2010 (Sainsbury, 2018; Roulstone, 2015; Roulstone & Prideaux, 2012). Political and popular media attention on ‘fraudulent’ disability status has been compared to 17th and 19th century claims about vagrants faking disability (Roulstone, 2015). A range of recent research suggests this narrative has been used to legitimate reducing entitlement to disability benefits (Ryan, 2019; Patrick, 2017; Grover, 2015).

At the time of the research, the two income-replacement benefits for disabled people and those with long-term health conditions were ESA and its successor, UC. ESA was itself introduced in 2008 to replace Incapacity Benefit. The number of people claiming Incapacity Benefit had risen sharply in the 1980s, absorbing people made redundant by de-industrialisation and the decline of manufacturing, and in response to government policies designed to manage politically damaging unemployment figures (Beatty & Fothergill, 1996). Successive governments had attempted to reverse this rise, implementing substantial cuts in spending both in real terms and as a proportion of national income since the 1990s, but the numbers remained stubbornly high (Banks et al, 2015; Lindsay & Houston, 2013). This reflects factors working against the (re)entry of long-term disability benefit claimants into the labour market, particularly on-going ill-health conditions, low qualifications and age (Patrick, 2017; Beatty & Fothergill, 2013; Wood, 2012).

Claimants applying for disability-related income-replacement benefits have to complete a Work Capability Assessment (WCA), a points-based assessment. The WCA was introduced in 2008, alongside ESA, as a “stricter” health assessment than that used for Incapacity Benefit (Banks et al, 2015: 177). The WCA has been controversial since its introduction, with long-running concerns being raised within and outside parliament about “delays, accuracy and fairness” (Sainsbury, 2018;43), but also its adverse impact on claimants’ mental health including being associated with “suicides, self-reported mental health problems and anti-depressant prescribing” (Barr et al, 2016:339). ESA’s history as a benefit designed to reduce the number of claims for disability benefits (Sainsbury, 2018), together with the implementation record of the WCA, suggests a policy intention to increase the pressure on disabled people to make “efforts to become more capable of working” (Grover & Piggott, 2013a:377) and therefore more included, by separating out those judged as incapable of paid work as a much smaller excluded group (Grover & Piggott, 2013a).

Both ESA and UC use the WCA to categorise claimants as either ‘fit for work’ or not. Those deemed ‘not fit for work’ are then further categorised into two groups and only those in the ‘more severe condition’ group are freed from work-related conditionality. Under UC, and under ESA since April 2017, only those in the ‘more severe’ group are entitled to the supplementary ‘disability element’, currently worth £341.92 a month within UC.

ESA claimants may also be entitled to a range of ‘disability premia’ which are not provided under UC, potentially resulting in a significant drop in income for those who move to UC. Following a High Court ruling in July 2018 that this was discriminatory, the DWP stopped anyone entitled to the Severe Disability Premium from claiming UC, and these claimants have to remain on ESA. However, DWP has continued to resist full compensation for those who had already moved to UC at the time of the court ruling, despite a further High Court ruling in 2019 and action pending in 2020 (Disability Rights UK, 2020). ESA claimants have also been discriminated against in the 2020 response to the Covid-19 pandemic, in which the standard element for UC was increased by £92 a month to £409.89, but ESA remained unchanged at the equivalent of £317.20.

The main ‘income supplement’ benefits relating to disability for working-age people are Disability Living Allowance (DLA) and its replacement, PIP. These are non-contributory, non-means-tested benefits that are not related to employment status. DLA was created in the early 1990s in response to criticism that the benefits it replaced did not cover people with moderate conditions (Sainsbury, 2018), and the benefit was structured at three levels of ‘care component’ and two levels of ‘mobility component’. PIP, introduced through the 2012 Welfare Reform Act, was expected to cover 600,000 fewer people than DLA, saving around £2.5bn. PIP can be categorised as one of a number of austerity measures introduced in the wake of the 2008 financial crash, but it also reflected an increasingly anti-disability and anti-benefit claimant media environment (Ryan, 2019). The over-riding rhetoric from government and the popular media was that the number of disability benefit claims was too high to reflect legitimate need, and that level of benefit was disincentivising disabled people from finding work (Gedalof, 2018; Roulstone, 2015). This stance negated the “successes of the disability rights movement in pressing its claims for recognition” and rejected evidence that the labour market was failing to provide “decent and suitable jobs” (Gedalof, 2018:89; Patrick, 2017).

PIP has been introduced gradually since 2013, replacing new claims for DLA and existing claims following assessments. The eligibility criteria are tighter, and the extent and frequency of re-assessment are greater, despite indications that these “confirm the obvious” or “duplicate information that is already held” (Spicker, 2017:78). The rolling out of PIP has been frequently criticised, including by the High Court, for delays to assessments, decisions and awards (Kennedy, 2015).

Around 2.4m people were entitled to PIP as at January 2020 (DWP, 2020), compared with around 3.3m DLA claimants in 2012 (DWP, 2013d). Award rates for PIP since it was introduced are 42% for new claims and 71% for DLA reassessment claims, with new claims much more likely to be subject to review within two years than for those transferring from DLA (DWP, 2020). Around 1 in 10 PIP decisions are challenged by clients and referred to an independent tribunal. These appeals have a high rate of success: at appeal hearings, 64% of DWP decisions are overturned in favour of the claimant where the PIP application was initially disallowed and 73% where the award was allowed but

restricted to one component or a lower rate (DWP, 2020). The process for challenging any benefit-related decisions, which is time-consuming and stressful for claimants (Farr & Cressey, 2019; Machin, 2017), is also obstructed by the DWP's system of 'mandatory reconsideration' (MR), during which an internal review of the decision is carried out, delaying the outcome by weeks or months, despite only 16% of MRs resulting in a change to the DWP's decision in the case of PIP (DWP, 2020). This is in the context of funding cuts to welfare advice and legal services, which have "left few other support mechanisms to advise people with disabilities on how to navigate the welfare benefits system" (Farr & Cressey, 2019:255).

The cumulative effect of these changes to the landscape of social security with respect to disability was summarised by the UN Special Rapporteur on extreme poverty and human rights, following his visit to the UK in 2018, as follows:

"British compassion for those who are suffering has been replaced by a punitive, mean-spirited, and often callous approach apparently designed to instill [sic] discipline where it is least useful, to impose a rigid order on the lives of those least capable of coping with today's world, and elevating the goal of enforcing blind compliance over a genuine concern to improve the well-being of those at the lowest levels of British society." (Alston, 2019:5).

The next chapter considers the theoretical lens of social justice used in this research and how it is relevant to issues of disability and to exploring the experiences and views of people with mild learning difficulties.

Chapter 2 Social justice

This research was initially conceived shortly after the publication of the 2012 White Paper Social Justice: Transforming Lives, the first White Paper expressly claiming to focus on social justice. The documenting of an official policy on social justice by a Conservative-dominated coalition government was part of a long-term strategy of modernising and re-positioning the Conservative Party as actively engaging with “a range of societal issues” (Hayton & McEnhill, 2015:134) after 13 years in opposition during the New Labour governments. The widespread use of the term ‘social justice’ in Conservative policy documents and speeches from the mid 2000s onwards drew on New Labour’s language of “the social exclusion that poverty could cause” (Hayton & McEnhill, 2015:140) while imbuing the term with “more traditionally conservative meaning” (ibid:140), most notably in the speeches of the former Secretary of State and one-time party leader Iain Duncan Smith, and his proposals for radical restructuring of the UK welfare state (Craig, 2018). This attempt to “capture” the concept of social justice from “the progressive tradition of politics, policy-making and practice” (Craig, 2018:2), raised the profile of the concept itself, encouraging a new type of scrutiny of Conservative government policy from theoretical perspectives on social justice (for example, Craig, 2018; Crossley, 2017; Hayton & McEnhill, 2015) which included critiques of the White Paper itself, as well as a range of policy initiatives on social issues.

In that context, this research began with a question about the relevance of concepts of social justice to the particular situation of unemployed people with mild learning difficulties, in the face of the changes to the labour market and changes to the welfare state discussed in the previous chapter. To explore this further required not only analysis of the government’s approach to social justice as enacted in social policy, but also a theoretical lens of social justice through which to examine the empirical evidence gathered by the research. This chapter presents description and analysis of that theoretical lens, with a particular emphasis on its relevance to people who may be ascribed with the social identity of disability. The chapter concludes with an exploration of the relevance of the selected social justice lens to disability-related research. This is revisited in the concluding chapter of the thesis.

What does social justice mean?

Although much of the literature on social justice focuses on “the distribution of benefits and burdens between different individuals or groups.” (Clayton & Williams, 2004:1), social justice itself has long been held to be a “contested concept” (Ellison, 2018:271). Social justice theories attempt to reconcile potentially unreconcilable issues relating to the fair reward of virtue and merit, dealing with the effects of luck and misfortune, the recognition of difference and different needs, and the fair distribution of social resources.

Ellison suggests the understanding of three “foundational concepts” of social justice - liberty, fairness and equality - underlie how social justice is applied to policy issues (Ellison, 2018: 272). ‘Liberty’ is conceptualised as a trade-off between “the right to autonomy and freedom of choice” and compromising “the freedom of others”; ‘fairness’ as the adequacy of public justifications of unequal benefit; and ‘equality’ as a measure of “how difference has been taken into account” such that “greater equality of treatment” is produced (ibid:276-7). Goodlad and Riddell suggest that “desert or merit” and “need” are also key values “commonly used to justify distributional processes” but often neglected or undermined by policies addressing the position of disabled people in society (Goodlad & Riddell, 2005:51). For the purposes of this thesis, consideration of these five concepts is accepted as essential to mark the boundaries “within which socially just policies can be expected to fall” (Ellison, 2018:276).

These different facets of social justice reflect different aspects of individual lives, their relative resources and social status (Craig, 2018). Craig identifies five groups of values that inform social justice to underpin a “framework of political objectives”: fairness, which is related to equality of outcomes and treatment; recognition of equal worth and dignity; meeting basic needs; reducing inequalities; and participation (Craig, 2018). These values have guided this research, informing the way that social justice has been operationalised within the research, and informing the analysis of government policy. It is acknowledged that other views of social justice, expressed in social justice theory, empirical studies and policy, might reject some of these values, for example contesting the idea that social justice is not compatible with substantial

inequalities of wealth (Craig, 2018:6). These contestations are explored further in this chapter and in the policy analysis in Chapter Five.

In selecting the theoretical approach to use in the research, priority was given to being consistent with a view of disability as a product of social barriers more than individual impairment (discussed in more detail in the next chapter). The selected approach needed to respect the view of learning difficulties and learning disabilities as “status categories...a passing phase in the broader history of how human beings represent themselves” (Goodey, 2016:2), rather than fixed and inferior identities.

In line with these values and priorities, the research has used Fraser’s participatory parity approach as a conceptual lens. Fraser’s approach tackles systemic inequalities head-on, questioning “the politics of need interpretation” that are involved in the way that issues of social welfare are “framed” (Fraser, 1989:145), referring to how people’s needs are defined and whose interpretations of these needs dominate (Fraser, 1989). Fraser’s work challenges the narrow, often quantitative, ways that social welfare debates are cast and the idea that the “needs in question... [are] self-evident and beyond dispute” (ibid:145). This approach appears well-suited to the situation of people facing barriers to employment relating to how their physical and mental capacities are perceived, whether or not they are categorised as, or self-identify as, disabled.

Fraser’s concepts of social justice

Fraser’s approach derives from a commitment to “the equal moral worth of human beings” (Fraser, 2003b:231). Her central focus is on the conditions needed for “parity of participation” (2003a:36) such that members of society can “be ensured the *possibility* of parity if and when they choose to participate in a given activity or interaction (ibid:101 note 39, italics in original). Her approach focuses on barriers to participation, emphasising the socio-economic and political, rather than the individual and psychological, character of these barriers.

The concept of participatory parity is developed as a progression from earlier work by Rawls and Sen, belonging to “the family of capability approaches.. [and] ...the deontological tradition of justice as fairness” (Fraser, 2007:319). However,

Fraser challenges what she identifies as four central weaknesses of the liberal model of the “public sphere” (Fraser, 1997:69). These are:

- the failure to recognise that participation is affected by social inequality, which leads to the marginalisation of subordinate groups;
- the assumption that ‘the public’ has or should have a unified voice and that there is a single common interest, rather than recognising the benefits of “discursive contestation” (Fraser, 1997:82) for the representation of diverse needs and the articulation of identities;
- the designation of matters relating to private property and intimacy to the private sphere, usually to the advantage of dominant groups;
- the separation of civil society from the decision-making powers of the state, weakening the potential for democratic change (Fraser, 1997).

Parity of participation, as an ideal, is therefore a complex concept addressing these weaknesses and focusing on “the *social* character of social life” (Fraser, 2007:319, italics in original). Fraser suggests that this focus on ‘the social’ distinguishes her approach from the more individualistic focus of Sen’s capabilities-based approach (Fraser, 2007). She developed her concept of participatory parity in response to political issues and activism of the 1980s and 1990s, with the rising influence of neoliberal ideas and efforts to dismantle welfare state institutions, particularly in the US and the UK, and the development of what became known as identity politics. Fraser’s work addresses concerns about the potential divisiveness of identity politics and the risks and dangers associated with a focus on difference, particularly related to gender, race and sexuality. In doing so, she maintains a focus on socio-economic inequalities and issues of redistribution but brings a new approach to addressing issues of identity and difference that cannot be subsumed under class politics (Fraser, 2003a).

Fraser positions redistribution (socio-economic justice) and recognition (cultural justice) as two analytically distinct but intertwined dimensions of social justice. This is a challenge to the concept of misrecognition, embedded within identity politics, as a matter of “psychical deformation” or “impediment to ethical self-realization” (Fraser, 2003a:29). It is also a challenge to a class-oriented view of

social justice (“difference-blind economic egalitarianism” (Fraser, 2003a:8), which is criticised for failing to “assure justice for minorities and women” (ibid:8).

Participatory parity is proposed as a fundamental pre-condition for “fair democratic deliberation” (Fraser, 2003a:44), through which issues of maldistribution and misrecognition can be addressed. Until the mid 2000s, Fraser resisted the idea that “primary political concerns” and claims about legal rights might not be subsumed as either issues of recognition or redistribution. From 2005 she responded to rising concerns about globalisation, the power of global capital and the perceived threat to democratic politics by adding a third dimension to her approach: representation (Fraser, 2005). This development of her approach to social justice will not be discussed further here but it is noted to illustrate her commitment to a dynamic approach that provides analytically useful concepts to explore contradictions and incompatibilities, rather than overarching normative principles of a just society or a deterministic explanation of all social injustices.

Parity of participation needs two conditions to be satisfied: the “objective condition” and the “intersubjective condition” (Fraser, 2001:29). These relate respectively to redistribution and recognition. Fraser confronts the question of whether these two terms are “conceptually incompatible” on the basis of their philosophical roots (Fraser, 2003a:33). She proposes that, despite their “divergent philosophical provenances” (Fraser, 2003a:11), redistribution and recognition can be defined, or redefined, so that they can be combined to provide “a coherent programmatic perspective” on social justice (ibid:94).

Redistribution

Fraser’s “objective condition” for parity of participation is that material resources are distributed so as to ensure “independence and voice” (Fraser, 2001:29). This condition precludes “social arrangements that institutionalize deprivation” (Fraser, 2001:29) and socioeconomic injustices such as exploitation and economic marginalisation (Fraser, 2003a). Both exploitation and economic marginalisation refer to conditions of or access to paid work (“fruits of one’s labor”, “undesirable or poorly-paid work”, “denied access to income-generating labor”, (Fraser, 2003a:13)), whereas deprivation is about the “material standard

of living” (ibid:13). Fraser refers to material inequality as “gross disparities in wealth, income and leisure time” (Fraser, 2001:29). Here she is not proposing the complete elimination of material inequality but highlighting it as a potential barrier to parity of participation. Participatory parity is the key criteria for judging the point at which “resource disparities” become unacceptable (Fraser, 2001:40 note 13).

For the objective condition to be met, it is therefore necessary to reject social arrangements that institutionalise these socioeconomic injustices. These are the traditional concerns of theories of distributive justice, associated with economic structures and class differentials (Fraser, 2001). However, Fraser’s conception of class does not refer to the means of production but to “an order of objective subordination derived from economic arrangements” (Fraser, 2003a:49), resulting in insufficient resources for participatory parity. This conception of class directly corresponds to maldistribution as the “quintessential class injustice”, but it is not exclusively about economic resources and wealth: it may be accompanied by misrecognition (Fraser, 2003a:50). As a consequence, socio-economic injustices may be addressed by enhancements to recognition as well as, or as a route to, redistribution. For example, measures to enhance respect can result in improved access to housing and employment, resulting in an improved socio-economic position.

Recognition

Recognition is Fraser’s “intersubjective condition” (2001:29) for parity of participation. However, this is a specific concept of recognition intended to be conceptually compatible with redistribution. This conceptual issue arises because Fraser’s approach was developed out of concerns about the potential negative implications of dominant “identity models” (Thompson, 2006:26). Fraser highlights three problems with current campaigns for recognition. Firstly, that they encourage separatism rather than promoting respect, secondly that they may “marginalize, eclipse, and displace” struggles for redistribution (Fraser, 2003a:92), and thirdly that they may fail to take into account the impact of globalisation and the “increased mixing of populations” (ibid:92).

Fraser provides a critique of identity models, associated with identity politics and the writings of Axel Honneth and Charles Taylor (Thompson, 2006). She describes this as a focus on misrecognition as “damaged identity” (Fraser, 2001:24), emphasising “psychic structure over social institutions and social interaction” (ibid:24). Fraser suggests such conceptions of recognition have three main drawbacks. Firstly, they are normative, relying on a sectarian or specific view of “the good life” (Fraser, 2001:26), whereas Fraser proposes that agreement about normative matters should be the outcome of democratic deliberation. Secondly, they identify injustice as located in the individual rather than in social arrangements. In doing so, they risk victim blaming or authoritarian policing of individual attitudes and beliefs, rather than challenging those social practices (Fraser, 2001). Thirdly, they suggest that everyone has an equal and moral entitlement to self-esteem, a view that Fraser suggests is untenable because esteem is “accorded differentially on the basis of persons’ specific traits, accomplishments, or contributions” (Fraser, 2001:39 note 6).

To steer away from these weaknesses and to provide a model of recognition that is conceptually compatible with, but analytically separate from, redistribution, Fraser proposes a “status model” of recognition (Fraser, 2001:24). In this model, recognition is conceptualised as non-sectarian, acceptable to people with divergent views of “the good” (ibid:27), because it focuses on participatory parity as a right (Fraser, 2001). The status model conceptualises misrecognition as “status subordination”, shifting the focus away from “internal distortions ...in the self-consciousness of the oppressed” (ibid:27) and towards institutional and social practices. Rather than demanding an equal right to self-esteem, the status model demands an equal right to “pursue self-esteem under fair conditions of equal opportunity” (ibid:28).

Misrecognition, in this sense, is addressing issues of cultural or symbolic injustice, “rooted in social patterns of representation, interpretation, and communication” (Fraser, 1995:71), rather than “prejudice in the minds of the oppressors” (Fraser, 2001:27). Fraser suggests three types of injustice related to misrecognition: cultural domination, nonrecognition and disrespect and gives examples (Fraser, 2001) relating to the exclusion of same-sex couples from marriage rights (and associated tax breaks and other legal arrangements) in the

US, and the French ban on Muslim girls wearing headscarves in state schools (discussed below).

Fraser's status model of recognition shifts the focus from the individual to "institutionalized patterns of cultural value" which cast some as "inferior, excluded, wholly other, or simply invisible" (Fraser, 2000:113). Her approach therefore seeks to address subordination rather than to promote group identity. Justifiable claims for recognition need to support parity of participation, that is, it must be possible to show that misrecognition is preventing participatory parity, and that the recognition that is claimed will not itself reduce or deny participatory parity or cause maldistribution. In her discussion of the headscarf ban, for example, Fraser argues that allowing the headscarf might enable greater participation by Muslim girls but could also in effect validate a symbol of their subordination. Her point is not to deny the complexity of such recognition arguments but to refer to participatory parity as the "evaluative standard" for assessing the merits of claims for recognition (Fraser, 2001:32).

Perspectival dualism

One of the justifications Fraser gives for separating the concepts of recognition and redistribution (analytically) is that they may "impinge on one another in ways that can give rise to unintended effects" (Fraser, 2003a:64). Using this "perspectival dualism" (ibid:63) to assess claims for social justice, and policies to address injustice, enables the possibility of identifying where enhanced recognition might cause maldistribution or redistribution might cause misrecognition. Fraser gives the example of means-tested welfare benefits which, by targeting particular groups, can increase the stigmatisation of benefit recipients, a common theme in welfare research (see, for example, Lister, 2007), discussed further below in relation to disability benefits.

Fraser's analytically distinct concepts guide an exploration of potential and actual contradictions between claims for recognition and redistribution, as well as negative consequences of a failure to take both into account. This may help to expose weaknesses in policy responses to social injustices and to strengthen the case for "integrated" reforms that address both misrecognition and maldistribution (Fraser, 2003a:83).

Applying Fraser's concepts to the experiences of people with disabilities and learning difficulties

Disability remains marginalised in mainstream theoretical discussions of recognition despite appearing to be “so neatly fitted” with it (Calder, 2011:107). Disability in general and learning difficulties in particular are under-represented in social research. This may be the effect not only of “historically dominant views of the disabled” (Calder, 2011:106), including prejudice and discrimination, but also because of the complexities involved in conceptualising and understanding disability. It also reflects the constraints on self-organising among disabled people, and especially among people with learning difficulties. There are substantial differences between disability and other ‘protected characteristics’ (referring to legislative measures which address discrimination against people on grounds such as gender, ethnicity and sexuality) (Shakespeare & Watson, 2018; HMG, 2010): people with impairments may experience inequalities even in the absence of prejudice and discrimination; impairment may also be “an outcome of social injustice” (ibid:202), arising from inadequate nutrition or poor housing conditions, for example. These matters are explored in more detail in Chapter Three.

The range of injustices faced by disabled people and the failure of social policies to address them adequately (Fitzpatrick, 2011), indicate that a “pragmatic, hybrid approach” (ibid:158) to social justice, such as Fraser's, may be helpful, despite the absence of references to disability in her writings. Fraser's primary focus is gender-based injustice, although she frequently also addresses injustices relating to ethnicity, nationality and sexuality. Nevertheless, disability politics exemplifies “many of the themes in Fraser's work” (Lister, 2007:161), from the struggle against medical models of disability to claims for social rights and access to material resources (Shakespeare & Watson, 2018; Danermark & Gellerstedt, 2004). To explore this further, the following considers examples discussed in Fraser's explanation of her conceptual approach and comparable disability-related examples. Where possible, examples have been drawn from disability research applying Fraser's conceptual framework.

Fraser begins with a “thought experiment” to illustrate the extremes of a “conceptual spectrum” of social divisions, from redistributive at one end to

recognition-based at the other (Fraser, 2003a:16). To illustrate the redistributive extreme, she proposes the exploitation of the working class through the appropriation of “surplus productivity” for the private benefit of the capitalist class (ibid:17). Since the working class is defined as “the body of persons who must sell their labor power” (ibid:17) the definition includes working-class disabled people, regardless of whether they suffer similar or different “serious cultural injustices” (ibid:2017) to non-disabled working-class people. A disability-oriented example of maldistribution is provided by the payment of levies by employers to avoid meeting quotas for employing disabled people. Gould & Parker Harris discuss this with reference to workfare and employment policy in Slovakia, noting the gap between the policy rhetoric of compelling employers to employ disabled people and the reality of employers making funding contributions to “disability services” to “opt out of hiring” (Gould & Parker Harris, 2012: unpaginated).

Similarly, at the other end of the spectrum, Fraser’s example of the social division between heterosexuals and homosexuals would include disabled people in either category. A disability-oriented example, in a similar vein, would highlight the way in which “institutionalized patterns of cultural value” (Fraser, 2003a:18) construct non-disability as “natural and normative”, and disability as “disorder” to which the social response is “phobia” (Goodey, 2016:10). Fraser’s examples of how such institutionalised patterns play out for homosexuality - “shaming and assault”, “demeaning stereotypical depictions in the media”, “harassment and disparagement in everyday life” (Fraser, 2003a:18) – can be matched with similar examples for disability (Ryan, 2019; Dixon et al, 2018; Miller et al, 2004).

Fraser points out that most forms of social division lie between the extremes of maldistribution and misrecognition, using the example of gender-based injustice to explore this. However, even the extreme examples given (as above) have both distribution-based and recognition-based implications. One effect of employers paying out to disability services to avoid hiring disabled employees is to reinforce the misrecognition of disabled people as “financial burden” (Gould & Parker Harris, 2012: unpaginated). The consequences of negative media stereotypes are frequently maldistributive and material (Grover & Piggott, 2013a), including disabled people within a broader stigmatising of benefit recipients as “deviants

and scroungers” (Fraser, 2003a:65), especially where disabled people are depicted as fraudulent or fake (Ryan, 2019; Grover & Piggott, 2013a).

Fraser also gives two examples to show that misrecognition is not always a by-product of maldistribution or vice versa. For the first (misrecognition is not always the by-product of maldistribution), she gives the example of the African American Wall Street banker who cannot get a taxi to pick him up; for the second (maldistribution is not always the by-product of misrecognition), the redundancy of the skilled white male industrial worker in a corporate restructuring. Comparable reports can be found of discrimination against high-salaried disabled people (Croft, 2020) or the failure of facilities or services for high-profile paralympians (BBC, 2019).

Discussing how claims of maldistribution and misrecognition might conflict, Fraser considers two current controversies: the different ways that US states have recognised the legal status of same-sex couples; and the banning of headscarves by Muslim girls in French state schools. In both of these controversies, Fraser’s approach highlights how recognition may not lead to parity of participation. For example, civil partnership rather than marriage may mean weaker legal rights for same-sex couples; banning headscarves on the grounds that they are restrictive may result in the exclusion of Muslim girls from schooling. Relating this to disability, Vedeler uses Fraser’s concepts to highlight how recognition involved in the awarding of a “disability pension” to an unemployed disabled woman undermined her determination to participate in the labour market by implying “no prospect of work” (Vedeler, 2009:70). Another empirical study guided by Fraser’s concepts showed that, without redistributive measures enabling the provision of information and the training of professionals, young disabled people remained marginalised in decision-making about their lives, even where their need for participation was recognised (McNeilly et al, 2015).

Fraser’s conception of maldistribution and misrecognition as analytically separate, not reducible to each other but “interpenetrated”, leads to her “perspectival dualism” (Fraser, 2003a:63), which enables “the complex connections between two orders of subordination” to be theorised (ibid:64). She illustrates this with the example of single mothers who claim social security

benefits, showing how such redistributive measures, associated with benefit stigma, exacerbate the cultural devaluation of female caregivers. There are clear similarities with “media attacks” on disability benefit recipients (Briant et al, 2013:887, Grover & Piggott, 2013a).

Hugemark and Roman’s research on the Swedish disability movement uncovers how recognition (through membership of disability organisations) can have “unintended effects” (Fraser, 2003a:64), for example, where “intersecting social divisions” are overlooked (Hugemark & Roman, 2007:38). In focusing on disability identity politics, some of the organisations discussed in their research “silenced and ignored” women and neglected a “gender perspective” (ibid:39). Questions of recognition and access to resources, especially over who had “the right to interpret and communicate the needs of the group” resulted in “more or less open conflicts” (ibid:37) and, in some instances, splits and sub-groups. Fraser’s concepts of parity of participation and perspectival dualism (Fraser, 2003a) provided the means to explore power relations and practical changes, widening the focus beyond relationships between people with or without impairments, to analyse the complexities of “questions concerning the construction of group identities (ibid:43). Similarly, Ferguson explores how “an emphasis on difference (as opposed to a recognition of diversity)” may undermine the efforts of mental health service users to “challenge discrimination and oppression” by obstructing alliances with other oppressed groups (Ferguson, 2003:84).

The complexities of the interconnections between maldistribution and misrecognition are further illustrated in an application of Fraser’s approach to analysing the impact of the UK government’s austerity programme on disabled people (Dodd, 2016). In exploring how “cultural demonisation and material deprivation can become mutually reinforcing” (2016:154), Dodd uncovers the isolating effects of material cuts to support services and the “feedback mechanism...between cultural subordination and economic disadvantage” (ibid:156) when disabled people become excluded from community life.

Interconnections between redistribution and recognition are also illuminated by Fraser’s application of her concepts to political action. Fraser considers solutions to maldistribution and misrecognition within two broad categories: “affirmative

strategies” and “transformative strategies” (Fraser, 2003a:74). These are delineated by the extent to which they address “inequitable outcomes...without disturbing the underlying social structures that generate them” (ibid:74). So, in the context of distributive justice, the “liberal welfare state” is a classic affirmative strategy, whereas “socialism” is a transformative strategy (ibid:74). Applying the same approach to misrecognition, Fraser suggests comparing the revaluing or enhancing approach of gay identity politics with the deconstructing or destabilising approach of queer politics (ibid:75). These have direct equivalents in disability politics, in disability identity politics and crip politics (Kafer, 2013). These aspects of disability politics are described and discussed in the next chapter.

Limitations and concerns

Fraser’s approach rejects the idea that “a philosophical expert can and should decide what is needed for human flourishing” (Fraser, 2003a:43). Instead “only the full, free participation of all the implicated parties can suffice to warrant claims for recognition” (ibid:43). This exposes her approach to criticism that it is circular: “inclusive deliberation requires just redistribution and recognition; but just redistribution and recognition require inclusive deliberation” (Thompson, 2006:140). Fraser accepts this circularity as expressing the “reflexive character of justice” within which the conditions for democratic participation can be realised (Fraser, 2003a:44) and suggests that the same circularity would arise for any approach that “envisions a transition to more just social arrangements via political processes that occur by definition in unjust circumstances” (Fraser, 2008a:340-341).

Fraser’s approach to social justice was developed as a response to the “culture wars” in North America, itself a challenge to “difference-blind liberalism”, and splits on the Left over whether harms relating to class or identity should take precedence (Olson, 2008:1). Although her writings on social justice have concentrated on maldistribution and misrecognition, she has responded to critics who have highlighted the absence of a “political dimension” (Olson, 2008:6), and her later work includes representation as a third aspect of social justice. The focus of this is largely on global and transborder politics rather than on

representation and political rights within national borders (Olson, 2008), so her concept of misrepresentation has not been applied within this research.

This 'participatory parity' approach to social justice is deontological: citizens can "endorse different and often conflicting sets of values" (Thompson, 2006:143). The range of options they can choose between is limited by the commitment to parity of participation: democracy "determines" justice and justice "constrains" democracy (Thompson, 2006:143). The effect is to produce a conception of social justice that largely avoids prescription, apart from "good enough" democratic deliberation: "the parity principle can serve as a substantive norm for evaluating the outcomes of deliberation as well as a procedural principle for evaluating deliberative processes (Fraser, 2008a:342).

The capabilities approach (Nussbaum, 2011; Sen, 2010), which may offer more prescriptive guidance on what 'a good life' or 'human dignity' might mean in day-to-day practice, was considered as an alternative approach for this research. A full discussion of that approach is beyond the scope of this thesis, but it is acknowledged that a capabilities approach to social justice offers significant potential for contributing to the development of social policy, including addressing "more spiritual and emotional realms" that are rarely considered in relation to people with learning difficulties and disabilities (Johnson et al, 2010:127).

Fraser's definition of misrecognition as status subordination inevitably attracts criticism for "downplaying" the psychological harms associated with experiences of injustice (Lister, 2007:165), such as not paying enough attention to "the harm made to people with disability... in everyday personal encounters" (Danermark & Gellerstedt, 2004:347). Lister accepts Fraser's view that misrecognition is not "simply" about attitudes, beliefs and disrespect, but questions whether Fraser's status subordination definition of misrecognition leaves room for consideration of "psychological pain" (Lister, 2003:6). Similarly, it can be argued that psychosocial, psychological and biological barriers to participatory parity cannot be reduced to the cultural or socio-economic (Calder, 2011; Danermark & Gellerstedt, 2004).

Fraser's response, expressed in consideration of domestic violence, is that social injustices "are not best conceived psychologically...but are better conceived

socially, as forms of subordination” (Fraser, 2003b:219). However, Lister’s challenge is particularly pertinent to the experiences of disabled people and people with learning difficulties, and the widespread occurrence of hate crimes, bullying and disrespect, as discussed in general terms in the next chapter, and in the later chapters about the research participants’ experiences.

Chapter 3 Learning difficulties, learning disabilities and disability

This chapter presents a discussion of the term 'learning difficulties', as used in this research, its relationship to concepts and theories relating to disability, and how those concepts and theories guide the research. The research has operationalised the term mild learning difficulties to cover a group of people whose cognitive impairments have affected their search for work but who may or may not identify themselves as disabled. The literature reviewed in this chapter provides a foundation for exploring the complexity of these identification and identity issues, and their connections to issues of social policy.

The chapter begins by exploring statistical information about prevalence and connections to poverty and inequality. This is followed by a critique of the basis of statistical data and a discussion of the complexities involved in using labels and terminology relating to disability, learning disabilities and learning difficulties. From there, the focus broadens out to consider key theoretical ideas about disability to explore the challenges involved in identifying whose experiences this research is about, and why that matters. Building on this, and a discussion of other disability constructs currently influencing government policy, the chapter concludes by considering related research about the lives of people with mild learning difficulties and the challenges for research design.

The most frequently used terms in discussions about disability, such as 'disorder', 'impairment', 'deficit', 'incapacity', and 'disability' itself, all have negative connotations associated with a lack or insufficiency. If 'normal' is an ideal that is a "shared social goal" (Smith, 2009:19), then 'deficiency' becomes a "social problem" (ibid:19). The very act of writing about disability involves the use of this kind of language without which the topics being researched here cannot be discussed. Yet using this language risks conveying and promoting those negative connotations with their potentially stigmatising effects. However, the disablism (Barnes, 2012) inherent in language cannot be disentangled from "the persistence of negative social and cultural attitudes towards disabled people" (Scully, 2010:26) and "everyday experiences of disablement" (Barnes, 2012:24), which leave the majority of disabled people "the poorest in all societies" (Barnes, 2012:24). Knowledge of the official data on the prevalence of learning difficulties and related statistics about inequalities should therefore be recognised as useful

to understanding both the experiences of people with learning difficulties and the policy response to ‘problems’ such as the disability employment gap (DEG).

Prevalence

Around 1.3 million school pupils (15%) in England are identified as having special education needs (SEN) (DfE, 2019: unpaginated). A much smaller proportion of pupils (3%) have an Education, Health and Care Plan (EHCP), a legal document providing entitlement to additional support beyond SEN support. Pupils categorised as having primary needs relating to physical or sensory impairments account for 5% of SEN support and 9% of EHCPs. The top three needs categories are labelled “speech language and communication needs” (23% SEN, 15% EHCPs), “moderate learning difficulty” (23% SEN, 11% EHCPs) and “social, emotional and mental health” (18% SEN, 13% EHCPs). The largest category of EHCPs is “autism spectrum disorder” (29%), which accounts for 6% of SEN support (DfE, 2019: unpaginated).

Beyond school-age education, however, figures of the prevalence of learning difficulties rely on administrative data, based on people who are known to be using specialised services, and this is also the case for “the vast majority of research studies involving people with intellectual disabilities” (Emerson & Hatton, 2014:41). People with less severe conditions, who make up the majority of people with intellectual disabilities (ibid), are unlikely to use specialist services beyond the years of compulsory education (ages 5-18). This may be a choice (Simons, 2000), where services are deemed inappropriate to people’s needs. More likely, it is because these services are tightly rationed and people with less severe conditions are therefore less likely to meet eligibility criteria (Emerson & Glover, 2012). In consequence, there is a “marked discrepancy” between the likely ‘true’ prevalence and the “administrative prevalence” (Emerson & Hatton, 2014:42), arising because the “hidden majority” (Emerson & Glover, 2012:141) largely disappear from the administrative data through exclusion from services (Emerson & Glover, 2012; Emerson & Hatton, 2014).

This “transition cliff” (Emerson & Glover, 2012:139) is illustrated in Figure 3.1. It indicates that, although around 3% of the population may have been identified as having special educational needs at the end of compulsory schooling, most are subsequently excluded from administrative prevalence data. The sense of a hidden majority is also supported by comparing estimates from Public Health

England of just over 1 million people with learning disabilities, and records from GP registers showing around 250,000 adults and children identified as having learning disabilities (Public Health England, 2016). Even lower numbers of people with learning disabilities receive local authority adult social care support (129,000 in 2017, according to National Audit Office estimates (NAO, 2017)).

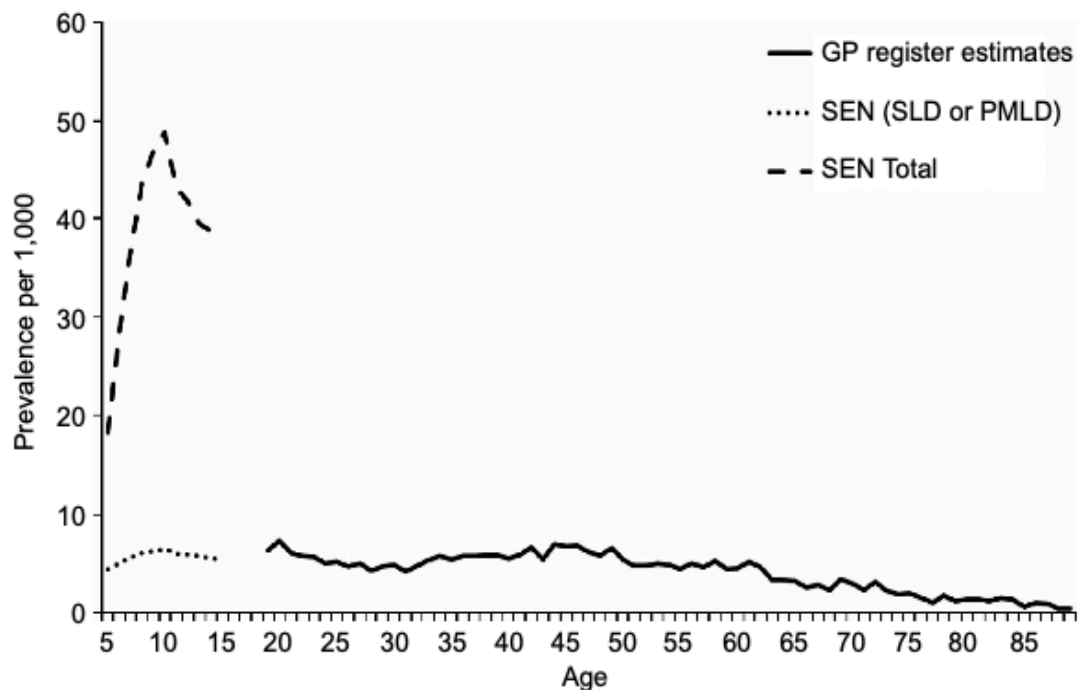


Figure 3-1 Estimated age-specific administrative prevalence (rate per 1,000) of learning disabilities in England, 2010

Source: Emerson & Glover, 2012

The term ‘mild learning difficulties’, as used in this research, broadly refers to this ‘hidden majority’. Although learning difficulties are “neither a disease nor a disorder” (Emerson & Hatton, 2014:19), public health data may help to expand knowledge of the social, cultural, economic and environmental aspects of the lives of people with learning difficulties who fall outside the administrative categories for learning disabilities. Public health data indicate that compared with their “non-disabled” peers, this hidden majority have:

“lower levels of psychological well-being, poorer self-rated health, increased rates of smoking, reduced access to social capital, more problems in personal and social relationships, lower occupational prestige, lower income and are more

likely to be involved with the criminal justice system" (Emerson & Glover, 2012:141).

Exposure to this range of adversities, and others such as being much more likely to have been a victim of violent crime and hate crime, is "predictive of poorer well-being amongst people with intellectual disabilities" (Emerson & Hatton, 2014:71).

Significantly for this research, epidemiological research consistently reports "an association between poverty and the prevalence of less severe intellectual disability" (Emerson, 2007:108). This association is linked to three processes. Firstly, the effects of poverty, through "exposure to a range of environmental and psychosocial hazards that are likely to impede children's intellectual development" (ibid:109), including accidents, infections, poorer schooling and other adverse events. Secondly, the large financial and opportunity costs associated with supporting a child with intellectual impairments, which increase the likelihood of the family experiencing poverty and reduce the chances of them avoiding it (Emerson, 2007). Thirdly, that "having an intellectual disability" significantly increases the likelihood of long-term unemployment (Emerson, 2007:109).

Hatton et al report not only that "British adults with intellectual impairments... are at significantly increased risk of potential mental health problems than their non-disabled peers" (Hatton et al, 2017:194) but also that this risk "may be attributable to their increased risk of exposure to well-established social determinants of poorer mental health rather than their intellectual impairments per se" (ibid:195). They conclude by pointing out that this is "not inevitable" but the result of "social and cultural practices", including discrimination, and the failure of "social policy interventions" to protect people's living standards (ibid:195).

Factors such as the increased likelihood of experiencing childhood bullying are also significant. Children with SEN are twice as likely as children with no SEN to experience bullying all of the time at school, even when other risk factors are taken into account (such as socio-economic factors, family circumstances, age and physical size, ethnicity) (Chatzitheochari et al, 2016). The increased risk of bullying associated with SEN and disability, combined with the greater likelihood of experiencing poverty, place those young people at a "double disadvantage...

during critical periods in their school careers and development” (Chatzitheochari et al, 2016:708). Moreover, childhood bullying experiences have a “strong negative impact on social and psychological later life outcomes” (Chatzitheochari et al, 2016:708) including “poor mental, physical and cognitive health in adulthood” (Takizawa et al, 2014:782, Brimblecombe et al, 2018).

Two other features of prevalence data are also particularly noteworthy for this research. The SEN data suggests a much higher prevalence among boys than among girls, with almost twice as many boys getting SEN support and more than twice as many getting EHCPs (DfE, 2019: unpaginated). It also indicates disproportionate variations in SEN by ethnicity, such as 8% of Chinese pupils but 15.5% of Black pupils (Public Accounts Committee, 2020:5).

There is some evidence to suggest that the lower rate of identification among girls relates more to gendered expectations about behaviour (Benjamin, 2002) and gender bias than “physiological or biological factors” (Wehmeyer & Schwartz, 2001:30). The rate of identification among ethnic minority groups is “generally lower” once socio-economic factors are taken into account (Emerson, 2012:222). These factors remain under-researched: the Department for Education recently acknowledged that it is unable to explain “the wide variations between different demographic groups” but that it “suspects there is under-identification of some special needs, for example of autism in girls” (Public Accounts Committee, 2020:5). These prevalence-related issues highlight the connection between disability and other types of oppression (Goodley, 2017; Morris, 1993; Stuart, 1993) which are only touched upon in this thesis but are flagged in the concluding chapter as areas for further research.

Official statistics on employment rates for “the whole population of working age adults with learning disabilities”, including the previously discussed ‘hidden majority’, are “lacking” (Hatton, 2018:117). However, large scale surveys suggest only 15-20% of this group may be in some form of paid employment (Hatton, 2018). Analysis of survey data indicates that British “people with intellectual disabilities” are more likely than their peers to experience “non-standard employment conditions and job insecurity”, which is “typically associated with poorer health” (Emerson et al, 2018:201). They are also more likely than their peers to transition from non-standard employment to economic inactivity, which is associated with “poorer health status” (ibid:202). Data about adults with

learning disabilities who receive social care support, which are the only annual data available relating to the paid employment of adults with learning disabilities in England (Hatton, 2018), suggest the employment rate peaked at just over 7% in 2011/12, declining to below 6% in 2016/17 (Hatton, 2018). These data also indicate a consistently higher employment rate among men than among women in this group.

There is a wide range of regional variation in this data from 12% in the top quartile to under 2% at the bottom, although this may in part be attributed to “issues with collecting and collating the statistics” faced by local councils (Hatton, 2018:121). Addressing questions about improving these employment rates, such as links between local provision of supported employment and rates of paid employment, might be aided by improvements in the quality and scope of such data (Hatton, 2018).

Labelling and terminology

Labels relating to identity, disability and impairment have economic, political, social and cultural consequences for the individual and for social groups. Labels may signify belonging and pride or rejection and stigmatisation. Labels may confer eligibility for rights, services and resources, but may also exclude or marginalise. This thesis explores how these consequences are experienced by people with mild learning difficulties.

The history of labels relating to cognitive impairment is one of negative connotations (Northway, 2017), with stigmatising terms used both informally and in the language of professionals and institutions (Bartlett et al, 2007). Extreme views, associated with early 20th century eugenics and fascism, that question the very humanity of people with cognitive impairments have not been entirely eradicated (Scior, 2016). Pejorative terms such as ‘disorder’ remain in common use in many areas, with some historical labels such as ‘moron’ and ‘idiot’, which were once medical categories of learning disability, becoming “generic insults” (Scior, 2016:4). As the younger participants in this research indicated, even the term ‘special needs’ has become a term of abuse and playground bullying.

The term ‘learning disabilities’ is the most commonly used term in public policy and the third sector within the UK, especially in relation to health and social care.

Learning disability is defined in the influential Valuing People White Paper (DoH, 2001) as including “the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development” (DoH, 2001:14).

This individually-oriented definition highlights the on-going influence of the medical model of disability within UK social policy, despite “an outward show of embracing the principles of the social model” (Cluley et al, 2020:249). In other English-speaking countries, the term ‘intellectual disabilities’ is used in a broadly similar way. The term ‘learning difficulties’ is also found within UK government documents, in place of ‘learning disabilities’, but is more commonly found in third sector documents and in educational settings (Cluley et al, 2020). Claims that it is the preferred term of “the majority of people who live with these labels” (Willetts, 2011:99) are harder to verify, but are consistent with usage by some self-advocacy organisations (Goodley, 2001; People First (undated)).

To complicate matters further, however, the term ‘learning difficulties’, or ‘specific learning difficulties’, is sometimes used to refer to distinct conditions, such as dyslexia, which can occur “across the range of intellectual abilities” (British Dyslexia Association, 2010, unpaginated). In North America, the term ‘learning disabilities’ is used to refer to these specific conditions. In everyday language, the term ‘dyslexic’ continues to be negatively linked to “being stupid” (Evans, 2014:367).

Table 3.1 provides descriptive summary of the terms which may be referred to in this thesis. All of these terms are currently in use at the time of writing, either in government documents or in the broader literature referred to in this research.

Table 3-1 Terminology in use

Term	Where found/used
Disability, Impairment	<i>Disability</i> is used in academia and among some disability activist groups to indicate a socially created concept, in contrast to (but not necessarily separate from) <i>impairment</i> , which is an attribute of the body or refers to “an individualised medicalised phenomenon” (Goodley, 2017:35). Many policy reports use the terms interchangeably (e.g. EHRC, 2017).
Ill-health	Used in government surveys (e.g. Labour Force Surveys) to indicate a medical condition. Not necessarily a long-term impairment or disability but may be included in disability statistics. This may mean the disadvantage associated with disability may be “understated” (Berthoud, 2011:11).
Cognitive disability, cognitive impairment	Umbrella terms that include learning difficulties, intellectual disabilities and learning disabilities, but may also include dementia, autism and other cognition-related conditions.
Learning difficulty	UK term, most frequently used by self-advocates and in education; used in this research to refer to people with permanent, non-specific cognitive impairments which have been present since before age 18. In some educational settings learning difficulties is used to refer to specific conditions such as dyslexia which do not necessarily affect other aspects of cognitive functioning. That is not the sense in which the term is used here.
Intellectual disability	Often found in non-UK research and human rights-related documents; used here when referring to these sources.
Learning disability	UK term, used in government, legal, health and many 3 rd sector contexts; referred to here when referring directly to UK sources which use the term. In North America, this term is used to refer to specific conditions such as dyslexia which do not necessarily affect other aspects of cognitive functioning.
Special educational needs (SEN)	Used in educational settings and legislation relating to people up to the age of 25. The latest statutory guidance on SEN includes any child or young person if they have “a learning disability or difficulty which calls for special educational provision to be made for him or her” (DfE & DoH, 2015:15).

Sources: Carlson, 2016; Berthoud, 2011; Porter & Lacey, 2005; Corker & French, 1999; Jenkins, 1998.

Hereafter, the term 'learning difficulties' is used to refer generically to include a spectrum of conditions relating to broad cognitive impairments which start before adulthood and have a lasting effect. The word 'difficulties' has been used in preference to 'disabilities' to open up discussion about the relationship between learning difficulties and disability itself. The term 'learning difficulties' has been widely used within compulsory and post-compulsory education for many years, as well as by many service providers, and was therefore considered likely to be familiar to those participating in the research.

Traditionally, the medical identification of learning difficulties has been associated with measures of IQ (Fulton & Richardson, 2014; Porter & Lacey, 2005). IQ measurement rests on two key assumptions. Firstly, that intelligence is statistically normally distributed in the population and, secondly, that intelligence can be accurately tested and assessed. IQ measures are used to define terms such as "borderline intellectual functioning" (Peltopuro et al, 2014:419) as one to two standard deviations below average, and the qualifying terms mild, moderate, severe and profound originate from medical understandings relating to IQ scores of 50-70, 35-50, 20-35 and below 20 (Fulton & Richardson, 2014). However, these cut-off points are arbitrary and have been subject to revision with "little scientific rationale" (Webb & Whitaker, 2012:441).

Flaws in the concept and testing of IQ have been widely documented (Webb, 2014) including errors in the design and administration of testing and a lack of evidence linking IQ scores to "autonomous functioning" (Webb, 2014:12). Nevertheless, these IQ-related qualifiers remain in widespread use within the literature, and in education, health and social care practice, as signifiers of the degree of impairment experienced and the level of support a person may be entitled to. It is important to acknowledge the weakness of the testing and diagnostic basis of statistics relating to the categorisation of people by intellectual competence (Jenkins, 2014) and to note how IQ-related cut-off points for categorising people have been altered historically to reduce eligibility for services (Simons, 2000). In effect, the categorisation of people by intellectual competence "derives largely from the treatment and services its members receive", rather than "'intrinsic' individual or collective characteristics" (Jenkins, 2014:200).

Goodey's historical analysis shows how the process of attempting to link personal intelligence to "neutral, objective and permanent rationality...of scientific

knowledge systems (Goodey, 2016:13) was connected, through the development of IQ testing, to a “quest for racial purity”. This supports the earlier discussion on connections between disablism and other forms of oppression: the very concept of “intellectual disability...feeds other forms of discrimination”, including racism and sexism (ibid:124).

These are major criticisms of the official categorisation processes currently in place to identify people with learning difficulties, and this research embraces those criticisms. They also serve to illustrate how terms such as ‘learning difficulty’ and ‘learning disability’ can be viewed as social constructs which are “a function of time and place” (Simons, 2000). Some would go so far as to argue that such labels are effectively meaningless, signalling a “status category” identified solely by the response of those with the “urge to exclude” (Goodey, 2016:2-3). In this research, however, it is argued that the concept of learning difficulties is useful, despite being highly complex, and does have meaning relating both to the consequences of intellectual impairments themselves and to the responses of others. The concept of learning difficulties may be illuminated further by considering how disability is understood more broadly, and how cognitive impairments might be similar to and different from other types of impairment.

Concepts and models of disability

Until the 1960s, disability was “almost exclusively” considered as a medical problem and personal tragedy (Barnes, 2012:12). Medical approaches to disability continue to develop and what is now frequently referred to as the medical, or individual, model of disability remains the “dominant framework” for the way disability is viewed in most of the world (Emerson & Hatton, 2014:1). The medical model centres on individual impairment and functional limitations as “inevitable” aspects of individual deficit (ibid:1). From the perspective of the medical model, disability is characterised as deviation from the norm, where the norm is represented by “only one, or a very limited number, of ‘valid’ embodiments” (Scully, 2002:52).

Within the medical model, disability is positioned as an individual problem associated with disease, to which the appropriate response ranges between ‘cure’, ‘treatment’, ‘rehabilitation’, ‘therapy’ or ‘prevention’, through a mixture of medical intervention and changes in individual behaviour. While an

individualistic, medically-oriented approach to disability might be viewed as a benign, if paternalistic, theoretical construction, it can underpin practice which undermines the autonomy of disabled people. At the extreme, it can be linked to theoretical justifications for “assisted suicide, euthanasia and antenatal termination” (Goodley, 2017:8) and eugenics (Smith, 2009).

Although the medical model remains dominant in the identification and treatment of disabled people, political and social responses to the injustices they face have moved away from “the inevitable consequences of ill health” toward “social structures and socio-cultural practices” for explanations of the disadvantages faced by people with impairments and health conditions (Emerson & Hatton, 2014:32). The driving force behind this shift in the UK was the development of the social model of disability (Oliver, 2009).

The social model of disability was developed by a group of physically disabled people in the 1960s and 1970s as the foundation for activism to reject residential care and campaign for disability income benefits (Barnes, 2012). Although it was not developed as a theoretical framework, it provided the foundation for a new way of theorising the position of disabled people in society. The social model of disability draws on Marxist theories to “probe the conditions of disablement” (Goodley et al, 2012:2), rather than focusing on individual, medical conditions. These materialist underpinnings of the social model link disability oppression to social and economic structures, and particularly to the exclusion of disabled people from paid employment (Grover & Piggott, 2013b).

Disability campaigners in the 1970s argued that disability was “a complex form of social oppression similar to that encountered by women, ethnic minorities, lesbians and gay men” (Barnes, 2012:13). The social model “became a way in which to link up” the diverse experiences of disabled people and develop “a collective consciousness” (Oliver, 2009:52). It was the inspiration for disability activists’ campaigns for anti-discrimination legislation, the development of user-led services, direct payment schemes, and the emergence of a disability arts and culture movement and disability studies as an academic discipline (Barnes, 2012).

The influence of ideas and activism related to the social model of disability over policy development can be seen in the rise of person-centred practice, putting “individuals with disability in control of decision making about their own lives”

(Fyson, 2020:234). For people with cognitive impairments, this has also been reinforced by social role valorisation theory, which focuses on how the organisation of support services can maximise “social integration and acceptance” particularly through active participation (ibid:226). The emphasis in theory, practice and activism on personal autonomy and rights, including the right to work, has chimed with the rise of neoliberal ideas of “activated citizens” and the “philosophy of choice” in adult social support policy (Roulstone & Prideaux, 2012:119-120). Ideas of empowerment and “potentially enabling discourses of personalisation” (Roulstone & Prideaux, 2012:16) have merged with views of “responsible autonomy” (Dowse, 2009:576).

The influence of this valorisation of personal choice and autonomy can be seen in the espousal of a commitment to the social model of disability in current government disability policy (for example, DWP & DoH, 2017:33), despite its continuing focus on the individual and on medical assessments determining entitlement to disability benefits. For people with cognitive impairments and communication difficulties, the linking of “choice” with the determination of “personal satisfaction” may be particularly unsatisfactory (Schelly, 2008:724). However, there are also wider implications for people who “remain on the margins of social and political life” and tend to be “high frequency users of a wide range of welfare services” (Dowse, 2009:576). These issues are explored further in Chapter Five of this thesis and in the concluding chapter.

A conceptual separation of impairment from disability was central to the original social model of disability which claimed that “most impairments are not curable; and all disability can be eradicated by changes to the way we organize society” (Oliver, 2009:44). This position has been modified in response to subsequent debates within disability studies about how to theorise impairment, the risks associated with overlooking individual “impairment effects” (Thomas, 2007) and the impact of “individual bodies and brains” on the way that disability is experienced (Shakespeare, 2014:17). While Oliver’s position is not intended to ignore “the realities of impairment” (2009:48), developments in Critical Disability Studies have challenged the idea of impairment as “naturally occurring”, arguing that it is as much a cultural, socio-economic and politically constructed term as disability (Mallett & Runswick-Cole, 2016:115).

However, the conceptual distinction between disability as a “historically contingent, socially constructed phenomenon” (Grue, 2016:958) and impairment as “bodily structure or function” (ibid:958) may help to clarify why people may be disabled but not recognise themselves as such or be recognised by others as such. This is a major barrier to the practical application of a “single category” of disability, which is the way that disability is often understood in legal, policy or academic terms (Grue, 2016; Shakespeare, 2014). Recognition of the “always-already disadvantaged” position of disabled people (Shakespeare & Watson, 2018:202) can also expose the difficulties of developing a social movement around disability, in contrast to “social movements based on gender, sexuality and ethnicity, for example” (ibid:202). Impairments of the body and mind are not only socially stigmatised but also functionally limiting. As Kafer points out, “as much joy as I find in communities of disabled people, and as much as I value my experiences as a disabled person, I am not interested in becoming more disabled than I already am” (Kafer, 2013:4).

Solidarity among disabled people may also be undermined by the existence of hierarchies of disability (Shakespeare, 2014). These hierarchies are reinforced by prejudice and discrimination against people with learning difficulties (Stalker, 2012; Goodley, 2014). This reflects wider social patterns of discrimination against people deemed less ‘competent’ (Jenkins, 1998) and the dominance of neoliberal discourses of “ability, competence, good health, autonomy and self-sufficiency” (Goodley, 2017:126). The interplay between “disablism and ableism, disability and ability, incapability and capability, impairment and normality, learning disabilities and learning abilities” (ibid:126) underpins the construction of disability as deficiency.

Intersectional analysis (Collins & Bilge, 2016) can expose connections between the construction of disability, and sexism, racism and homophobia. Disability is gendered in the sense that disabled women tend to be poorer, less well educated and more at risk of sexual abuse than disabled men (Goodley, 2017; Mohamed & Shafer, 2015). However, disability also intersects with gender in shaping how both are experienced (Mohamed & Shefer, 2015) through the connection of expectations of the masculine and feminine and expectations of the “disabled role” (Malhotra & Rowe, 2014:154). The association of “weakness, dependency and passivity” (ibid:154) with both disability and “things coded as ‘feminine’” (Fraser, 1995:79) is significant in marginalising and stigmatising both

disabled women and disabled men (Malhotra & Rowe, 2014; Thomas, 2007). Gendered and racialised expectations of behaviour may also influence the identification and diagnosis of intellectual disabilities (Nowell et al, 2015; Wehmeyer & Schwarz, 2001) as noted earlier in relation to prevalence statistics.

Cultural depictions of disability provide further insight into the complexities of the ways in which disability is constructed as deficiency. For example, recent 'positive' cultural depictions of disability in reality television, Paralympic events and superhero fiction reinforce ideas of individual merit, personal achievement and independence (Grue, 2015). The effect is a "displacement of qualities", in which impairments are held up as sources of "extraordinary" achievement and transformation rather than "instances of human variation" (Grue, 2015:120).

Such analyses not only problematise the concept of a positive disabled identity, but also provide theoretical insights that can be drawn on in the analysis of policy and in the way that individuals talk about their experiences. The implications for people with learning difficulties of the valorisation of the "autonomous reflexive individual self" (Davies, 1998:124), and its association with neoliberal values and concepts of meritocracy discussed in Chapter One, are explored through this research and provide a central focus for the concluding chapter.

Disability constructs within the policy arena

The most influential attempt to synthesise the medical and social models, integrating ideas of rehabilitation and care with notions of social and environmental barriers, is the international Classification of Functioning, Disability and Health (ICF) developed by the World Health Organisation (WHO) (Emerson & Hatton, 2014). This model, sometimes referred to (outside the UK) as a "biopsychosocial" model (Emerson & Hatton, 2014:2), is influenced by the Nordic "social relative model of disability" in which "disability exists on a continuum shifting between the individual and their environment" (Owens, 2015:386). The ICF model remains strongly influenced by the medical model, but with a more "holistic" view of health that includes the effects of environmental and social factors (Emerson & Hatton, 2014:4).

In the UK context, the term 'biopsychosocial' has been significant in relation to the work of Waddell and Aylward (2010), which has been frequently referenced in support of government welfare reforms since 2010. Waddell & Aylward's

“biopsychosocial model” (Waddell & Aylward, 2010) is proposed as “a systems model... of the process(es) that promote health or lead to sickness and disability” (ibid:26). This “does not reject or replace the medical model, but supplements and extends it”, aiming to “strike the right balance between providing the most effective care and achieving the best social and occupational outcomes” (ibid:28).

In Waddell & Aylward’s work “common health problems” of mental health, musculoskeletal and cardiorespiratory conditions, are distinguished from “severe medical conditions and permanent impairment” (ibid:6). The former are “insufficient in themselves to explain long-term incapacity” (ibid:8) and therefore “recovery is normally to be expected”. They are defined as “common” on the basis that they account for around two-thirds of “long-term sickness absence, incapacity benefits and ill-health retirement” (ibid:6). If the condition is not “severe” that only leaves the category “common health problems” (Waddell & Aylward, 2010:12). Learning difficulties is thereby made invisible, as it does not fit within either category.

Building on Waddell’s earlier work on back pain, Waddell & Aylward imply that work “has the psychological effect of making people believe themselves to be well, which in turn has a positive effect on their physical wellbeing” (Davies, 2011:66). In its application to policy, Waddell & Aylward’s work has been linked with research indicating that unemployed people have “much lower levels of mental well-being than those in work” (Clark & Oswald, 1994) and the turn to “wellbeing” and “happiness economics” (Davies, 2011:68). The result is that it has been used as a “causal explanation of sickness absence” (Shakespeare et al, 2017:29).

Waddell & Aylward’s ‘BPS model’ has been strongly criticised by disability researchers, activists, scientists and charities: their analysis highlights the weakness of evidence behind the claim that work is therapeutic, the neglect of the negative effects of low paid work, links between the researchers and commercial insurance interests, and the application of the model to support increased welfare benefit conditionality and benefit sanctions (Ablashi, 2017; Shakespeare et al, 2017; Faulkner, 2016; Friedli & Stearn, 2015). Shakespeare et al conclude “there is no coherent theory or evidence behind this model” (2017:24). Nevertheless it has been highly influential within government policy-

making (for example DWP & DoH (2016), see also Chapter Five of this thesis) and is connected to policy around incapacity and out-of-work benefits, arguments about deservingness and the distinction between 'genuine' and 'fraudulent' claims, as discussed further in the concluding chapter.

Researching disability and learning difficulties

The development of the social model raised challenging questions about the control, conduct and evaluation of disability research (Oliver, 1998). Twenty years ago, Aspis, a social researcher and disability self-advocate, wrote about "researchers jumping on the bandwagon of learning disability research", while "disabled people with learning difficulties are on the whole unsuccessful in being funded to set out our own agendas and find our own solutions" (Aspis, 2000:3). However, there are a number of challenges involved in including people with cognitive impairments in research, including the prospect that such involvement might lead some to doubt their "status as people with learning disabilities" (Walmsley & Johnson, 2003:141).

Prioritising the accessibility of discussions about methodology or research findings may itself become "a barrier to clarifying and theorising" (Walmsley & Johnson, 2003:15), confining the understanding of the oppression faced by people with learning disabilities to "narratives of personal experience" (ibid:187). Even where there are efforts to increase inclusion in research or policy discussions, there are risks of "recreating the same kinds of hierarchies that exist in wider society – one which favours the most able and articulate" (Fyson & Fox, 2014:252). Involving self-advocates who can "articulate well for themselves" or who are more politically engaged may set up a power imbalance with those who are "less able to articulate their wishes" (Thomas & Woods, 2003:110). In practice, that is likely to mean those with more severe impairments, those facing multiple barriers, and those from ethnic minorities and other marginalised communities will face greater disadvantages and exclusion (Fyson & Fox, 2014).

Despite these concerns and challenges, the principles on which the idea of inclusive research is based (Walmsley & Johnson, 2003:16) remain compelling:

- 1. address issues that really matter to people with learning difficulties, in order to improve their lives*

2. access and represent their views and experiences

3. treat people with learning difficulties with respect

Walmsley and Johnson describe the evolution of inclusive research in this field pointing to the “early voices” (ibid:68) such as Edgerton’s pioneering study carried out during the 1960s (Edgerton, 1993), which applied Goffman’s (1990) concept of stigma and the management of self-stigma to explore the lives of people living in the community after long periods in residential institutions. Edgerton’s study has serious limitations, principally due to his medically-oriented view of learning difficulties and the dominance of his “authorial voice” in his analysis and conclusions (Walmsley & Johnson, 2003:68). Nevertheless, his work broke new ground by focusing on people previously absent from research and it was the forerunner of a number of subsequent studies exploring self-stigma among people with learning difficulties (Sheehan & Ali, 2016).

Walmsley and Johnson review a number of other studies that make greater efforts to meet their definition (2003:64) of inclusive research with people with learning difficulties. These highlight not only the richness of the data collected, but also the range and depth of issues addressed, albeit from a relatively small number of studies compared to other areas of research. However, for the purposes of this research, their significance is particularly of interest in relation to the “dilemmas... tensions and frustrations” that they illustrate (Walmsley & Johnson, 2003:77). Firstly, attention is drawn to the risk that inclusive research underplays suffering in attempting to avoid “victimhood” and present positive and emancipatory stories about the lives of people with learning difficulties (ibid:77). This refers particularly to a publication entitled *Know Me As I Am: an anthology of prose, poetry and art by people with learning difficulties* (Atkinson & Williams, 1990), which meets most of Walmsley & Johnson’s criteria for inclusive research.

Secondly, and of more significance for this research, there is a risk that inclusive research restricts itself to “only examining questions which [people with learning difficulties] are able to articulate” (Walmsley & Johnson, 2003:91). This is a recognition of “a resounding silence” that may surround the oppressive experiences of any marginalised group. Researcher-initiated research may provide the space to discuss issues that are neglected or un-named. For example, Simons’ research into the experiences and views of people with learning disabilities who had “disappeared from view” (Simons, 2000:2), either

because they had chosen not to engage with specialist services or because they had been excluded by the tightening of eligibility criteria. Riddell et al concluded from their participants' group discussions that "intellectual impairment, far from being celebrated, was too shameful to be discussed openly even with those who were being consigned to this category", with inevitably limiting consequences for discussions about identities (Riddell et al, 2001:234). That study also rejected the possible implication that there might be "some essential quality in having an intellectual impairment that specifically enabled people with learning difficulties to empathise with each other in a way that others could not" (ibid:230).

Thirdly, there is the question of theory. Research relating to learning difficulties tends to be dominated by "relatively concrete applied areas" such as service provision, or personal experience (Walmsley & Johnson, 2003:186). This is partly a reflection of the tendency for people with learning difficulties to have a "concrete frame of reference" that may restrict "their capacity for looking back on their own past with the sort of reflexivity the evaluative function demands" (Booth & Booth, 1996:57). Involving people with learning difficulties in data analysis and engaging with theoretical concepts is acknowledged to be a "tricky area" (Stalker, 1998:16), and there is a risk of anti-intellectualism arising from research involving people with learning difficulties as self-advocates, if theorising is rejected as too complex (Stalker, 2012).

This is not to suggest that people with learning difficulties cannot be involved in theorising. On the contrary, there is a strong case that researchers should commit to making this possible (Walmsley & Johnson, 2003; Stalker, 2012), as well as considering other ways in which people with learning difficulties may contribute to research, while recognising that challenges relating to "the reality of intellectual impairment" cannot be wished away (Walmsley & Johnson, 2003:187).

Ultimately, the development of theoretical ideas about disability has been dominated by a focus on physical and sensory impairments and a neglect of people with cognitive impairments, especially people with learning difficulties (Chappell, 1998) and autistic people (Woods, 2017). Theoretical approaches that focus on the consequences of disability risk underestimating or neglecting "the variety of ways disability may be experienced" (Owens, 2015:388) and the differences between the experiences of people with cognitive impairments or

fluctuating impairments and those with physical impairments (Owens, 2015). Medically-oriented perspectives on cognitive impairment remain dominant. Although the terminology has changed multiple times in the last forty years, Ryan & Thomas' observation that "Medicine... has been the main instrument for excluding mentally handicapped [sic] people from society", categorising people "in terms of their supposed pathology, what is wrong with *them*" (Ryan & Thomas, 1987:15, italics in original), remains pertinent.

As noted above, the social model of disability, with its focus on political action led by disabled people, may marginalise those who do not identify with a "singular" identity (Owens, 2015:391) or do not identify as disabled because they do not see themselves as "other" and reject an identity based on difference (Watson, 2002). Nevertheless, the social model remains highly relevant to the situation of people with learning difficulties, as for disabled people more generally, because they share experiences of oppression relating to socio-economic structures, higher rates of poverty, inequalities in citizenship rights, attitudinal barriers, psycho-emotional disablism and barriers in information provision (Stalker, 2012).

This thesis acknowledges the influence and importance of the social model in exploring how shared experiences of oppression are manifested in the lives of the participants. However, the analysis also considers aspects that challenge the social model. These include the complexities of labelling and questions about why some people with learning difficulties might reject or distance themselves from "being labelled as disabled" (Stalker, 2012:125) or might not experience solidarity from other disabled people; the significance of personal experience; and whether the injustices experienced by people with learning difficulties have more in common with other forms of oppression or marginalisation, such as sexism or racism (Stalker, 2012).

Some of the complexities surrounding the identification of people with mild learning difficulties are indicated by the above diagnostic, boundary and exclusion issues. The approach taken in this research is to focus on people who self-identify with the label 'mild learning difficulties', a label with widespread use in the school-age education system. This may include people with no diagnosis, or with diagnoses of learning disabilities, autism, ADHD or other cognitive conditions. This is not an attempt to dismiss the conceptual and definitional complexities but to take a pragmatic view in order to move forward with the

research. More detail of the sampling strategy is included in the following chapter. The concluding chapter reconsiders these definitional issues in the light of the research findings.

A further challenge to operationalising the label of mild learning difficulties arises in because of its relationship to autism. During the process of carrying out this research it became increasingly clear that there was an overlap between the use of these two labels and that the participants sometimes used autism as an alternative, with very similar meaning, to mild learning difficulties. The complexities of autism studies are beyond the scope of this thesis, but it may be helpful to note a recent proposal to conceptualise autism as a “politically useful classification” (Chapman, 2020:3). This acknowledges that, while autistic people may share “clusters of characteristics”, what defines the boundaries of “typical social functioning, emotionally relating and so forth” is *social* norms rather than medically-oriented or identity-based factors: “these traits are grouped in light of collectively being disabled by the same norms and structures” (Chapman, 2020:15).

Finally, it is important to note the paucity of studies that have explored the experiences of people with mild learning difficulties in relation to work, looking for work and being unemployed. That is partly a reflection of the factors discussed above that are barriers to research about people with learning difficulties in general. It is also a reflection of the very low employment rates suggested by statistical data.

Those studies that have been undertaken have highlighted the difficulty of reaching people who do not access specialist services, especially adult social care services, for whatever reason. Simons discussed how his focus on non-users of services hampered recruitment not only because of the difficulty of identifying who might be included, but also because of a lack of co-operation from specialist and non-specialist organisations who might have been expected to help with the project but whose “organisational priorities” did not include concerns about non-users (Simons, 2000:1).

Other related studies have largely depended on service providers to support recruitment (Simmons et al, 2014; Humber, 2011; Dean et al, 2003). A major study about unemployment of people with multiple needs, with 8 of the 50 participants identifying as having learning difficulties, recruited all participants

from “voluntary sector projects” (Dean et al, 2003:20). Humber’s PhD research on the employment of people with learning difficulties noted the importance of the researcher’s “personal contacts developed through previous work collaborations” (Humber, 2011:83). Similarly, a case-study based report of research on young people not in education, employment or training, which included a small number of participants with learning difficulties, noted that “the practicalities of gaining access and the ‘gatekeeping’ role of practitioners...limited the diversity of our participants” (Simmons et al, 2014:75). It also highlighted the possibility that “the most vulnerable young people are precisely those *not* accessed by researchers because they stay out of the reach of support agencies” (ibid:75, italics in original).

The next chapter turns to the research design, reflecting on the theoretical and practical challenges explored in this chapter and considering how theoretical concepts of social justice discussed in Chapter Two might be applied to expand understanding of the experiences of people with mild learning difficulties.

Chapter 4 Research design and methodology

This chapter sets out the aims and research questions addressed in this thesis, and discusses the philosophical, methodological and ethical approach taken to them. The chapter considers the practical and ethical issues and decisions involved in gathering and analysing the research data. It concludes with some personal reflections on the researcher's values and decision-making.

Research aim and questions

As discussed in previous chapters, the experiences of people with mild learning difficulties are under-represented within research about unemployment and employment, and rarely addressed in research into the lives of disabled people. The characteristics of the contemporary labour market and the social security system suggest new or intensifying challenges for people with mild learning difficulties who are looking for work.

The central research question is therefore:

How do people with mild learning difficulties experience looking for paid work?

There are six subsidiary questions, which are intended to clarify the scope of the research and inform the research design:

- 1. What are the tensions and contradictions in government policy towards supporting the employment of people with learning difficulties and promoting social justice?*
- 2. How do people with mild learning difficulties relate to concepts of disability and how does that affect their sense of their rights and entitlements?*
- 3. What stories do people with mild learning difficulties tell about unemployment, looking for work, and being in work?*
- 4. What do these stories reveal about the labour market and the social security benefits system?*
- 5. What do the stories of people with mild learning difficulties who are looking for work reveal about the adequacy of the government's policy approach to supporting the employment of disabled people?*

6. *Are concepts of social justice useful to understanding the position of people with mild learning difficulties who are looking for paid work, and if so, how are they useful?*

Language and terminology – mild learning difficulties

A fuller discussion on labelling was presented in Chapter Three, in the context of a wider review of the literature on learning difficulties, cognitive impairments, learning disabilities, intellectual disabilities, autism and disability, as diagnostic, social and moral categories. As that discussion showed, there is a long history of different labels used in this area, each of which has developed negative connotations over time (Northway, 2017). Labels may confer eligibility for rights, services and resources, but also exclude, essentialise and stigmatise.

The terms ‘learning disabilities’ and ‘intellectual and developmental disabilities’ are commonly used in UK legislative and government policy documents, including equalities legislation. They refer to people with conditions which started before adulthood, with a “lasting effect on development”, “a significantly reduced ability to understand new or complex information and to learn new skills”, and/or “a reduced ability to cope independently” (DoH, 2001:14).

However, these terms are open to interpretation because of ambiguity surrounding phrases such as “significantly reduced ability to understand” and “reduced ability to cope” (ibid:14). Similarly, the 2010 Equality Act, uses phrases such as “substantial adverse effect” and “normal day-to-day activities” (HMG, 2010:136). Such ambiguities in practice enable restrictions to the scope of ‘disability’ as a label or category (Stone, 1984) to a much smaller proportion of the adult population than is consistent with the “administrative prevalence of learning disabilities” among children (Emerson & Glover, 2012:140). The research explores how disability labelling and eligibility for support are manifested in the labour market and the social security benefits system, and how they are experienced and understood by people with mild learning difficulties.

The term ‘mild learning difficulties’ is a contested and ambiguous term, used differently in different contexts, so its use in the research needs to be carefully documented. ‘Learning difficulties’ has been used in preference to ‘learning disabilities’ primarily to enable the research to explore the relationship between self-identification with some form of cognitive difference, and acceptance of

labels of disability (addressed in Chapter Seven). Exploring the implications of such labelling for rights and entitlements involves making a distinction between the inclusion criteria and the acceptance of the label 'disabled'. There is no term that has meaning for the participants themselves and is value-neutral.

The research accepted people as having mild learning difficulties if they self-identified as such. They may also have been given this label by service providers such as schools, colleges or community groups. In order to focus the research on people with *mild* learning difficulties, who would not automatically be treated as eligible for disability support within the administrative processes of the welfare state, participants were only included if they were *not* eligible for adult social care services. Without access to services designed for people with learning disabilities, there may be little or no benefit to voluntarily identifying as having mild learning difficulties. Establishing these criteria was important to ensure the research focused on this under-researched group but it also meant participants were hard to reach and hard to recruit. Recruitment is discussed in more detail below.

Ethical approval and key ethical challenges

Ethical approval for the research was granted by the University of Nottingham School of Sociology and Social Policy Research Ethics Sub-Committee in June 2017 (Appendix 1). In the application for ethical approval, ethical issues were addressed in particular detail relating to two matters: the inclusion of people with learning difficulties and mental health conditions; and the possibility of collecting data in a participant's home. For the first matter, clearly central to the research, additional safeguards were proposed to enable informed consent, including adapting the information sheet (Appendix 2) and consent form (Appendix 3) for a lower reading ability and highlighting participants' unconditional rights to withdraw from the research at any time. During the fieldwork, participants were reminded of this unconditional right at each interview.

The ethics application acknowledged that participants might get upset during interviews and referred to the researcher's extensive experience as a support worker, as well as steps to be taken to offer support. In practice, participants did talk about a range of distressing experiences, from bullying to attempted suicide. These were deliberately not shied away from, respecting participants' decisions about what they chose to talk about. As far as possible, the interview provided a

supportive and empathetic space for participants to talk openly, but participants were in no sense under pressure to reveal personal details. A list of local support services was made available to participants.

For the second matter, it was proposed that interviews would be carried out in public spaces as far as possible, but that the School's Fieldwork Safety Policy and the Suzy Lamplugh Trust guidelines on lone working would be followed where interviews were carried out in a participant's home. In practice, only one participant was interviewed at a private house (Lillian, at her parent's house, second, third and follow-up interviews) and the lone working procedures were used effectively.

Research with people with disabilities and impairments must address issues of language and respect from the very beginning (Nind, 2008). For example, the term 'potentially vulnerable' is widely used in ethical standards (e.g. ESRC, 2018) to denote people needing additional protection in the research processes, but this term may have negative connotations suggesting people are objects of pity and lack agency, and the term 'most vulnerable' can be linked to political narratives of "deservingness" (Morris, 2015). In recognition of this, the consent form (Appendix 3) referred to 'adult at risk', rather than 'vulnerable adult'. This is also now the terminology used in social care and adult safeguarding (e.g. Ann Craft Trust, 2020).

The guiding ethical principle of the research was respect for the dignity of individual participants (Swain et al, 1998). However, there was also a recognition that qualitative research with people with learning difficulties involves particular ethical complexities and dilemmas for which there may not always be solutions (Josselson, 2007; Swain et al, 1998). This is a factor in their long-standing exclusion from research (Booth & Booth, 1996). This research prioritised the demand that researchers should "attend more to their own deficiencies" (Booth & Booth, 1996:67) to ensure people with learning difficulties *are* included. Similar warnings were noted against excluding participants because they are perceived as "too 'difficult' to recruit or include" (Aldridge, 2014:125) in recognition that "the exclusion of voice is also oppressive". (Swain et al, 1998:35). Three issues are discussed further here: consent, privacy and exploitation.

Consent

Informed consent may be an oxymoron in narrative inquiry research because “much of what will take place is unforeseeable” (Josselson, 2007:540) and the research “evolves throughout the circular stages” (O’Reilly & Kiyimba, 2015:48) as data collection and analysis develops. Care was taken to ensure that anyone who did not appear to understand the nature of the research and how their data might be used within it was excluded from participation. For example, the researcher was approached by someone who did not want their responses to be recorded either as an audio recording or in written notes. This person was not accepted as a participant. Although the researcher was not able to foresee exactly what would be discussed during the research interviews, participants were regularly reminded about the general direction and purpose of the research and the voluntary nature of their participation in it. I was alert to the risk that participants might feel coerced into participating. Their permission to be recorded and their right to withdraw from the research was clarified and reiterated at the start of each interview.

The researcher was aware of claims that people with mild learning difficulties may have a “tendency to acquiesce” (Porter & Lacey, 2005:91), as well as the importance of not assuming acquiescence (Goodley, 1998; Simons et al, 1989). Pressure to acquiesce for people with mild learning difficulties is likely to be related to being treated disrespectfully or having a lack of control over many aspects of their lives (Stalker, 1998:6). I aimed to avoid putting participants in situations where they might feel pressure to acquiesce by providing space for them to tell their story or respond to open questions, wherever possible.

Privacy and anonymity

Participants were expressly assured that the full recording of their interviews would be kept secure and only available to the researcher and her supervisors. Participants’ names were anonymised in transcripts and in the analysis of the data. Personal details were removed from all documents relating to the participants, except their consent forms which were stored securely within University of Nottingham premises. Geographic and other local details that might identify the participants were also either removed or changed. Although complete anonymity cannot be “guaranteed” (Swain et al, 1998), it should not be possible

for someone who does not know the participants to be able to identify them from this thesis or related publications.

Participants were asked to choose a pseudonym rather than having it assigned by the researcher, in recognition that “acts of naming are political and personal” (Allen & Wiles, 2015:163). They were asked not to choose an alias that they already used elsewhere, such as on social media, that might compromise their anonymity within the research. Ten of the participants declined to choose their own pseudonym. These participants were informed of the pseudonym used where possible and given the opportunity to change it if they wished.

Exploitation

The researcher and participants may have different interests in the research, and this can be a source of a range of ethical dilemmas including possibilities for “exploitation, invasion of privacy, manipulation, deceit and abuse of power” (Swain et al, 1998:34) in research with people with learning difficulties. Shifting control towards participants within the research may make it less likely to “infringe their rights” (ibid:35), but the practicalities of achieving this are not straightforward. The effect of attempts to obtain corroboration of researcher interpretations, for example, may not only be complicated but also misleading, in the sense that the “theoretical commitments” (Riessman, 2008:197) of the research may not have any meaning for participants. Although a participatory approach was not considered to be manageable within the constraints of this research, a commitment to respecting the authority of the participants and avoiding their exploitation was reflected in efforts to renew contact with them after the data analysis was completed, to discuss the main findings and document their comments. Above all, there was a personal commitment that the research would not be damaging to the lives of the participants and would aim to be supportive of them (Riddell et al, 1998).

The power imbalance between researcher and participant is exacerbated where participants have learning difficulties, not only because of their cognitive difficulties but also because they are more likely to have more restricted social contact than the rest of the population (Stalker, 1998). While it would be mistaken and arrogant to assume all participants with learning difficulties want a continuing friendship with the researcher, it is important to acknowledge ethical issues about establishing clear boundaries in the relationships between

researcher and participants, managing the ending of the fieldwork stage of the research sensitively, and being aware of the risks of (unintentionally) manipulating or coercing participants who may be lonely and socially isolated (Porter & Lacey, 2005; Reinders, 2002; Stalker, 1998; Swain et al, 1998). Care was taken throughout the research to establish that the fieldwork was time-limited, and that the research relationship would come to an end. Where possible this was underscored by the presentation of a gift card to participants at the final meeting with them. It should be noted that no offer or mention of remuneration was made before or during the fieldwork, out of concern that this might unduly influence participation and undermine participants' confidence that they could withdraw from the research.

Research approach

The research questions focus on issues of the social world of people with mild learning difficulties and their experiences and perspectives, and on policy narratives and assumptions. The questions are consistent with an interpretivist, qualitative approach which can "respect the uniqueness of each participant" (Ritchie, 2014:4). However, the approach maintains an element of scepticism towards binary choices in the underpinnings of research design and unquestioning commitments to philosophical consistency (Wertz et al, 2011). Consequently, although the research takes an interpretivist approach to its primary data, it also draws extensively on secondary data which may have been gathered using other approaches.

The ontological basis of the research is that social reality is socially constructed, and the meaning of social phenomena is dependent on, produced and reproduced by social interaction (Bryman, 2012). This is consistent with the research questions which focus primarily on the lived (that is, first-hand) experience of participants and explores their social reality, as far as possible from their perspectives, which may be different from each other.

The epistemological position of the research is that understanding people's perceptions of their experiences is central to understanding social phenomena (Della Porta & Keating, 2008:25). Subjective meanings are "negotiated socially and historically" (Creswell, 2013:25), so interpretation needs to include a view of the historical, social and cultural background to people's lives. The research is informed by a feminist commitment to useful knowledge, useable to make a

difference, and to questioning oppressive attitudes and behaviours (Kelly et al, 1994). There is an “emphasis on experience” (Maynard, 1994:23), recognising the epistemic authority of the first-hand accounts of lived experience, including people with cognitive impairments whose voices have been “doubted, dismissed or silenced” (Carlson, 2016:548) and are traditionally absent from research (Swain et al, 1998; Booth & Booth, 1996). However, the research also acknowledges that making sense of experience is an “interpretive and synthesizing process which *connects* experience to understanding” (italics in original, Maynard, 1994:24). This approach underpins the decision by the researcher, who does *not* have learning difficulties as defined in this research, to undertake research about the experiences of people who *do* have learning difficulties. It also supports the decision to draw on other sources of data as well as the first-hand accounts of people with learning difficulties.

Research is not “value free” (Bryman, 2012:39) and the beliefs and values of the researcher and participants should be acknowledged openly to reduce bias and enable the research to “surprise” (Griffiths, 1998). This chapter concludes with reflections on the researcher’s personal values and how these influenced the way that the research was carried out and the interpretations drawn from the data. The fundamental value underpinning the research is a belief that disability and learning difficulties are “dimension[s] of human difference”, with socially constructed meanings, rather than “defects” (Creswell, 2013:34). This implies that people with learning difficulties have as much right to live a ‘good life’ as anyone else, however that is defined (Johnson et al, 2010).

The interpretations presented in later chapters draw on the researcher’s experiences and values, which were subject to critical reflexivity and review, as discussed later in this chapter. To aid the trustworthiness of the interpretations, they are supported in the reporting by direct quotation from the primary data. However, the possibility remains of “silences and absences” in the research data, resulting from the limitations of the researcher, since “we cannot break out of the social constraints on our ways of knowing simply by wanting to” (Holland & Ramazanoglu, 1994:133).

Methodology and methods

*“Stories from the bottom provide a glimpse into a world the majority ignores”
(Malhotra & Rowe, 2014:9).*

The research questions are addressed primarily by exploring the lives and experiences of unemployed adults with mild learning difficulties, how they made sense of their experiences and how they understood their social world (Bold, 2012). The research aimed to be alert to the “messiness” of the “contradictions, richness, complexity, connectedness, conjunctions and disjunctions” of the social world (Cohen et al, 2011:219), and actively explored these. A narrative inquiry approach was used, strongly influenced by the work of Riessman (2008, 1993), who suggests that narratives are strategic, functional and purposeful, and that people tell stories to “make sense of the past” (Riessman, 2008:8), reflecting their social context and drawing on wider social narratives and concepts.

The narrative methodology guided the collection and analysis of the empirical data, focusing on stories of individual experiences and “life as it is experienced ...contextualized within a longer-term historical narrative” (Clandinin & Connelly, 2000:19), through active collaboration between the researcher and participants (Creswell, 2013). Stories were viewed as “natural cognitive and linguistic forms through which individuals attempt to order, organize and express meaning” (Mishler, 1986:106). This approach was successfully trialled in a pilot study in 2016, involving narrative analysis of interview data gathered from two of the four participants (Tarlo, 2016). The pilot study concluded that the multi-layered analysis produced insights into what employment and unemployment meant to the participants, illuminating “weaknesses, inconsistencies and contradictions in current measures aimed at improving employability, reducing unemployment and supporting those who are unable to find paid work” (Tarlo, 2016:53). Methodologically, the pilot study contributed to the development of the researcher’s research skills and supported the identification of priorities for this research.

Narrative inquiry is particularly well suited to a focus on social justice, not only by giving a voice to marginalised people, but also by highlighting the local context and circumstances that condition what can and cannot be said (Lawler, 2002), providing “a window to the contradictory and shifting nature of hegemonic discourses” (Chase, 2011:422). Ethnography was not considered appropriate for this research, because it was not focusing on a “culture-sharing group” (Creswell, 2013:91-2), but the approach included spending time with participants, outside of the interview setting where possible, to aid the researcher’s understanding of their circumstances and how these “shape and are shaped by” their narrative

practices (Gubrium & Holstein, 2009, quoted in Chase, 2011:422). This is discussed further in the fieldwork and reflexivity sections later in this chapter.

Narrative inquiry provides an opportunity to explore the whole account, which can “illuminate the parts, which in turn create the whole” (Josselson, 2011:226). That can help to show the participant as a fully rounded person (Elliott, 2005), and to focus on their point of view, rather than breaking up the text into “thematic chunks” which are analysed out of context (Griffin & May, 2012:445). The methodology provides opportunities to focus on stories of experience and the “meaning life events have for people” (Polkinghorne, 2007:479), positioning participants as “expert witnesses” of their lives (Atkinson, 2010:8) while exploring reasons for the absence of their voices elsewhere (Dennison & Mee, 2012:133).

Narrative approach to data collection

Narrative inquiry requires research questions which are “conducive to producing stories” (Kim, 2016:96). This consideration was influential in the iterative development of the research questions and subsequent drafting of the fieldwork plan and interview guides. To facilitate the building of rapport and opportunities to “generate detailed accounts” (Riessman, 2008:23) essential to a narrative approach, the fieldwork plan involved multiple interviews with each participant (see below) and all but one of the participants were interviewed at least twice. These interviews focused on the collection of stories about individual experiences, including turning points, tensions, specific context, place and time; and data analysis focusing on content, structure and performance of the story (Creswell, 2013:chapter 4). The value of these methods was demonstrated in the pilot study (Tarlo, 2016).

The pilot study (Tarlo, 2016) considered the risk that “storied description” diverges from the “actual meaning experienced” (Polkinghorne, 2007:480-2). This risk was identified as deriving from three features of the research. Firstly, it was anticipated that participants with learning difficulties might have difficulty in articulating meaning through language and might lack reflectiveness (Booth & Booth, 1996). Booth & Booth highlight challenges relating to inarticulateness, unresponsiveness, difficulties with abstract concepts and generalising, and problems with time (ibid:56-7). Secondly, participants might be resistant to socially negative or stigmatised self-revelation (Roulston, 2014). Thirdly, the perception of a power imbalance between the researcher and the participant

might have a distorting influence on participant responses (Owens, 2007). These challenges are not unique to people with learning difficulties; they may also be less problematic than anticipated, and none should be an “insuperable barrier” to the telling of people’s stories (Booth & Booth, 1996:58).

The research design included various measures to address these challenges and to encourage the perception of the participants as experts in their own life stories (Czarniawska, 2004). These included spending time with participants, such as carrying out multiple interviews, participant observation, and walking with participants to build rapport and trust. The language used in the research information sheet (see Appendix 2) was designed to position participants as authorities on their own experiences. Some participants did have difficulty articulating meaning and reflecting on their experiences but there was little evidence of a lack of co-operation or of reticence arising from a sense of a power imbalance. Multiple interviews helped with building rapport and trust, as well as providing opportunities to clarify and explore responses to questions. Repeatedly listening to interview recordings, and the transcribing of interviews in the intervals between meetings, also supported the researcher’s understanding of “gaps in the interviewer’s questioning” and how these might be “followed up” in subsequent interviews (Roulston, 2014: 290), although this was not always possible or successful. The specifics of interviewing are discussed further below.

Recruitment of participants

Sixteen people with mild learning difficulties were recruited as participants in the research, through a process of purposive sampling (Bryman, 2012:418). The approach to recruitment took into account an expectation that it would be difficult to find participants willing to discuss their first-hand experiences, not only because ‘learning difficulties’ is a stigmatised term but also because people with mild learning difficulties are unlikely to be familiar with the “somewhat esoteric activity” that is research (Walmsley & Johnson, 2003:156). The challenges of recruiting participants with learning difficulties are internationally recognised (Corby & Sweeney, 2017; Cleaver et al, 2010; Lennox et al, 2005). The choice to focus on ‘mild’ learning difficulties added to these challenges, because their ineligibility for adult social care services meant that participants would not be contactable through such services.

The initial intention was to recruit a group of participants who would be leaving a local Further Education college. Unfortunately, due to restructuring at the college, the level of co-operation needed to enable this was not forthcoming. Instead, recruitment efforts focused on contacting employment-related service providers, as well as direct contact through posters in public spaces such as libraries and community centres. Two participants were recruited directly, responding to the poster. The other 14 participants were recruited through a variety of service providers (Table 4.1).

All of the service providers contacted were viewed as 'gatekeeper organisations' (Nind, 2008) who might promote the research to their service users, suggest potential recruits and offer locations for interviews. Many of these gatekeeper organisations offered support to people facing multiple barriers to employment, including people with mild learning difficulties. Several offered services such as job clubs, open to anyone looking for work. Most prioritised 18-25 or 18-29 age groups and the long-term unemployed, due to the availability of funding for these groups.

The gatekeeper organisations were identified through a process of chain-referral or snowball sampling (Bryman 2012:716), beginning with transition services at a local Further Education college. Where possible, a face-to-face meeting was arranged with a named contact, to build rapport and trust, to encourage them to publicise the research and to introduce the researcher to potential recruits. That person was asked directly for advice about contacts at other organisations. These meetings were also useful opportunities to gather contextual information about the variety of employment support services available to people with learning difficulties and disabilities in and around the region, to discuss the aims and objectives of the research and broader issues about employability and employment support. A research record was kept of each meeting, documenting the researcher's recollection of the discussion. Details of gatekeeper contacts (anonymised) and numbers of participants recruited from each are shown in Table 4.1.

Table 4-1 Contact with gatekeeper organisations (anonymised)

Organisation type	How contacted and how many times		Recruits
	Phone	Face-to-face	
Charity – mental health support for BAME communities	2	0	0
Advice centre/community organisation	1	1	1
Foodbank/Job club	0	2	1
Charity working with migrants and refugees	0	1	0
Charity – community regeneration	1	1	0
FE College	2	3	0
FE college-based employment advice and support service + job club	1	2	0
Community interest company supporting employability	1	1	0
Housing association and homelessness charity	4	2	0
Local authority employment advice and support service	2	2	0
Charity provider of Talent Match scheme	3	2	4
Charity 1 supporting people with learning disabilities	1	1	0
Local authority employment support scheme	2	2	1
Voluntary sector employment support project	0	1	0
Mencap	1	0	0
Housing Association support service	2	0	2
Private sector company supporting people with learning disabilities	1	1	0
Private sector provider of employment advice + job club	2	2	1
Local authority careers service	1	1	0
Women's centre	2	1	0
Local Authority learning disability team	1	1	0
Charity 2 supporting people with learning disabilities	1	0	0
Social Enterprise for people with learning difficulties	1	1	2
Remploy	2	1	1
Advice centre/community centre	1	1	1
City farm	1	1	0
Supported training and work experience project	1	1	0
Total	37	32	14

Note: Where national organisations are shown, the contact was with the local branch; all other organisations were local.

Use of gatekeeper organisations is recognised as bringing a risk of bias, particularly that of cherry-picking or unfairly excluding participants (Ritchie et al, 2014). However, in this instance the issues that emerged were rather different. The meetings held with gatekeeper organisations, and the resulting small number of participants recruited from each, indicated that a heavy workload and a protectiveness towards client data were significant barriers to providing access to potential participants, despite good intentions. While gatekeeper organisations may facilitate access, they may also block it (Stalker, 1998). The recruitment process faced dealing with organisational barriers including multiple layers of management in larger organisations and an overwhelming workload in smaller ones (Lennox et al, 2005). Research access was also restricted by some of the organisations having laudable commitments to participatory, consensus-based decision-making practices which tend to be “time-consuming, labour-intensive and slow” (Lennox et al, 2005:301).

There was some evidence that gatekeepers overestimated the stigma associated with the label mild learning difficulties and were over-cautious about the risk of using it. This sometimes led to a reluctance to approach people who might fit the criteria for the research. For example, managers at an organisation focusing on young people not in employment, education or training (NEET) suggested that their service users would be reluctant to come forward as potential participants, because of the stigma of being identified as having learning difficulties, and that it would be more acceptable to talk about ‘stress’, ‘anxiety’ or ‘mental health problems’. However, when the researcher gave a presentation about the research at a monthly meeting with service users, eight of the attendees put their names forward to participate and four were subsequently recruited to the research.

Sampling and inclusion

The sampling process had to directly confront the issue of how someone is identified as having mild learning difficulties. It was considered unlikely that anyone would claim the label inappropriately, given the associated stigma. However, it was also assumed that there would be some indications of cognitive impairment evident at the first interview, such as some difficulties with communication or limited responsiveness to questions (McCarthy, 1999; Booth & Booth, 1996). The researcher was able to draw on extensive experience of

working with people with mild learning difficulties to support the recruitment process, as discussed in the section on researcher reflexivity.

It was intended that self-identification with the label would be a sufficient indication of having mild learning difficulties, on the basis that to do otherwise would be patronising or offensive. Nevertheless, where participants were recruited through organisations involved in supporting people with learning difficulties or disabilities there was clearly an additional layer of assurance that they did indeed meet the criteria of the sampling strategy. However, as these specialist organisations have quite limited capacity, it is important to question what factors enabled their service users to access that support and whether those factors might also influence their experiences of employment and unemployment. Where possible, this was considered in the analysis of the interview data.

The direct approach to recruitment was also potentially problematic, since it may have only reached people with the literacy skills to read the poster, who accessed libraries, and who had the confidence to contact an unknown researcher. Two participants were recruited in this way.

Having established that the most important point about the term mild learning difficulties was that the participants self-identified with it, there were three main points of clarification or further definition needed when discussing recruitment with gatekeepers or potential participants. These were:

- ineligibility for adult social care services;
- the importance of differentiating mild learning difficulties from 'specific learning difficulties', such as dyslexia, which may not affect general or broader cognitive functioning;
- and clarifying that autism and Asperger's syndrome are not the same as learning difficulties although they may co-present (Research Autism, 2016).

Gatekeepers and participants recognised the intention behind the use of mild learning difficulties in this way and it was generally not a source of confusion. However, in addressing concerns about the use of a stigmatised label, it is important to recognise the value of face-to-face meetings, as in the example of the NEET group. The beneficial effects of face-to-face contact on participation

rates have been documented widely (Carey & Griffiths, 2017; Corby & Sweeney, 2017; Cleaver et al, 2010; Lennox et al, 2005). Face-to-face meetings were also valuable in building trust with gatekeepers and providing reassurance about the researcher's competence and the ethics of the research (Carey & Griffiths, 2017).

As discussed in Chapter Three, it is widely recognised that there is a lack of clarity about terms such as dyslexia, autism, learning difficulties and learning disabilities, which may be used interchangeably in everyday language to indicate impaired general cognitive functioning. Self-identification along with capacity and willingness to consent were the guiding principles for participation and were fulfilled for all the participants. Access to adult social care services was used as a proxy to exclude some people mentioned by gatekeepers as possible participants. Issues around self-identification, what 'their' learning difficulties means to the individual and how they relate to the term 'disabled' were explored in the interviews and formed a significant element of the data analysis, relating to issues of personal identity and "discourses of impairment and disability" (Swain & Cameron, 1999:68), as discussed in Chapter Seven. There was a considerable variation of cognitive difficulties and differences among the participants and this is also explored in the analysis.

Three people came forward who were not accepted as participants because they were not considered to have mild learning difficulties. One was a recent immigrant with apparently very weak English language skills, who contacted the researcher directly having seen the poster in his local library. After an initial discussion, which highlighted the localised meaning of the term learning difficulties, it seemed likely that he did not understand its meaning in English and that he thought it related to his own financial and eligibility difficulties accessing the education system. The second person was referred by a gatekeeper organisation and agreed to a preliminary meeting. On meeting, he said he did not have learning difficulties and he was looking for work while waiting to go to university. Possibly he had been referred because of a misunderstanding about the nature of the research by the gatekeeper contact.

The third person did not make contact directly, but contact was made by her mother, who had seen the research poster towards the end of the fieldwork period. After communication by email and an initial interview with both daughter

and mother (pseudonymised here as Melanie and Julia), it was established that Melanie was eligible for adult social care and therefore did not meet the criteria for participation. Melanie had had a very positive experience of supported employment which had resulted in permanent paid work. The interview presented an example of positive outcomes from good quality support for someone with more severe impairments than the 'main' participants. It was therefore accepted as a valuable opportunity to contribute lived experience data to the research discussion of the position of people with mild learning difficulties in the labour market. Consent was obtained from both Julia and Melanie to record the interview and draw on it for the research, but it was agreed not to include Melanie as a participant with mild learning difficulties and no data was collected beyond that from the initial interview.

Towards the end of the recruitment period, in recognition that only four of the participants recruited so far were female, recruitment efforts via gatekeepers specifically focused on finding female participants with mild learning difficulties. The aim was to gather more data to explore gendered aspects of employability and employment and also to explore gendered aspects of learning difficulties. However, no further female participants were recruited. The greater number of male participants in the sample may reflect the greater numbers of males with autistic spectrum diagnoses (Timimi & McCabe, 2016) and recognised as having SEN within the education system. The relationship between learning difficulties and gender was discussed further in Chapter Three.

The sampling process also became purposive in terms of age. This was partly a reflection of information provided by gatekeepers which indicated that funding for services and programmes to support employment and employability was predominantly focused on the 18-25 age group, extending to 29 in some cases. Additional efforts were therefore taken to find participants aged 30 and older, whose experiences might be affected by a reduced level of support. It was also recognised that older participants, with more experience of being of working age, might have a different perspective on their employability than people who had been in school or college within the last year or two.

The key inclusion-exclusion criteria for the research are summarised in Table 4.2 overleaf. The participants themselves are introduced in Chapter Six, which also

includes details of a follow-up meeting with 12 of the participants 12-18 months after their interviews.

Table 4-2 Inclusion-exclusion criteria

Inclusion criteria	Exclusion criteria
In paid employment or looking for paid employment (or self-employment)	Not in, or looking for, paid employment or self-employment
Identifies with the term mild learning difficulties	Does not identify with the term mild learning difficulties
Able to describe their mild learning difficulties to indicate cognitive impairments	Not able to identify their mild learning difficulties at all, or to indicate cognitive impairments
Ineligible for or not receiving adult social care	Eligible for or receiving adult social care
Age 18 or over	Under 18
Wishes to participate in the research	Does not wish to participate in the research
Willing and able to give informed consent	Unwilling and/or unable to give informed consent

Fieldwork with people with mild learning difficulties

In order to encourage the production of narratives and to explore each participant's social background, it was important to build rapport with the

participants and give them time to talk about their experiences (Nind, 2008). The main method of data collection was interviews, with each participant invited to participate in three interview sessions, as described below. About half of the participants also agreed to be accompanied while doing an activity related to their job-search, such as travelling to or attending a Jobcentre meeting. Full details of interactions with the participants are included in Chapter Six. Both the participant observation activity and the use of multiple interviews relate to recommendations arising from the pilot study, to mitigate risks arising from participants' difficulties in articulating meaning through language, as discussed above.

Interviews

All three interviews were intended to be “active” conversations, encouraging participants' “interpretive capabilities” and acknowledging their abilities as competent narrators (Holstein & Gubrium, 1995:17, 21) and experts on their own life experiences (Czarniawska, 2004). Although interviewing people with learning difficulties involves the same challenges as interviewing anybody else, there are also some specific considerations to bear in mind (McCarthy, 1999).

As discussed in the section on the narrative approach, particular challenges were acknowledged relating to interviews with people with learning difficulties. Various techniques were used to encourage responsiveness, including adaptation of questions, repeating back, asking for clarification, and offering reassurance (Way et al, 2015; Booth & Booth, 1996). The interviewing and transcribing processes also drew on and developed the researcher's skills of empathetic and active listening, an awareness of body language and facial expression and close attention to individual speech patterns (Owens, 2007).

The way the question is phrased may help or hinder the response of participants with cognitive impairments. The way that the participant responds to questions may also provide information to the researcher about how the question is perceived and how the relationship between researcher and participant is perceived and developing (McCarthy, 1999). Efforts were made to provide a non-threatening approach to interviewing and to reduce the likelihood of inconsistent responses arising from mixed feelings about participation (Goodley, 1998; Simons et al, 1989). The interviews used a variety of question formats and drew on techniques to check and clarify responses. Questions were adapted to each

participant, using a mixture of open and closed questions, and re-phrasing questions where the response seemed unclear or ambiguous. The participants were also asked to clarify some responses and some responses were reflected back by the researcher to check or summarise. The researcher's input to the interview was clearly recorded both in the audio-recording and in the transcript (see further detail on transcription below).

The first interview involved a set of questions to facilitate the gathering of background information about the participant's early life, family and schooling, parental occupations and geographical locations, as well as basic demographic information. This was useful contextual information for the analysis of participants' stories about looking for work and being in work. The first interview questions were also intended to identify periods of unemployment, employment and voluntary work, interactions with employment agencies (jobcentres, employment support, placements and other schemes), supported employment, and the claiming of out-of-work benefits, to be explored in more depth in the second interview. While the approach aimed to be broadly chronological, there was awareness that many people with learning difficulties find concepts of time challenging (Booth & Booth, 1996). Consequently, little emphasis was placed on establishing the exact order of events to minimise participant anxiety and to avoid inhibiting communication.

For the second interview, the approach focused more on encouraging the telling of stories, so questions mostly took the form of "tell me about...". However, given that participants with mild learning difficulties may struggle to articulate their responses, due to their communication difficulties, the interview was designed to be adaptive, with more structured, closed questions provided where open questions did not produce much in the way of a response (Owens, 2007; Booth & Booth, 1996). Narratives produced in this way are more obviously co-constructed between researcher and participant, with the participant as "primary storyteller" and the researcher as "animator" or "vicarious storyteller", keeping the story close to the participant's perspective and respecting their position as 'author' and expert (Hyden & Antellius, 2011:593).

Drawing on the responses from the first interview, which were transcribed before the second interview, the participants were asked questions relating directly to their employment and unemployment experiences and episodes that they had

mentioned. For each of these, participants were encouraged to describe the situation, focusing on concrete, specific events and incidences. Although some narratives may have emerged in the first interview, it was in the second interview that these were specifically encouraged, with fewer direct questions from the researcher and a stronger focus on questions which offered “narrative opportunities” (e.g. how did you become aware of....?) (Riessman, 2008:24), allowed for a narrative response (e.g. what was it like?) or were “narrative pointed” (e.g. can you remember a situation where....?) (Wengraf, 2001:126). Questions in the second interview linked directly to the research objectives by focusing on issues of fairness (“do you think you were treated fairly?”, “do you think you were treated the same as other people?”) but these were used with discretion, depending on how participants responded to narrative questions about their experiences. In some cases, recollections about these experiences also reminded participants of other employment-related events which they had not mentioned at the first interview.

Broadly, in the third interview the focus was future oriented and more abstract, to discuss expectations and but also to discuss policy issues, such as participants’ views about the idea of paying disabled people less than the minimum wage or offering unpaid placements as work experience. The third interview was also an opportunity to follow up any matters discussed in the previous interviews that were unclear or unfinished, and to get an update on the participant’s work and benefits situation.

At the end of the first interview, participants were asked to take photos on their phones of anything they felt related to looking for work, to be discussed (but not retained) at the second interview. This was originally intended as a prompt for discussion and also a way of encouraging participants to attend the second interview. Some of the participants were not interested in doing this, said that all their job-hunting was online, or did not have working cameras on their phones. However, where offered, the photos did provide an opportunity for building rapport and getting to know the participant a little better, at the beginning of the second interview.

Efforts were made to contact all of the participants after the data analysis was written, specifically to discuss the research progress, to ask for feedback and to find out about any major changes in their lives, especially in relation to

employment. Twelve of the sixteen participants were contacted at that point and a brief summary of their responses is included in Chapter Six.

Timing of interviews

For each participant, interviews mostly took place at least one week apart, allowing time for basic transcription, reflection and adaptation of the interview guide for the next interview. All the interviews took place during the day, at the convenience of the participant. With three participants, introductory meetings were held (not audio recorded) to discuss the nature of the research and to provide some reassurance, before scheduling the first interview.

Most of the interviews lasted around 45 minutes, with the shortest being 28 minutes and the longest 75 minutes. This was led by the participant but partly varied depending on the age of the participant, older participants having a longer employment history to discuss, and their willingness to talk. Some participants commented that their tendency to 'talk a lot' and to 'go off on a tangent' was an aspect of their mild learning difficulties or autism, and this was inevitably reflected in longer interviews, which may have included material not entirely pertinent to the research questions but contributing to maintaining rapport with the participant and sometimes providing contextual material.

Location of interviews

Most of the interviews were held in public spaces such as libraries, coffee shops, pubs, community centres and gatekeeper offices. These had the advantage of being known to participants, which may have helped to put them at their ease or reduce the stress of meeting a stranger. They are also safe places for the lone researcher, who was also meeting a stranger. However, public spaces are often unpredictably noisy, and this can have a significantly negative impact on the interview process. Most obviously it can interfere with the quality of the recording, and this was the case on occasion, including interviews held in libraries. The first interview with one participant was held in a popular café where he was used to meeting his support worker. This was not only problematic for the recording but also made it difficult to formulate questions and actively listen to the participant's responses, to enable a conversation in which "alternate considerations are brought into play" (Holstein & Gubrium, 1995:17). For the second interview,

meeting as acquaintances rather than strangers, the participant was willing to go to an unfamiliar but quieter venue.

One participant suggested holding the second and third interviews at her parents' house. This had the advantage of being quiet and a place where she felt safe and 'at home'. The lone worker policy was followed, with texts sent to one supervisor at the start and end of the interview.

Observation activity

The aim of having a separate opportunity to observe participants outside the interview setting was to help contextualise participants' stories, as well as to provide some insight into participants' social interactions. Where possible, observations were of interactions with people offering support for job search. While this could be referred to as participant observation, the level of participation by the researcher was limited, being peripheral to the social interactions of the participants being observed (O'Reilly, 2009).

The intention was to accompany participants to some activity associated with employment, looking for work or claiming out-of-work benefits, planning to spend a half or full day. In practice, this was difficult to achieve and fairly limited. For example, one participant (Jeff) was accompanied to the local Jobcentre Plus office when he was due to sign on. I walked with him from his home and back, spending about 90 minutes with him. Six other participants (Sam, Emily, Jack, Anthony, Louise and Paul) were accompanied to their local Jobcentre Plus offices. With two of these participants (Anthony and Louise, a married couple), I observed a meeting with their Jobcentre Plus work coach. On another occasion, I was able to sit nearby while Paul talked to his work coach, and to discuss his thoughts about the meeting afterwards.

I also spent a short time with two other participants (Kevon and Sergei, on separate occasions) walking to a different location for interviews. Although these events were shorter than anticipated, they did provide useful opportunities to observe participants interacting with other people and their environment, and to provide information about the form and content of Jobcentre Plus meetings, as well as opportunities to talk to participants away from the interview setting.

Clark & Emmel (2010) suggest walking interviews provide opportunities for participants to have a greater degree of control over the research process, to show rather than tell and to articulate their thoughts in a less intensive setting than the interview room. Walking alongside participants, in some instances, I was able to prompt discussion about issues that had not arisen during interviews or simply observe how participants negotiated some of the complexities of everyday life. For the most part, these discussions were not audio-recorded, but I made audio notes and written field-notes shortly after the event and these were included in the dataset for data analysis, as discussed below.

Transcription

Although the transcribing of interviews is somewhat neglected in research methods guidance (Davidson, 2009), decisions about transcription involve fundamental assumptions about the nature of data collection and representation which may have a significant impact on data analysis. Translating talk to text is a selective process, reflecting practical and theoretical factors (Davidson, 2009). In this research, the process of transcribing was undertaken in the spirit of Hammersley's argument that it is "an attempt to capture features that are in an important sense given" (Hammersley, 2010:560) and to represent "what occurred" (ibid:558). This justifies working to include as much detail about the interview as possible, given time and resource constraints. However, these constraints are also significant, and it is therefore noted that there should be some correspondence between the level of transcription and the planned level of analysis (McLellan et al, 2003). In this, the research was guided by an intention to carry out narrative analysis not only of what was said, but how it was said (Riessman, 1993). This needs a less detailed level of transcription than proposed for Conversation Analysis, but a level of detail which includes some indications of pitch, emphasis, repetition and so on.

In order to make valid interpretations of unusual speech patterns (for example, for emphasis or to signal a stronger emotional response), it is clear that the speaker's habitual speech patterns should be established. For people with communication difficulties, habitual speech patterns may be untypical of the wider population and therefore need to be documented carefully, so that 'the unusual' can be identified. The following example may help to clarify this. The

numbers in parenthesis are a rough estimate of pause length; my speech is also in parentheses. This is Ryan, talking about how good he is at using PowerPoint:

It's, it's all, it's all, it's, it's, it's, it's called having the, having the knowledge when you, when you been in the, when you been in the school, the IT room at school (mm, yeah, yeah) (4), and people look at it, they're doing, cos I was doing presentations, PowerPoint presentations and all the, all my class-mates were looking at me, as if to say (2), "how you done, how have you done that" (2) I say, it's call, it's, it's called having patience, and it's, and it's, and it's called sitting there and, and getting on with it (3) (yeah) you know (yeah) yeah. I'm PowerPoint, PowerPoint's, you know, master (yeah, yeah) (2), so.

This type of repetition and stuttering is typical of Ryan's speech patterns. However, in this extract, responding to a question about how he got a paid job, it is so prominent that it can reasonably be interpreted as demonstrating strong feelings of frustration:

I, it's, it's been a long while since I've, since I've done, this, this, this thing I'm trying to tell you, Ruth, is the fact that, I'm trying my hardest to get a job (1) (mm), and when I want a job, and I try, and I try, and try, and try, and try, and try, and try, and try, and try, people just, people get on at me. I get, I get, I get people, j-just (2) (mm), you know (2), and this is why, this is why, J [advice centre worker] says to me (2), you know, what, don't let people just walk all over you, just (2) i-it's, it's, it's time that you started to be you, just be you (2) (yeah, yeah) but I can't, I can't be, how, how can I be me, why are people, why can't people let me be myself? You know what I mean?

Although the transcriptions produced for this research were intended as a document of what was said, the transcription represents what the researcher could hear and understand. When the recording was inaudible or the participant's speech was unclear, it was noted on the transcript, along with my estimate of what the participant was likely to be saying, based on context and memory. It is acknowledged that the sounds heard, and the meanings identified were partly a reflection of the my assumptions and interpretations about the participant and the context of what was being said. Such assumptions and interpretations were recorded, reviewed and questioned, and they do not imply that the transcription itself is a fiction (Hammersley, 2010; Lloyd et al, 2006).

The accuracy and completeness of the transcript also has to be balanced with readability and a sense of “narrative flow” (Jaffe, 2000:501). The transcripts included some phonetic recording of the way that words were said by participants, including words half-spoken, accents, stuttering, and non-word sounds, such as ‘erm’. One of the central aims of the research was to place the experiences of participants at centre-stage, including people with “expressive language difficulties” (Lloyd et al, 2006). ‘Translating’ their speech into ‘standard English’, using standardised spellings, would undermine that aim, transforming their voices into the voice of the researcher or the wider academic community. However, as well as trade-offs with readability, there is also a balance to be struck with a stigmatising effect of “linguistic non-standardness” (Jaffe, 2000:509). There is a risk that inarticulateness and ungrammatical forms of speech may unintentionally frame participants as ‘stupid’, reproducing inequalities (Owens, 2007). It is hoped that an appropriate balance has been struck in the way participant voices are included and represented in this thesis.

Data analysis

Qualitative data analysis involves a general process of familiarisation, labelling and sorting of data (Spencer et al, 2014). This can be described, for example, as identifying codes and concepts, linking them to categories, identifying patterns from categories and creating themes that link similar patterns (Kim, 2016), although there are semantic differences between the way these terms are used in different methodological approaches (Saldana, 2016; Spencer et al, 2014).

Following the pilot study, and in keeping with the narrative inquiry methodology, a narrative analysis approach was used for the data relating to participants’ experiences of looking for work, being in work and losing work. This approach was both “substantive”, focusing on interpreting what is said, and “structural”, exploring the construction of talk (Spencer et al, 2014:272).

For the substantive analysis, the research used a combination of framework analysis (Ritchie et al, 2014), thematic analysis (Braun & Clarke, 2006) and narrative analysis (Riessman, 2008), beginning with the writing of “analytic memos” (Saldana, 2016:44) and the identification of “key themes and patterns” (Coffey & Atkinson, 1996:26), as a basis of a deep familiarisation with the data, “setting the stage for interpreting and drawing conclusions” (Coffey & Atkinson, 1996:27). This process formed the basis of identifying stories for substantive and

structural analysis. NVivo qualitative analysis software was used extensively to aid the management of a dataset consisting of 47 interview transcripts, seven observation fieldnotes and notes of three phone conversations, and to support the coding process. Within NVivo, coding decisions and reasons for the classification and re-classification of nodes, were recorded in a separate document, alongside descriptive memos about the codes, tracking the development of the analysis.

Riessman suggests narrative thematic coding is guided by prior theory, as well as looking for new theoretical insights, preserves sequences and stories for interpretation, attends to contextual factors such as time and place, and remains committed to a “case-centred” approach (Riessman, 2008:74). The data analysis drew on Fraser’s social justice concepts, explored further in Chapter Two, as well as sociological concepts relating to the meaning of work, unemployment and disability.

There are two “structural” aspects of narrative analysis described by Riessman (2008), which she refers to as structural analysis and performative analysis. Using the former, the analysis explored *how* participants told their stories, recognising that people draw on a range of linguistic forms to persuade the listener of the significance of the story. The analysis explored how participants’ stories were structured to emphasise or deny agency and examined issues of acceptance and resistance. Looking at performative aspects, the analysis considered how the stories were constructed, the researcher’s influence and the “social circumstances” of the production of the stories (Riessman, 2008:105).

These approaches to data analysis enabled the researcher to “trace the unique plot” or “construct a plot out of disparate sources” for each of the participants, valuing their uniqueness (Freeman, 2017:40). This was also important to demonstrate that the participants were active in “defending their personhood” through storytelling and were “competent storytellers” (Hyden & Antellius, 2011:595-6), rather than merely being “sources of data” for the researcher’s narrative (Booth & Booth, 1996:56).

A thematic analysis approach (Braun & Clark, 2006) was used to address the research question relating to concepts of disability. This provided a way of exploring the tensions and contradictions in the ways that participants spoke about disability, drawing on all of the interview data not only the narratively-

oriented parts, and not necessarily confined to the sections on employment and unemployment.

Policy analysis

In order to address the research questions relating to government policy, the research identified a relevant area of government policy and analysed a sample of government policy documents relating to this policy area. The policy analysis used a combination of post-structural policy analysis (Bacchi, 2016) and political discourse analysis (Fairclough & Fairclough, 2012). Further details are included in the next chapter.

Researcher reflexivity

The process of evaluating and creating narrative coherence is a co-production between the participant and the researcher, involving questioning, listening and interpretation which is “saturated with concepts” (Riessman, 2008:32). The effectiveness and trustworthiness of the interpretation requires not only that personal narratives are situated in “social and political contexts” but also that “alternative interpretations are considered” through careful documentation of data collection and analysis (Riessman, 2008:190-1). This can be aided by reflexivity, acknowledging that the researcher is not “simply observing from a position of detachment” but has an active role in the co-construction of knowledge (Cooper & Meadows, 2016; Finlay, 2002:211). In this research, reflexivity was used to maintain critical awareness of the impact of the researcher, while aiming to avoid “interminable self-analysis” (Finlay, 2002:225). What follows here focuses specifically on the research design; the concluding chapter includes further reflexive comments on the research findings.

I began this research after ten years of working with people with learning difficulties in adult community education. As a teacher and learning support tutor, I had engaged with people with learning difficulties and autistic people on accredited and non-accredited courses in a range of settings, covering subjects such as functional maths and English, employability skills, arts and crafts, and healthy eating. During those ten years, course specifications increasingly demanded the embedding of ‘employability’ in all lesson plans. As my students talked openly with me about their aspirations and frustrations around looking for work, I became increasingly concerned that this ‘employability’ focus was not

relevant to barriers that students with learning difficulties were facing. Exploring what employability and employability support might mean for people with learning difficulties was one of the motivating factors at the start of the research.

My teaching experience broadened my understanding and underpins my appreciation of learning difficulties as aspects of human diversity. I anticipated that my experience of working with people with learning difficulties would be helpful in establishing a relationship of trust with potential participants in the research. However, I was also concerned not to replicate a teacher-student relationship with participants and to openly acknowledge them as experts being consulted about their experiences, to actively address the impact of the power imbalance between participants with mild learning difficulties and a researcher who did not have learning difficulties. This was reflected in the information provided to potential participants about the research, in the language I used in the interviews, the way I described myself, my body language and dress, and in all other communications with the participants.

Nevertheless, I also acknowledge the influence of living in a disablist society with a long history of linking “moral deficiencies” (Carlson, 2016:543) to perceived deficiencies in ‘intelligence’ and ‘independence’. These factors increase the risk that researchers of disability reinterpret the actions of participants “in disablist terms that emphasize victim images of disabled people” (Goodley, 1999:43) and “otherness” (Goodley, 2000:200). Having supervisors with experience in this field helped to mitigate this risk, as did discussions with practitioners and activists, including people with learning difficulties, not directly involved with the research.

The other major influence over my approach to data collection, analysis and interpretation was my experience of working for Citizens Advice, first as a volunteer advisor and, from early 2019, as a part-time paid support worker. In that year of paid advice work, which ended with the start of the Covid-19 lockdown in March 2020, I supported a wide diversity of people needing advice about UC and dealing with some of the most complex problems associated with new claims. During that time, I was based in the main offices of three different Jobcentres and I was able to observe the day to day work of UC and legacy benefit work coaches, their supervisors and specialist disability colleagues.

Although this work took place after I had completed the fieldwork and much of the analysis for this research, nevertheless it did influence the later stages of that

analysis and the writing up of the research. In particular, I gained first-hand experience of the practical aspects of the social security context of the research and the typical range of relationships between claimants and their Jobcentre Plus work coaches. Through this, I also became more aware of the day to day pressures and dilemmas facing these work coaches, their increasing workload and the range and limits of their discretionary power. My observations were consistent with the themes covered in a recent article drawing on interviews with “street-level employment advisers” at “contracted-out welfare-to-work providers” (Kaufman, 2020:209), and discussed in Chapter One. They have particularly informed my conclusions about the need for professional standards for Jobcentre Plus staff and for greater scrutiny of their discretionary powers.

Narrative research needs to be presented in ways that show the interpretations are plausible as well as persuasive, and that the underlying data is genuine. One aspect of this is to show “a critical self-awareness of how the research was done” (Riessman, 2008:191). This was supported in the research by maintaining a research journal in which I documented critical decisions made during the research process. The suggestion that reflexivity should be used to “take some responsibility for producing an analysis which can be applied to support a particular view of the world, whilst recognising researcher involvement in the production of the account” (Gough, 2003:32), has guided my approach.

It is important to recognise that the research was accountable to experienced supervisors with whom research decisions and interpretations were discussed regularly at every stage. For example, there were extensive discussions about issues of sampling and the inclusion of participants during the fieldwork. My initial response to contact with participants with higher level educational qualifications, especially Nick, Ravina and Sergei, was to question whether their inclusion challenged the adequacy of the sampling criteria: could they be said to have learning difficulties if they had gained these qualifications? During discussions with my supervisors, it became clear that to exclude them would be to assume that academic success was impossible for people with learning difficulties. We agreed that was an unwarranted assumption, based on stereotypes. By including them, the research might be able to explore differences and commonalities relating to educational qualifications.

Having multiple interviews with the participants provided opportunities to follow up questions that I thought participants might not have understood or where I had not fully understood their response. Participants demonstrated active engagement with the interview questions, including asking for clarification or refusing to answer questions that they did not understand, and this provided me with some reassurance over concerns about acquiescence (see section on consent, above). However, the style of interviewing was necessarily informal and intentionally supportive, aiming to build trust and rapport with a group of people who had routinely experienced disrespect and worse.

In general, I tried not to disclose my opinions in my questions or in my reactions to the participants disclosures, but I was not always successful in doing so. For example, when discussing the issue of whether it was reasonable to suggest people with learning difficulties could be paid less than the national minimum wage, I aimed to present the scenario initially as neutrally as possible, to avoid influencing participants' responses. However, when they expressed outrage at such a suggestion (which some did), I found it impossible not to agree with them. However, to ensure that I had not obstructed them in expressing views about the relationship between work and pay, I also asked further questions about voluntary work, unpaid work placements, work probationary periods and work trials. Their responses provided a much richer source of data that could then be analysed together when exploring issues of fairness around monetary reward for work.

Nine participants' narratives are represented centrally within the two narratively-oriented chapters about the research findings (Chapters Eight and Nine). Inevitably this raises questions about the seven participants who are not represented so fully. This was not merely a matter of word count constraints or avoiding repetition, although I had initially hoped to include each participant at least once if possible. Each of the participants had unique experiences as well as experiences that had connections to the others. All of the interviews were transcribed and coded within the data analysis process. However, what these transcripts show is that some participants did not have work-related or benefit-related stories to relate, due to age or the length of time that they had been actively looking for work, and some participants were less forthcoming or actively resistant when talking about specific experiences of being in or out of work. After each first interview I reflected on possible narrative opportunities and aimed to

provide openings for participants to talk about these within the second interview, but this was not always successful and partly reflects the development of my skills in research interviewing. It should be noted that three participants (Jack, Ryan and Sergei) clearly expressed a refusal to discuss experiences that had been particularly distressing, and I respected their position.

The decision to carry out a follow up interview with each participant was taken towards the end of the period of writing up Chapters Seven, Eight and Nine on the interview data analysis. The aims of these follow up meetings were to thank the participants in person and give them a £30 gift card; to deliver on an earlier commitment to let participants know what the research had found and to listen to participants' responses; and to get an update on participants' employment situation.

As mentioned above, participants were not offered any monetary incentive or reward for participating. I was concerned that offering payment, even in the form of a gift, could distort my relationship with the participants, making them feel some obligation to me or to the research which might make them feel unable to withdraw consent. Participants were reimbursed for any travel expenses to and from interviews, but I was conscious that they had given freely and generously of their time. The small gift made at the end of the research was a personal way of recognising the value of their participation and it was a surprise for participants to receive it. Unfortunately, that also meant that the four participants that I was unable to contact did not receive anything by way of thanks.

Throughout the research I have reflected on what difference my prior experience of working with people with mild learning difficulties has made. This is difficult to summarise without risking over-claiming or under-claiming. Working as a teacher of 'basic skills' for 10 years before starting the research brought me into regular face-to-face contact with people with learning difficulties in a way that I had not experienced in any other parts of my life. Before that experience, my understanding of what having learning difficulties means was based on (usually negative) stereotypes from popular media images, rather than first-hand interactions. I thought of learning difficulties not only in much narrower terms, but also in relation to people with more severe impairments, high care needs and very limited or no verbal skills, and I have found a similar level of ignorance among many of the academics that I have met while on the PhD programme.

My experience of working with people with mild learning difficulties provided me with confidence that I would be able to discuss their experiences with them, that they would be able to communicate their ideas, hopes and fears, and that they would trust me to respect their equal worth and humanity. This confidence was borne out during the research. The knowledge that I had gained about the barriers they faced and the prejudice and discrimination that they often experienced provided me with a strong motivation to persist with the research and complete the thesis. This was particularly valuable during a period of my life that included a number of family-related challenges, as well as writing up this thesis during the Covid-19 pandemic.

Throughout the research I have reflected on issues related to participatory research and the role and responsibilities of non-disabled academics or those who do not have learning difficulties in research about the experiences of people with learning difficulties or disabilities. In maintaining a view of learning difficulties as aspects of human diversity, while also recognising that people with learning difficulties may have less power in society than people without learning difficulties, I have hoped to avoid 'othering' or objectifying. By referring to 'them', there is a risk of implying 'lesser' or of less value, in a similar way to the othering of 'the poor' (Lister, 2004) or 'the benefit claimant' (Patrick, 2017).

One way of reducing that risk is to strengthen the involvement of the participants in the research (Beresford, 2016). This was not a user-led research project and the participants were not involved as researchers, but the participants were also not thought of as "passive research 'subject[s]'" (Beresford, 2016:223). Returning to the participants towards the end of the research provided an opportunity to discuss the range of different stories gathered, the areas of connection and difference between them, and their responses and reflections. That provided an element of accountability to the participants that would otherwise have been lacking, but nevertheless the involvement of the participants in this research remained largely restricted to the recounting of their experiences and views. I am personally disappointed that I have been unable to add a more participative element to the research, in which participants could have interacted directly with each other, and I hope that further research in this area will involve handing more control to participants. However, I also accept that this is ethically complex in terms of consent, privacy and anonymity, and potentially problematic in terms of managing expectations. For example, if people share their experiences in the

expectation of influencing policy and then find they are ignored, this could be personally damaging as well as counterproductive (Patrick, 2020).

Chapter Six introduces each of the 16 participants and describes their involvement in the research. The participants are deliberately represented in this research by (pseudonymised) names rather than depersonalised numbers. The choice of pseudonyms was discussed earlier in this chapter in the section on privacy and anonymity.

Efforts to contact all the participants towards the end of the research resulted in a follow-up meeting with 12 of the 16 and Chapter Six includes a brief update on their lives. I was wary about the risk that “dropping back into people’s lives” (Miller, 2015:297) might have unintended consequences. Re-connecting with the participants might have made them feel uncomfortable about further claims on their time or the limits of their involvement in the research. On the other hand, gathering new information about them, whether intentionally or otherwise, could “provide alternative and/ or contradictory versions of aspects of the earlier research” (Miller, 2015:294). To mitigate against that risk, I discussed and agreed with my supervisors a clear and limited brief for the meetings. In practice, possibly because the gap between the last fieldwork interview and the follow-up meeting was at most 18 months, the follow-up meetings were useful and unproblematic. The participants who were contactable were very willing to meet again and said they had enjoyed being involved in the research.

The research design presented in this chapter guided the research fieldwork and data analysis, resulting in the material covered by Chapters Six to Nine. Detailed analysis of government policy was also central to addressing the research questions and this is presented in Chapter Five, covering the policy context and environment within which the participants’ experiences were set. The final chapter draws these five chapters together to discuss the findings and conclusions of the research, reflect on the research design and consider further possibilities.

Chapter 5 Policy analysis

Introduction

The aim of this chapter is to explore the policy backdrop to the experiences of the research participants. This is a fundamental element in evaluating government claims to support social justice for disabled people, as demonstrated within the policy discourse. It directly addresses the research question:

What are the tensions and contradictions in government policy towards supporting the employment of people with learning difficulties and promoting social justice?

The subsequent analysis of the research participants' interview data is informed by this policy backdrop, to enable consideration of the research question:

What do the stories of people with mild learning difficulties who are looking for work reveal about the adequacy of the government's policy approach to supporting the employment of disabled people?

The chapter explores how governments since 2010 have conceptualised and embedded constructions of disability in general, and learning difficulties in particular, within policy, especially in relation to employment, unemployment and employability. For the purposes of this analysis, the elements of policy in focus are *ideas*, defined as “historically constructed beliefs and perceptions” (Beland, 2019:4) and *institutions*, defined as “embedded rules and norms” (ibid:4). Policy is explored with a view to understanding “the ways in which ideas and institutions interact” (ibid:4-5).

To do this, the analysis covers 23 specific policy documents produced between 2010 and 2019 (see Appendix 4); references to these sample documents are italicised throughout this chapter (for example *DWP, 2019b*). These documents have been selected to include major legislation on social justice, disability and unemployment-related welfare reform. They have been identified through a search of the www.gov.uk web pages for policy documents authored by the DWP, using the search term ‘disability’ or ‘disabled’. The results of this search have been narrowed by excluding documents that:

- explicitly focus on a form of impairment that is not a cognitive impairment;

- exclusively focus on issues relating to the employment of people close to retirement age;
- exclusively focus on disability-related welfare benefits that are not related to employment, unemployment or employability, for example, PIP.

In many policy areas there are multiple documents that refer to the same policy or provide minor updates. For example, a search of the government website gov.uk for references to Disability Confident, an employer-oriented scheme, produced over 100 results. Of these, over two-thirds were produced by the DWP, and half since 2015. This plethora of documents might be considered to demonstrate government commitment to supporting the employment of disabled people as a policy priority. Alternatively, it could be viewed as an attempt to camouflage the absence or insufficiency of proposals for government action or legislation in the context, as discussed in Chapter One, of a period of austerity-related downward pressure on state spending and Brexit-related upward pressure on legislative time. In either case, such a multitude of documents can have an obscuring effect on the identification of policy ideas, providing a barrier to public participation in democratic deliberation.

In consideration of the limited time available to this research, the focus here is either on the central or concluding item in a series of reports (for example the White Paper (*DWP & DoH, 2017*), rather than the Green Paper (*DWP&DoH, 2016*) or on the version most relevant to the period covered by the qualitative interviews (for example, the UC business case summary (*DWP, 2018c*)). The analysis also draws on extensive reading of related documents, ministerial speeches and parliamentary debates, as well as sources of critical reviews and reports of government practice. Given the quantity of policy papers published during this period, it is acknowledged that the analysis that follows may not reflect every aspect of government policy towards the employment of disabled people. However, the analysis does cover the key policies of the period.

The sample documents have been classified into three categories: social justice and rights; disability employment; and unemployment-related social security, as shown at Appendix 4. These three categories represent the three areas of government focus relating to disability employment, during the period, and are consistent with the focus of this thesis and the principal issues discussed by the participants.

As discussed in Chapter Four, the analytical approach used here is a combination of critical/political discourse analysis (Fairclough & Fairclough, 2012) and poststructural policy analysis (Bacchi & Goodwin, 2016). The intention is to explore the way that the relationship between disability and unemployment is problematised, in order to “make visible the politics...involved in the making of “problems”” (Bacchi & Goodwin, 2016:16).

Bacchi’s “what’s the problem represented to be?” (WPR) approach applies a series of questions to the policies under review:

- I. what is represented as ‘the problem’ in a specific policy or policies?
- II. what are the underlying and deep-seated assumptions and presuppositions of this representation?
- III. how has this representation come about?
- IV. how else could the problem be viewed and what is left unproblematic?
- V. what effects does the representation produce?
- VI. how is the representation presented and defended, and how can it be disrupted and replaced?

(adapted from Bacchi & Goodwin, 2016:20).

The analysis also uses the conceptual lens of Fraser’s participatory parity approach to social justice, drawing on the concepts of misrecognition and maldistribution (see Chapter Two). In particular, identifying misrecognition means examining “institutionalized patterns of cultural value... which cast some as inferior, excluded, wholly other or simply invisible” (Fraser, 2000:113). Identifying maldistribution means examining social arrangements that institutionalise material deprivation or gross disparities of wealth, income or leisure time (Fraser, 2003a; see also Chapter Two).

The approach taken to addressing the research questions relating to government policy and uncovering and exploring the “problematizations” within the policy ideas (Bacchi & Goodwin, 2016:21), also involves an acknowledgement of the strength of policy continuity and path dependency (Cairney, 2012). In the context of this research, understanding the influence of path dependency involves recognising the connections between current government policy, the long history of policy to address unemployment and employability and the changing role of the state within that history. References to this complex history are therefore

embedded within the analysis, with the necessarily limited aim of highlighting the practices that may have influenced or produced the way that the employability and employment of people with mild learning difficulties are represented within current policy.

What is represented as the problem?

As the table at Appendix 4 shows, the policy documents identified here as representative of the government's approach to disability employment have little to say about the situation of people with learning difficulties, learning disabilities or autism. Where direct reference is made, it is usually to suggest that special consideration will be given ("taken into account" (*DWP, 2018a:19*); "with the right support" (*DWP, 2019b:11*)), without any firm commitment but in recognition that the standard procedures are not suitable. Mainly, however, no reference is made at all. Across the policy documents, the main 'problem' identified is that too many disabled people and people with long-term health conditions, as a whole, are not in paid employment despite supposedly being capable of paid employment. This is further represented as three consequential 'problems' of a) cost to the economy b) cost to the state, and c) individual costs.

These problems are referred to or illustrated numerically in the government policy as the disability employment gap (DEG). Figure 5.1 shows this gap since 2013, drawing on data from the Labour Force Survey (ONS, 2019a). Earlier comparisons are complicated by changes within the data categories. The lower line on the chart shows the 'official' DEG and is based on the employment rate among people defined as disabled under the Government Statistical Service (GSS) Harmonised Standard. The upper line is based on the employment rate among people who self-report (within the Labour Force Survey) as having work-limiting disabilities. This is more likely to include people who are the focus of this research. Both lines show a decline in the DEG, but the decline is less for the self-reporting DEG and that gap remains substantially higher.

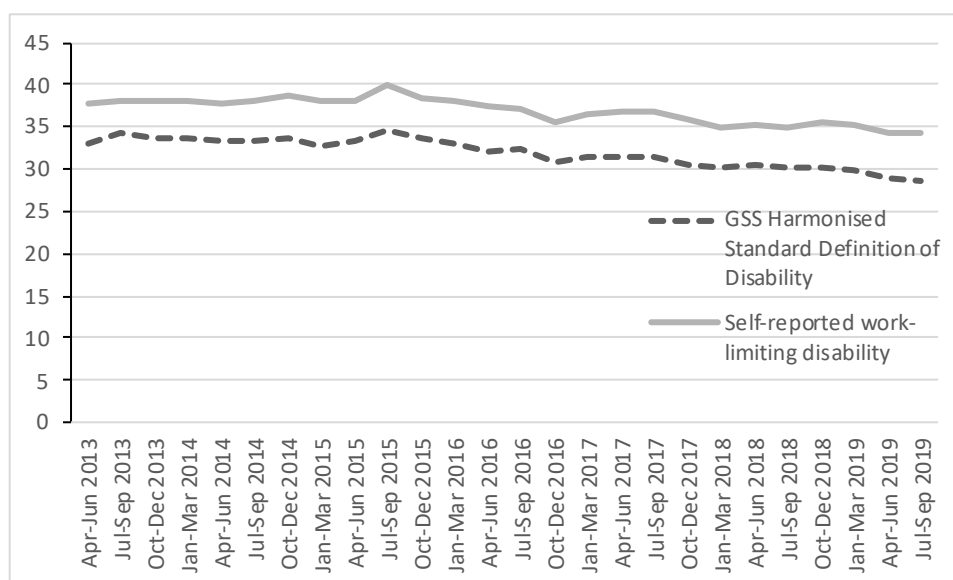


Figure 5-1 Disability Employment Gap (DEG) %

It is important to note also that the topline DEG figures mask the variation between different ‘types’ of disability: the employment rate for people with “severe and specific learning difficulties” was reported as 23.9% in 2016 and around 18% in 2019, a gap of over 60% relative to the employment rate for non-disabled people (Brown & Powell, 2018:9; Powell, 2020:8).

Numbers – what is ‘too many’?

There is no indication in any of the documents of how many or what proportion of disabled people the government believes *should* be in paid employment, but there is a clear indication throughout that there are “too many” who are not (*DWP&DoH, 2017:3*) and that the DEG is “still a large gap” (*DWP, 2013e:39*). Where this is not stated overtly, it is implied by language indicating that there are disabled people who *could* “make the choice to move into work” (*DWP, 2015e:7*) and *would* if certain changes were made, for example, if the government were to take action to “improve work incentives” (*DWP, 2015c*). This point about the importance of financial incentives and choosing work is discussed further below in relation to the problematisation of the DEG as a cost to the individual.

The Conservative government elected in 2015 pledged to halve the DEG by 2020, effectively committing to increase the number of disabled people in paid work by 1.2 to 1.5 million (out of a total of 3.5 million out of work at that point) (*WPC, 2017:6*). That pledge was reduced to one million by 2027 in the 2017

Conservative Manifesto (Conservatives, 2017) and included in the 2017 White Paper (*DWP&DoH, 2017*). The one million figure matches that identified by the DWP in the early 2000s, referring to a “missing million” disabled people out of work but wanting to work (Stanley, 2005:29). This is a much weaker target than halving the DEG, since population growth and general growth in employment is likely to increase the numbers of disabled people in employment but may have no effect on the DEG (Wass & Jones, 2017:4)

What these figures assume is that there is a substantial proportion of disabled people who are economically inactive but not incapacitated. What is implied or directly stated is that, given the opportunity, this ‘missing million’ would be able take on paid work on a similar basis as non-disabled people, possibly including standard expectations about full-time hours of work, holiday and sick leave entitlements. In that sense, they are effectively considered as “unemployed labour” (Grover & Piggott, 2005:714) and as such would provide employers with “increased labour supply” (*DWP, 2015c:1*).

Research into industrial decline in the 1980s and the impact on male employment levels suggests that a rate of around 5% or less is a reasonable benchmark for the level of “permanent sickness or early retirement” during a period of full employment (based on figures for male workers) (Beatty & Fothergill, 1996:635). As Figure 2 shows, the rate has been above 7.5% for most quarters since 2013, even on the basis of the more restrictive Equality Act definitions of disability (HMG, 2010), and significantly higher for self-reported disability and ill-health.

None of the documents make any suggestion that the numbers of people in these categories of ‘economically inactive’ might have been increased by government action. However, research by Beatty & Fothergill suggests that during the major industrial restructuring of the 1980s and the consequent rise in unemployment, Conservative government policy is “widely thought to have moved some of the long term claimant unemployed towards sickness-related benefits” (Beatty & Fothergill, 1996:634). As Stone indicates: “disability programs can have the effect of absorbing and disguising unemployment, and thus controlling the total supply of labor” (Stone, 1984:181). Current government policy is based on claiming that this is indeed what has happened, with disabled

people and people with long-term health conditions discouraged from “taking steps back to work” by “financial incentives” (DWP, 2015e:1).

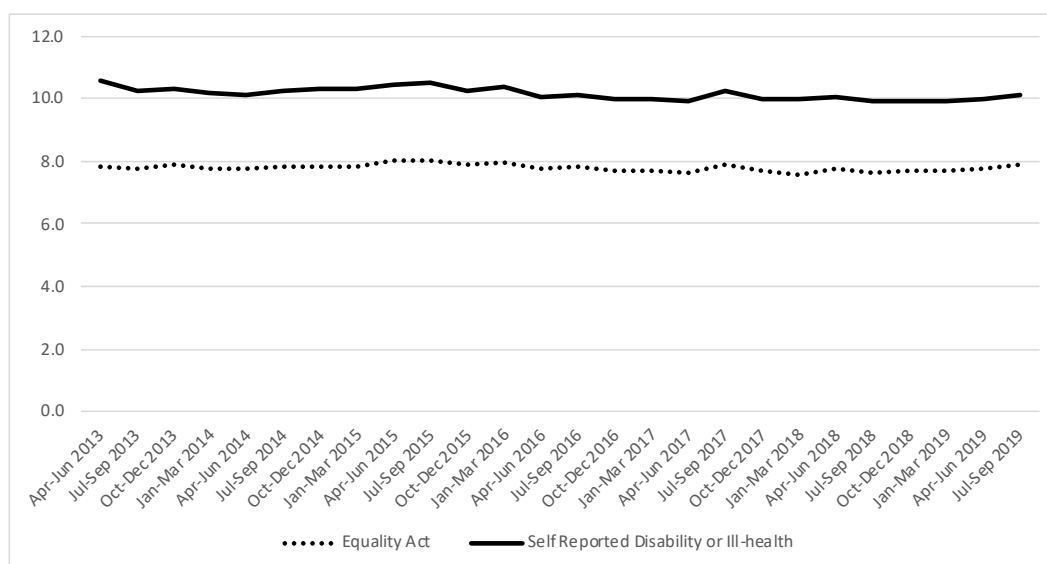


Figure 5-2 Economic inactivity among people with a disability or ill-health, as a percentage of the working-age population

Alongside this, it is frequently claimed that “many disabled people and people with health conditions want to work” (DWP&DoH, 2017:3). In the Impact Assessment for the proposal to cut out-of-work benefits for claimants assessed as capable of ‘work-related activity’, a figure of 61% is quoted as the proportion of those claimants who want to work (DWP, 2015e:1). This figure of 61% originated in a DWP survey carried out in 2013 in which only around 15% said they were *able* to work (DWP, 2013f; Disabled People Against Cuts, 2016).

This leads on to consideration of how disability and long-term health conditions are defined and delineated within the policy documents. The White Paper *Improving Lives: The future of work, health and disability*, published following consultation on a similarly named Green Paper, defines disability in relation to the Equality Act 2010 (HMG, 2010) as:

“...someone who has a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. ‘Long-term’ is defined as lasting or expecting to last for at least 12 months.” (DWP&DoH, 2017:86).

Throughout both the White and Green papers references to disability are accompanied by the phrase “long-term health condition”. While it is not always clear what distinction is being made between these two labels, the glossary indicates that:

*“An individual is considered as having a long-term health condition if they have a physical or mental health condition(s) or illness(es) that lasts, or is expected to last, 12 months or more. If a person with these condition(s) or illness(es) also reports it reduces their ability to carry out day-to-day activities as well, then they are also **considered to be disabled**.”*
(DWP&DoH, 2017:86, emphasis added)

To clarify, these documents indicate disability is equivalent to physical or mental ‘impairment’, ‘health condition’ or ‘illness’, lasting ‘at least 12 months’, and either ‘reduces’ or ‘has a substantial and long-term adverse effect on’ the person’s ability to carry out day-to-day activities. ‘Substantial’ is not defined. ‘Day-to-day’ activities, while not defined in the White Paper, are detailed, with some variation, in application forms for disability-related social security benefits and broadly follow the ten areas identified over thirty years ago by the now-defunct Office of Population Censuses and Surveys: locomotion, reaching and stretching, dexterity, seeing, hearing, personal care, continence, communication, behaviour, intellectual functioning (OPCS, 1988:10).

For policy purposes the definition of disability is effectively connected to “ideas and values about distribution” (Stone, 1984:172), as well as medical criteria. When the White Paper indicates that “ill-health among working age people” costs the economy £100 billion a year” (DWP&DoH, 2017:6), this is a statistic that results not from some externally or medically defined category of “ill-health” but from administrative and legislative decisions (Stone, 1984). The £100bn figure is another statistic with a long history, featuring in the Black report on “the economic costs of ill-health” in 2008 (Black, 2008:4).

The conflation of ‘disability’ and ‘long-term health condition’ throughout the White Paper is further qualified in the Executive Summary to highlight that mental health conditions and musculoskeletal conditions are “the most common conditions that affect participation in work” (DWP&DoH, 2017:9). The central policy focus is on keeping people *in* employment when they have ‘health conditions’: receiving income from employers rather than out-of-work social

security benefits. This relates to all three of the ‘problems’ discussed below. This central focus is irrelevant to people who have no experience of paid work, or whose experience is limited to temporary or zero hours contracts, as was the case for most of the research participants (see Chapters Eight and Nine).

Although ‘learning disabilities’ and ‘learning difficulties’ are mentioned in the White Paper (*DWP&DoH, 2017*) there is no specific consideration of the boundaries or definition of either term. There is an acknowledgement that people with “learning difficulties or with autism” have a lower employment rate than the average for disabled people (*DWP&DoH, 2017:19*) and a figure of 24% is quoted. In general, the policy documents refer to these terms in relation to a “primary medical condition” (*DWP, 2015b:8*). However, information provided to employers (*DWP, 2019b*) refers to learning disability without reference to medical or health sources or any other evidence base. The minimal information provided in this document risks trivialising the experiences of people with learning difficulties and contributing to further misrecognition of their value, with reinforcing maldistributive consequences if their employment prospects are worsened or they are considered to blame for failing to obtain or retain employment.

Costs to the economy

The DEG is problematised in many of the policy documents in relation to economic and business factors, especially productivity trends and the health of the labour market. These contextual factors were discussed in Chapter One. To summarise, very weak growth in UK productivity since the 2008 financial crisis has left both productivity and average wages around 19% lower than they would have been on the “pre-crisis trend” (Adam et al, 2019:3). At least nominally, employment rates have been at record highs, although marginally boosted by the inclusion of anyone in at least one hour of paid employment a week (ONS, 2020; Full Fact, 2019, Athow, 2018). There is evidence that official unemployment figures under-represent the numbers of people who may be willing to work (Barr et al, 2019). However, labour supply is currently considered to be “tight” (CIPD, 2019:3, ONS, 2019b) exacerbated, especially in lower skilled sectors, by Brexit-related falls in net migration from the EU. These two factors (weak productivity growth and more people in paid employment) have influenced the rise of in-work poverty: the Institute for Fiscal Studies (IFS) estimates 58% of those with

incomes below the official income poverty line are either in paid work or in a household with someone who is in paid work, compared to 41% 20 years ago (Adam et al, 2019). For a government committed to an economy that is “strong”, “vibrant and robust” and that “works for everyone” (Conservatives, 2017:13), these are major challenges in themselves, as well as to the government’s social justice strategy, with its focus on work as the “route out of poverty” (*HMG*, 2012:4).

Within the policy documents, there are clear indications that reducing the DEG is considered part of the solution to the challenge of increasing the availability of labour. References are made to the lower employment levels of disabled people as “a waste...for the economy” (*HMG*, 2014:3), “foregone potential and economic loss” (*DWP*, 2013g:8), alongside similar but more generalised remarks about “the economic costs of worklessness” (*DWP* 2012b:7) as a “symptom of the economic downturn” (*DWP* 2012a:37). Reducing the DEG is heralded as offering “potential to help businesses grow at a time of high employment” (*DWP&DoH*, 2017:24).

Phrases such as “underutilised reserve of talent” (*DWP*, 2013g:18), “widen our talent pool” (*DWP*, 2018b:9) and “increased labour supply” (*DWP*, 2015e:1), are clearly direct references to a perceived need to address tight labour market conditions. There are also less direct but similarly upbeat messages elsewhere: “a huge pool of potential employees” (*DWP*, 2019b:8); “skills that are critical to business success” (*DWP* 2015a:11). However, this association (between reducing the DEG and promoting economic growth) was directly contradicted by pronouncements made by the Chancellor of the Exchequer in 2017 that the UK’s low productivity rate was in part the result of “higher levels of participation” by disabled people (Slawson, 2017). While a convincing case can be made that his claims were wrong (Disability Rights UK, 2017), his high-profile assertions contradicted the messages in the policy documents and were likely to have a negative impact on business sentiment towards the employment of disabled people.

In recent years, a number of high-profile politicians and policy makers from government and opposition parties have made proposals about allowing employers to pay people with learning disabilities less than the national minimum wage (see for example, Private Eye, 2018; BBC, 2017; Bloom, 2017; Lyons,

2014). These proposals are predicated on similar grounds of weaker productivity or higher business ‘cost’, indicating that employers need “a financial incentive to take ‘the risk’ of hiring [disabled people]” (Ryan, 2019:61).

Such pronouncements and proposals, which expose disabled people to a greater risk of exclusion from the labour market or exploitation by employers (Ryan, 2019) represent a form of misrecognition by positioning disabled people as “comparatively unworthy of respect or esteem” (Fraser, 2008b:58). This misrecognition has maldistributive consequences, as indicated by the disability *pay gap*, a measure of inequality not mentioned in any of the policy documents even those directly referring to the disability *employment gap*. The TUC estimates that the disability pay gap is widening, currently standing at 15.5%, equating to over £3000 a year, on average, a major contributor to the “financial stress experienced by disabled workers” (Roache, 2019:2). Office for National Statistics figures show a pay gap of almost 19% for people with “mental impairment” (Romei, 2019).

The government’s policy pitch to employers also suggests that employing more disabled people will help business growth and profitability by reflecting their “diverse range of customers” (DWP, 2019b:3) and making “better connections with your disabled customers” (DWP, 2014a:2). This discourse around the idea of disabled people as a distinct set of consumers, whose demand has the potential to increase paid work opportunities of disabled and non-disabled people, is reflected in campaigns such as Purple Tuesday, a government-backed “accessible shopping day” (Office for Disability Issues, 2018) and #PurpleLightUp (purplespace.org). It has been strongly criticised by some disabled groups (Disabled People Against Cuts, 2018) as an attempt to commercialise the recognition of disability and legitimise government policy around the treatment of disabled people within the social welfare benefits system (as discussed further below).

This attention to the ‘spending power’ of disabled consumers ignores the evidence that disabled people face a much higher likelihood of living in poverty (31% compared to 20% for non-disabled people (JRF, 2020:55)), and if employed at all, are more likely to be working part-time (36% compared to 24% for non-disabled people (Brown & Powell, 2018:8)). Promoting the value of disabled people as active consumers might contribute to reducing cultural

devaluation and stigma but would have little direct impact on the factors behind the higher rates of economic and social deprivation experienced by disabled people. This mismatch is potentially even greater for people with learning difficulties, whose control over their own lives, and access to “resources necessary to defend their rights”, is likely to be more limited than for non-disabled people or people with physical or sensory disabilities (Fyson & Cromby, 2013).

Several of the policy documents make general comments about the cost to businesses of failing to retain the skills and experience of employees who become disabled or develop long-term health conditions. Although there is an acknowledgement that “disabled people can only be in employment if employers are willing to employ them” (*DWP, 2019a:3*), the principle demand side issue is described as employer “confidence in employing disabled people” (*DWP, 2014a:3*) a matter the government largely proposes should be addressed through information sharing.

Only one of the documents makes a direct financial claim about the cost to employers of the DEG, and it does so only with reference to mental health: “poor mental health costs the UK economy between £74bn and £99bn a year and employers between £33bn and £42bn a year.” (*DWP, 2018a:15*). This focus on mental health highlights a tension between the policy focus on employee retention and research findings that indicate people with poor mental health are “often overrepresented in high-turnover, low-pay and often part-time or temporary work” (Mental Health Taskforce, 2016:6). The relationship between work and individual health is explored further below, but it is pertinent to note here that the policy documents imply, if not directly claim, that mental ill-health is *not* a product of the work environment or the result of employer decisions and the organisation of work. Yet it is well known that there are causal links between mental ill-health and “insecure and poor quality employment” (Marmot, 2010: 26), such that “the health impact of jobs of poor psychosocial job quality may be equal to, or worse than, being unemployed” (Bevan, 2017). The policy documents also make no suggestion that this is a matter over which the government itself has any responsibility. Yet, for example in relation to the regulation of working conditions or the availability of mental health care, government action or inaction is clearly central to questions about the costs of the DEG to the economy and to business interests.

Costs to the state

The second way that the DEG is problematised is as a cost to the state. This is indicated in a variety of ways: the need to rein in spending, questioning affordability and sustainability; promoting fairness; and linking resources to deservingness.

A claim to be “committed to supporting disabled people ... even in these tough economic times” (*DWP, 2013g:15*), recalls the 2008 financial crisis and subsequent austerity politics. This “difficult and challenging economic situation... a time of spending restraint” (*DWP, 2013e:vi*) is linked to the issue of affordability and sustainability: “we need to ensure support is affordable – we spend 2.4% of our GDP on disability benefits” (*DWP, 2013e:2*). This affordability discourse relates closely to Conservative policy during the period under review, focusing on “deficit reduction through public spending constraints”, (Ellison, 2016:28), under which DWP spending was cut by over 35% between 2010 and 2015 (*ibid:34*). This is not only a matter of spending cuts, however, but also about policies towards reducing the role of the state in the delivery of services: “the resources of central government alone are insufficient” (*HMG, 2012:61*); “government will act as catalyst...working in partnership” (*DWP, 2013e:3*). These are signposts not only to the government’s austerity policies but also to a political aim to reduce the role of the state in the delivery of services, in favour of the private sector, social enterprises and voluntary organisations (Bochel & Powell, 2016).

The cost to the state is also positioned as a matter of fairness: “fairness to those who fund the system: taxpayers” (*HMG, 2012:36*). References to ‘the taxpayer’ can to be understood as signalling a “them and us” distinction between people who are in work and those who are not (Hills, 2015:2), as highlighted by the Chancellor of the Exchequer in 2015: “For our social contract to work, we need to retain the consent of the taxpayer, not just the welfare recipient” (Osborne, 2015). The implication is that ‘welfare recipients’ are not also taxpayers, ignoring any income tax paid during periods of employment and ignoring consumption taxes. The message is also transmitted more subtly as a matter of producing “better value for money for the taxpayer” (*DWP&DoH, 2017:57*). This misrecognition of claimants as separate from and lesser than ‘the taxpayer’ serves to reinforce maldistribution by offering justification for cuts to the rate and

availability of social security benefits and deterring people from claiming at all (Baumberg, 2016; Grover & Piggott, 2013a).

The fourth aspect highlights a focus on a particular group of recipients: “more vulnerable” (*DWP, 2018a:19*), “those who would benefit most” (*DWP, 2013g:39*), “people facing the greatest hardship” (*DWP, 2013a:27*), “those with the greatest need” (*DWP, 2014b:8*) and, more specifically, “the most severely disabled” (*DWP, 2012b:16*). These descriptors of the ‘most deserving’ are themselves potentially contradictory: ‘the most severely disabled’ may not necessarily be those ‘facing the greatest hardship’, since they are more likely to be awarded higher rate disability benefits. However, this qualifying of recipients of government spending indicates a hierarchy of deservingness that is deeply rooted in the history of the welfare state in the UK, within which those who are less visibly impaired are often held as less deserving (Roulstone & Prideaux, 2012:5). In addition, the implication that current recipients of state support include people who are not deserving, or are less deserving, can be seen to support restricting the availability and level of support. Misrecognition as ‘less deserving’ or ‘undeserving’ can have catastrophic personal consequences, including but not restricted to the obvious maldistributive effects. These are explored further in Chapters Eight and Nine.

Each of these facets of representing the problem of the DEG as a cost to the state constitute a break in the fundamental principle of the welfare state connecting provision with need. In practice, spending on disability benefits since 2010 has fallen by around £5bn (Butler, 2018). In 2017/18 around a third of disabled people were living in poverty, while the prevalence of disability itself increased from 19% to 21% from 2013/14 to 2017/18, mostly driven by rising numbers of people with “a mental disability” (JRF, 2020:55). As the UN Special Rapporteur noted, disabled people have been “some of the hardest hit from austerity measures” (Alston, 2019:17).

Costs to the individual

The third way in which the problem of the DEG is represented is as a set of individual costs or issues: a waste or loss of potential for a group of people who want to work; financial exclusion and poverty; causing or contributing to ill-health, especially mental health; and behaviourally and morally damaging. It is important to acknowledge that each of these is also a driver of a wider policy agenda

around unemployment, underemployment and welfare reform. Here they are discussed with particular reference to the position of disabled people and people with learning difficulties.

The idea of “potential”, which appears in the title of the 2013 Coalition government policy paper on disabled people (*DWP, 2013e*), and within in all of the documents about disability and employment, is predominately based on the proposition that unemployment is a ‘supply side’ (labour supply) issue. This is the fundamental principle behind active labour market programmes (ALMPs). ALMPs are a “human resource development” (Lødemel, 2001: 297) approach to the role of the state in improving the employment prospects of out-of-work benefit claimants. ALMPs, emerging in the 1990s and influenced by US and European ideas about the role of the “active welfare state” (Daguerre, 2004:41), cover a range of interventions from training courses and education to work experience, either on a voluntary or compulsory basis, often in combination with job search support.

The policy documents emphasise that moving from unemployment to employment requires the development of the skills, experience, confidence and aspirations of each individual unemployed disabled person. This individualised development is enabled through “greater personalisation” (*DWP, 2011:4*), “a more personalised and tailored approach” (*HMG, 2014:42*) or “personalised conditionality” (*DWP, 2013g:51*). The implication is that previous approaches have failed because they have not been sufficiently personalised, and also that the ‘demand side’ (the availability and range of paid work) is relatively unproblematic.

Looking more closely at the way supply side issues are discussed, there are direct references to skill-building, such as “equipping them with the skills they need for work” (*HMG, 2014:32*), as well as less direct references to skills deficits: “develop their talents” (*DWP&DoH, 2017:3*). Skills deficits are referenced in relation to the ‘digital by default’ design of UC, viewed by the government as “an opportunity to tackle digital exclusion”, because “those without such skills are considerably limited in their employment prospects” (*DWP, 2013a:7*). Promoting engagement with work placements and apprenticeship schemes, the policy documents suggest these will “help people with disabilities... gain valuable experience in the workplace” (*DWP, 2018b:9*), develop “work-based

competencies” (DWP&DoH, 2017:20). Supported internships, work placements for “young people with complex learning difficulties”, are promoted as a way to “enable... sustainable paid employment by equipping them with the skills they need for work” (HMG, 2014:32).

References to the “aspirations of disabled people” (DWP, 2013a:4), a need to “build their motivation” (DWP, 2018a:14) or to challenge “fixed beliefs about their abilities” (WPC, 2017:19) suggest that low expectations and negative attitudes among disabled people themselves are not only partly responsible for their exclusion from the labour market, but also result from, or are worsened by, not being in paid work. There are also moralistic aspects to this aspect of the discourse, discussed further below. The demand side is not entirely neglected, but where it is addressed, within the documents on the Disability Confident campaign (DWP, 2019a, 2019b, 2018b, 2014a), there is still an emphasis on supply side: “help people...gain valuable experience in the workplace” (DWP, 2018b:9), “we’re holding a Job Shadowing Day” (DWP, 2014a:7). In this way, the unemployment of disabled people is problematised not only as a product of a lack of skills, experience and confidence but also as a *producer* of these deficits.

Skills, experience and self-confidence, rather than jobs, are portrayed as the key objects that disabled people can acquire, with help from Jobcentre Plus work coaches and ALMPs, and metaphorically strap on to support their battle to win paid employment. The word ‘equip’, which also appears in the Social Justice (HMG, 2012) and Improving Lives (DWP&DoH, 2017) White Papers, has links to the notion of ‘resilience’, another concept with military overtones (Garrett, 2018:150) that is popular within the policy documents:

...helping people respond resiliently to challenges and overcome fixed beliefs about their abilities (DWP&DoH, 2017:17)

...to build resilience against the set-backs experienced while job seeking (ibid:56)

This concept of resilience implies a highly individualised view of the ‘problem’ of the DEG, suggesting that the barriers and challenges that disabled people face are inevitable characteristics of the labour market (Foster, 2018) and beyond the influence of government policy (Amery, 2019). Analysis of changes in the use of this term within government policy documents over recent years indicates an

association between resilience and resistance to “forms of activity regarded as undesirable” (Amery, 2019:370), such that “resilient subjects are self-regulating subjects” (ibid:371). In the context of unemployment and job-seeking, such undesirable behaviours include any activity that conflicts with the ‘claimant commitment’ associated with a claim to UC, as judged by a Jobcentre Plus work coach. These include refusing an offer of work, losing work, or insufficient time spent looking for work, and might result in a sanction or withdrawal of benefits (Dwyer & Wright, 2014).

Despite the apparent commitment to ALMPs and skill-building, in practice government funding for the new Work and Health Programme is forecast at £130m for 2019/20 compared to £540.8m for the programmes it replaces. Disability rights campaigners have concluded that the reduction would lead to “a reduction in numbers of disabled people supported from 300,000 to 160,000 over a 2.5-year period” (Disability Rights UK et al, 2017:12).

The DEG is also positioned in the policy documents within a wider discussion about unemployment and poverty, with the mantra “work is the best route out of poverty” (*DWP, 2011:3*) repeated throughout. Government policy on social security benefits, including freezing rates since 2015, capping the maximum amount a household can receive and re-aligning the taper rates within UC, have ensured that out-of-work benefit claimants’ incomes are at poverty levels, as attested by a string of independent research reports (see for example, Patrick, 2017), with recent figures indicating the switch to UC will increase the numbers in out-of-work poverty by 200,000 (JRF, 2019:4). This is a deliberate policy with a long history, related to the principle of ‘less eligibility’ embedded in the 19th century Poor Laws, designed to “deter able-bodied [people] from seeking relief” (Harris, 2004:50). However, being better off in paid work is not the same as paid work being “the most sustainable route out of poverty” (*HMG, 2012:4*), as shown by studies of in-work poverty (see for example, D’Arcy & Finch, 2017; Shildrick et al, 2012). The prevalence of in-work poverty undermines the government’s argument that closing the DEG is key to reducing poverty among disabled people.

The DEG is further problematised as an individual cost in relation to health, within a broader claim that work is good for health: “the route to recovery” (*HMG, 2012:37*); “beneficial for their mental and physical wellbeing” (*DWP, 2011:3*).

This a theme running through a raft of changes to the social security system in the UK since 2010, shifting from an earlier, more cautious acknowledgement that work “can improve an individual’s health and well-being” (DWP, 2006:2) towards claiming a causal link between work and health, as in “work can..contribute to recovery” (DWP, 2013g:4), to proposing “work as a health outcome” (DWP&DoH, 2017:37).

As noted in Chapter Three, much of this discourse is connected to the work of Gordon Waddell and his “biopsychosocial model” (Waddell & Aylward, 2010; Waddell & Burton, 2006), with its emphasis on work as “generally healthy, therapeutic and the best form of rehabilitation” (Waddell & Aylward, 2010:46). Despite the lack of robust evidence to support these claims (Shakespeare et al, 2017), Waddell’s work was referenced in the Improving Lives Green Paper (DWP & DoH, 2016). The suggestion that people who are out of work, and either disabled or ill, need to be financially incentivised to take paid employment, as part of a process of ‘recovery’, implies at the least a questioning of the ‘genuineness’ of their claim to limited capability for work, and at worst suggests fraud. This could be seen as an example of redistribution increasing misrecognition, by implying that those who might be enticed into work by the offer of financial rewards must be malingering.

Finally, the DEG is problematised within a wider behaviourally-oriented and moralistic discourse about the pernicious effects of unemployment. This discourse hypothesises a “welfare class” which becomes increasingly dependent on social security benefits (Walker & Howard, 2000:95). In part this is a long-running concern about benefit fraud, based on suggestions that claimants “work illicitly” or “find life on benefits congenial” and therefore reject offers of paid work, despite little evidence to support these claims (ibid, 2000:95). It is also about a more moralistic judgement about dependency that goes beyond the economic to indicate “an individual character trait, like lack of will power or excessive emotional neediness” (Fraser & Gordon, 1994:312).

The Social Justice White Paper draws on this problematisation when it proposes “challenging the culture of worklessness” by “making it clear that choosing not to work when you are able is no longer an option” (HMG, 2012:37). While this is not directly linked to the situation of people with learning difficulties, the matter of

‘when you are able’ is relevant, as it is decided within the DWP, based on Work Capability Assessments (WCAs).

WCAs are carried out under contract to the government by private companies using a range of ‘health professionals’ who may have little expertise in learning difficulties. Although the final independent review of the WCA recommendation about improving “interview practices for those with mental health conditions, learning disabilities and autism” was accepted (*DWP, 2015c:10*), the WCA continues to attract strongly critical attention of “basic deficiencies” both from within the House of Commons (WPC, 2018b:3) and from independent sources (Benstead, 2019; Pring, 2019; Ryan, 2019; Baumberg Geiger, 2018). There is evidence of widespread public distrust towards the WCA process and concern about “‘genuinely’ disabled people” being denied benefits (Baumberg Geiger, 2018:11). This is reinforced by news reports of the deaths of disabled people whose benefits have been withdrawn following a WCA or following failure to attend a WCA (see for example, Butler, 2020). Around three quarters of appeals against decisions not to award the main disability-related out-of-work benefit, ESA, are won at independent tribunal (Ministry of Justice, 2019).

The Impact Assessment document covering the withdrawal of a financial supplement for people assessed as capable of “work related activity” but not fit for work, notes that “financial incentives...discourage claimants from taking steps back to work” (*DWP, 2015e:1*). Similarly, the withdrawal of benefits (sanctions) from “vulnerable claimants” are justified on the grounds that they “motivate reluctant jobseekers” (*DWP, 2013a:23*). Documents relating to UC strongly promote the view that financial incentives are needed to motivate unemployed people, whether disabled or not, to “take the risk of moving into work” because of high and unpredictable “deduction rates” which reduce the “financial returns to work” (*DWP, 2012b:7*), and that people “choose” whether or not to work based on these incentives (*DWP, 2018c:7*).

The sense of a more moralistic view of unemployment is conveyed by use of the expressions such as “dependency culture” (*DWP, 2013a:13*) and “‘out of work’ behaviours” (*DWP, 2015e:2*). This is more illuminatingly described in a speech by the politician most closely associated with Conservative policy on ‘welfare reform’, Ian Duncan Smith, using expressions such as “fallen into a life of dependency”, “sickness benefit culture”, and “a path from dependency to

despondency” (Duncan Smith, 2015). The idea of ‘dependency culture’ draws on “traditional Conservative moral underclass discourse” linking unemployment to “individual and moral failings” (Daguerre & Etherington, 2016:212). In the process, unemployment and an “entrenched and intergenerational worklessness” (*HMG, 2012:41*) is linked to anti-social individual behaviours including alcohol and drug dependency and crime (Daguerre & Etherington, 2016). This is reminiscent of historical discourses around unemployment and the need to avoid policies that encouraged “those wilfully outside the realms of employment to desist from their recalcitrant ways” (Roulstone & Prideaux, 2012:5). As noted earlier, this discourse centres around the idea of categorising unemployed people in terms of ‘deservingness’, but it also suggests that unemployment in general, and claiming out-of-work benefits in particular, generates and exacerbates irresponsibility.

Several documents refer to issues of responsibility in relation to benefit claims, especially with reference to UC. This includes the document on penalties for fraud (*DWP, 2017b*) which highlights claimants’ “responsibility to provide accurate and timely information”. Elsewhere the focus is on “financial responsibility” and the concern that the benefits system supports a “dependency culture that treats too many adults as supplicant children” (*DWP, 2013a:13*). The implications of this discourse of deservingness and irresponsibility are discussed further in the final chapter.

It is significant that the government justifies a withdrawal from universal provision and an increased emphasis on personal responsibility by making reference to the social model of disability. The government states that it “remains committed to the social model of disability” (*DWP&DoH, 2017:33*). The social model of disability was discussed in detail in Chapter Three of this thesis; in summary it focuses on “...choices and rights and... giving disabled people the tools to overcome established social barriers” (Roulstone & Prideaux, 2012:xv). However, the government suggests that, because barriers to work are “societal”, this means that “those with functional capability above a certain threshold can, with the correct support and opportunities, work” (*DWP, 2018a:18*). This is a misapplication of the social model of disability, if it is intended to imply that the ‘personalised’ support on offer *is* sufficient, leaving the individual to ‘take responsibility’ for their unemployment. This form of misrecognition, which is also linked to rhetoric on meritocracy, is discussed further in the concluding chapter.

Conclusion

This chapter has drawn attention to tensions and contradictions within the policy discourse relating to the employment of people with learning difficulties and the promotion of social justice. Fundamentally, the policy discourse holds up disability as a catch-all category, while at the same time focusing actively on people with “mental health conditions and musculoskeletal conditions... as a key part of our programme” (DWP&DoH, 2017:9), because these are the most common reasons given for people taking sick leave or leaving employment for health reasons. In doing so, the policy documents appear to attempt to justify spending less, doing less and restricting the definition of disability such that most people with work-limiting conditions cannot get sufficient financial support.

The analysis presented in this chapter makes an original contribution to knowledge about the adequacy of government policy to support or increase the employment rate of people with learning difficulties. The analysis exposes a dearth of attention in policy on the employment of disabled people towards people with learning difficulties. Where the policy documents do refer to learning difficulties or learning disabilities, the information provided is trivial or focuses on a single individual. There are contradictory claims and assumptions about the productivity of disabled people and about their potential impact as consumers. The emphasis on levels of deservingness, epitomised by the term ‘most vulnerable’ highlights a rejection of the principle that provision should be matched to need. The analysis highlights how the policy focus on the supply side, particularly the motivation and aspiration of individuals who are not in paid work, implies a policy belief (Beland, 2019) that significant numbers of people are *choosing* not to work when they are able.

The following chapters provide evidence of the challenges faced by people with learning difficulties who are looking for paid work. The analysis substantiates the conclusions of this chapter that government policy towards disabled people is inadequate to meet the needs of people with mild learning difficulties and frequently irrelevant to the challenges they face in their search for paid work. Chapter six introduces the people who were interviewed during the research. It is followed by three chapters covering the analysis of the interview data: how the participants talked about notions of disability; their experiences of looking for work; and their experiences of being in work and losing work. The concluding

chapter draws these five chapters together, to argue that this policy failure is undermining social justice for people with mild learning difficulties.

Chapter 6 Introducing the participants

This chapter introduces the participants in this research. The aim of the chapter is broadly descriptive, to give a sense of the individuality of the participants so that their personhood is established in the mind of the reader.

The first part of the chapter explores some demographic characteristics of the participants. This is followed by 16 pen portraits which aim to summarise the life of each participant, as recounted in their interviews, highlighting their background, current situation and pivotal moments in their search for work. As discussed in Chapter Four, the participants' real names have not been used, to provide a degree of anonymity. The participants were given the opportunity to select the pseudonym used, although they did not always choose to do so. The participants' physical characteristics are not described, to protect their anonymity and to reduce the risk of being disrespectful.

These pen portraits were written at the end of the series of interviews, as a stage within the data analysis process. They are presented in the order that I met the participants. Twelve of the participants remained contactable and agreed to meet me again towards the end of the research, about 18 months after the fieldwork interviews were completed, as discussed in Chapter Four. During these follow-up meetings, I read the portraits out to the participants and their feedback was that they were a good reflection of their situations. Where contact was re-established, the portraits are followed by a brief update (in italics) on their later situation and where possible a note of their responses to the research findings. The decision to present the pen portraits within the main body of the thesis, rather than in an appendix, is part of the commitment of the research to recognise and respect the individual personhood of the participants.

The participants – overview

Table 6.1 shows the spread of age, gender, ethnicity, household structure, work status and housing tenure across the sample. This demonstrates the diversity of the sample, as discussed in Chapter Four. Tables 6.2 and 6.3 show the range of claims for working-age benefits, including disability benefits, among the participants at the time of the first interview.

Table 6-1 Participant demographics

	Age	Gender	Ethnicity	Lives with?	Work status	Any paid work ?	Housing type	Parental occupation (current or former)
Anthony	26	M	White British	wife	looking for work	Y	private rented house	care work
Emily	25	F	White British	parents	looking for work, volunteering	Y	parent's owned house	factory work/office work
Jack	30	M	White British	parents	looking for work, volunteering	N	parents' rented house	warehouse work
Jeff	58	M	White British	alone	looking for work, then in work	Y	social rented flat	factory work/mechanic

	Age	Gender	Ethnicity	Lives with?	Work status	Any paid work ?	Housing type	Parental occupation (current or former)
Kevon	18	M	White-black Caribbean British	parent	looking for work, volunteering	N	parent's owned house	catering
Lillian	37	F	White British	alone	in work, but contract ending	Y	parents' owned flat	professional practice
Louise	26	F	White British	husband	not looking for work due to health condition	Y	private rented house	catering
Nick	30	M	White British	parents or brother	looking for work, volunteering	Y	parents' owned house	business owners
Peter	26	M	White British	parent + siblings	looking for work	N	parent's owned house	care work

	Age	Gender	Ethnicity	Lives with?	Work status	Any paid work ?	Housing type	Parental occupation (current or former)
Phil	36	M	White British	alone	looking for work	N	social rented house	cleaning/warehouse work
Ravina	44	F	Sikh British Asian	alone or with brother	in work, but looking for alternatives	Y	mortgaged house	factory work/sales
Robbie	20	M	White British	parent + sibling	looking for work	Y	parent's social rented house	factory work/care work
Ryan	27	M	White British	alone	looking for work, volunteering	Y	social rented flat	gardening/retail
Sam	20	M	White British	parent + sibling	looking for work	Y	parent's rented house	catering/factory

	Age	Gender	Ethnicity	Lives with?	Work status	Any paid work ?	Housing type	Parental occupation (current or former)
Sergei	23	M	White British	parent	looking for work	N	parent's part-owned house	professional practice
Tyler	19	M	White British	grandparent + siblings	looking for work	Y	grandparent's social rented house	unemployed

Table 6-2 Out-of-work and Tax Credit benefits

Name	JSA (5)	ESA work- related group (5)	Disability premium (2)	Working Tax Credits* (1)	UC (2)	None (1)
Anthony		•				
Emily	•					
Jack		•				
Jeff	•					
Kevon					•	
Lillian		•	•			
Louise		•				
Nick				•		
Peter	•					
Phil			•			
Ravina						•
Robbie		•				
Ryan	•					
Sam	•					
Sergei						
Tyler					•	

* Refers to lower hours threshold for disabled person (16 hrs/week)

Table 6-3 Disability benefits (not work-related – see Abbreviations p.viii)

	DLA (4)	DLA during childhood but not as adult (2)	PIP (2)
Anthony			•
Emily			
Jack	•		
Jeff			
Kevon			
Lillian			
Louise			•
Nick			
Peter			
Phil	•		
Ravina			
Robbie	•		
Ryan			
Sam		•	
Sergei	•		
Tyler		•	

Only five participants (Anthony, Jeff, Louise, Phil and Ryan) were living independently (financially and physically) from their parents or other family members, although Nick, Lillian and Ravina were living away from family some of the time. All of the others were living with their parents. None of the participants had children. Those who were living with parents were contributing some proportion of their income to the household.

The portraits and feedback

Peter was a very talkative and thoughtful man in his mid-20s. Due to family issues, he was only available for the first interview. He lived at home with his mother, who worked full-time as a care worker, and his two adult brothers. All three brothers were on the autistic spectrum. Peter had stayed on at college until his early twenties, doing a series of vocational courses such as welding. Since leaving college, he had two short work experience placements where he was not given any support and the work was “*tedious*”. He also had a longer, unpaid, work experience placement organised by his mother at a local garage, but this did not lead to any paid work. Since college, he had been claiming JSA at times, but not continuously. He thought his benefits might have been stopped due to non-attendance at JCP interviews, but he was not sure. At the time of the interview, he was waiting for an assessment for a new ESA claim. He was hoping that if he was awarded ESA he would receive some help to find work without the stress of the full-time job-hunting and frequent reporting demanded of JSA claimants. He said he lived a very frugal life.

At 58, **Jeff** was the oldest participant in the research, and had the most work experience. He had always lived in the same economically-deprived area on the outskirts of the city. He had attended both special and mainstream schools, and he left school at age 16. He told me that he was quite aggressive in his late teens, narrowly avoiding getting into trouble with the police. Jeff had a difficult relationship with his dad, who died when Jeff was in his late 20s. Jeff lived with his mum until she moved into a care home two years ago, when she was too ill for Jeff to care for her at home. The housing association landlord moved Jeff to a smaller flat, where he lived alone in a street which he said was not safe. At the time of the research, Jeff was meeting monthly with a support worker but was worrying about how he would manage when that support ended.

Jeff had been employed in at least six jobs since leaving school, mostly cleaning. All the jobs were low paid (minimum wage since it was introduced). His first job was full time and lasted more than 10 years, but the others were all part-time. He had a few years of unemployment in the late 1980s and early 1990s, after being made redundant from his first job. When we first met Jeff was out of work, but he started a new job around the time of the second interview.

Jeff was claiming JSA. He was very careful with his money and knew the rate of all his regular bills to the penny. He was very concerned about taking work that might put his Housing Benefit at risk.

Jeff was almost relentlessly positive about his work situation, even about incidences which I interpreted as unfair (see Chapter Nine). However, he was critical of his most recent job where his supervisor had been rude to him. He hoped to continue with part-time cleaning work but was worried about his health.

Jeff lost his job during a “mental breakdown” following the death of his mother. He is claiming UC and is having some mental health counselling. At 60, and with various health issues, he is not keen to go back to cleaning work. He said about the research: “it gave me more confidence”.

Lillian was 37 and had recently moved into her own flat when we first met. However, she remained closely dependent on her parents, who lived nearby in a prosperous city suburb and had bought the flat for her. Her parents had both had professional careers and owned their own home. Lillian had two close friends who she saw regularly. Lillian was born with a rare genetic condition. She described the main cognitive impact in terms of anxiety and poor memory, especially working memory, which affected her ability to multi-task, to work at speed and to manage stress. Lillian was a very chatty, friendly person, articulate with a wide vocabulary.

Lillian went to mainstream schools but had a statement of SEN. She left college at 19 but went to a different college a few years later to study horticulture. In between, she worked part-time in a museum, first as a volunteer and then as a paid worker. After that she found it difficult to find other paid work. Problems with a series of part-time retail jobs (see Chapter Nine) led her to avoid retail or teamwork, mainly because colleagues and managers failed to acknowledge her learning difficulties, but also after experiencing bullying. She then did a series of

part-time cleaning jobs, always earning minimum wage, and claiming ESA. She was supported in this by a one-to-one support worker, provided through a local authority support scheme. Although Lillian enjoyed working as a cleaner on her own, and hoped to be able continue this work, she was finding it physically very tiring.

Lillian did not think she would be in paid work without the support of her parents and the support worker. She also said that continuing to live in her own flat depended on her remaining in paid work and getting ESA. She had recently applied for PIP, but her claim was rejected.

Lillian still worked at the cleaning job that started when we last met. She was enjoying it but finding the travelling hard - almost 3 hours by bus every day. She remained on ESA. About the research, she said "it's nice to know I'm not the only one who's had such barriers".

Although **Emily** was 25, she seemed younger and was quite nervous about participating in the research. She was an only child and lived at home with her parents in an ex-mining village about 10 miles from the nearest city. Emily thought her parents owned their house. Her dad worked in a factory and her mum was an office worker. Emily spent most of her time with her boyfriend, Jack (see below). They watched TV, played video games together and read books in the library, or wandered round the local shops. They also volunteered together in a charity shop once a week.

Emily left mainstream education at 19, having been persistently bullied at school and college. She had experienced three or four paid jobs since. All the jobs were time-limited contracts which were not renewed. The longest (one year) was doing part-time office work in the same company where her mum worked. Emily hoped to get paid work in retail.

Emily was claiming JSA and had been sanctioned twice (see Chapter Eight). When we met, she had been out of work for two years. She was not confident about finding paid work and had not been offered any support beyond help writing her CV and some interview practice.

For a few weeks, Emily had a zero hours job cleaning and washing up in a school kitchen but said "they had to get rid of me". She was very upset when she

was told bluntly that her work was too slow. As her claim for JSA had stopped, she had to move on to UC. She had not had any more sanctions. She was still looking for paid work but had not received any other offers. She and Jack got engaged and were looking forward to married life. Discussing the research, she said: "if you're struggling, no-one seems to care"

Jack was 30 when we met and he participated in the research with his girlfriend, Emily (see above). Jack was self-conscious about still living at home with his parents in his 30s and talked in quite traditional terms about wishing he could support himself and Emily to be financially independent. Jack's family lived in a council house in a small, once-industrial town about 8 miles from the nearest city. Jack's dad had retired early from manual work to care for Jack's mum, who had developed a long-term health condition, and for Jack. Jack had never been formally diagnosed, but his manner of communicating had some similarities with other participants with autistic spectrum conditions. Most of his days were spent with Emily, reading, watching DVDs or walking round the small town where they live, or volunteering in a local charity shop.

Jack left college at 20, having attended mainstream school. At college he did a series of foundation level courses including childcare, which he loved. However, he had not obtained any paid work to date and, after many years on JSA, had recently been transferred to ESA. Although that meant he was no longer expected to look for work by his Jobcentre, he remained determined to find paid work. Jack received DLA as a child but had been refused PIP as an adult. He was angry and anxious about the prospect of remaining out of work with ESA as his only source of income, aware that his eligibility for ESA would also be subject to future assessments. However, he was also worried about being bullied and made 'fun' of in a workplace. Jack did not hold back from telling me about some of his 'child-like' beliefs, and described himself as "*a child in a adult's body*", and it was easy to imagine him being mocked in a workplace.

Since we last met, Jack said he had "finally" been diagnosed with autism, after a very long wait. He was hoping this would lead to some support from a county-level autism organisation. He had started a work trial for a volunteer placement working one day a week at a community café and he was hopeful that this would be a long-term placement. He was looking forward to getting married to Emily in 2020.

Anthony was 25 and had been married to Louise (see below) for a year.

Anthony expressed a strong sense of loyalty to his family and looked to them to provide emotional and practical support, especially from his mum. He happily said how he liked being babied by his family (*"I'm a mummy's boy"*). He experienced years of bullying as a child, both in and out of school, and he and his mum moved around frequently. He was in contact with his dad.

Anthony attended a special needs school for most of his secondary school years, after a battle by his mum to get him a place. He then went to college for four years doing various foundation courses. These included two short work-experience placements. In his last year at college he felt that the teachers were treating them *"like babies"* and he left. The story of his first and only paid job is described in Chapter Nine.

Anthony was in receipt of ESA (WRAG) and PIP. Although he and Louise said they had a higher income than other members of the family who were in work, they were also paying off substantial debts. They were both aware that their entitlement to ESA and PIP was contingent on not 'failing' future assessments and had both experienced having to appeal against DWP decisions.

Anthony was participating in a work-related support scheme when we first met. This came to an end before the third interview and I was able to accompany him to meet his work coach at his local Jobcentre, where he was applying for another support scheme. One of Anthony's older brothers was a self-employed manual worker, and his role model. Anthony also hoped to be self-employed and run an animal rescue centre. However, he did not know how to set up such a business and he felt that his JCP work coach was being overly negative about his prospects.

Anthony told me that Louise had been sent to prison a few months earlier. He was not expecting her to be released for at least two years. He remained out of work and was struggling to cope on a much lower income on his own, having been moved to UC. He said: "the money's crap... by the time I've paid everything off, I can barely survive". All his plans for looking for work were on hold, waiting for Louise to be released.

Louise was 26 and the only participant not looking for work, due to poor health. She was married to Anthony (see above) and was attending employability

support services with him. They lived in a small town less than 20 miles from the nearest city.

Louise was an only child, brought up by her single mother who worked full-time in a canteen and may also have had learning difficulties. Louise described herself as having 'moderate learning disabilities', and she went to a special needs secondary school until she was 16. She spent four years at a mainstream FE college, doing foundation courses and performing arts courses. She said she avoided telling people about her learning difficulties because they would think she was "*thick*". However, she appeared quick-witted and sharp in her speech, assertive about her rights and outspoken in her opinions.

Louise had been looking for work until she became ill but remained unconvinced about her longer-term employability. She had received little support in job-hunting and had to take the DWP to an appeal tribunal to be awarded ESA rather than JSA, and to get PIP. With their joint ESA claim and both of them receiving PIP, she and Anthony had more money coming into the household than her mother did with her full-time job. Louise said that anyone employing her would find her to be too slow and she expressed no ambitions or ideas about what work she would like to do. The only paid work she had had in the past was very part-time, cash-in-hand work chaperoning children and young adults with special needs travelling to schools and colleges by taxi. That was the only paid work she thought she might be able to do in the future, if Anthony's plans for self-employment did not work out.

At the time of the research, Louise's main concerns were the state of her health and defending Anthony against his "*snobby*" JCP work coach.

Kevon left college a few months before we met, when he turned 18. He was the youngest participant. He had been in mainstream schooling throughout. He was hoping to join the Fire Service, so was only looking for short-term work while he waited for the next admission date. He had signed on for UC and had found it straightforward to claim. Kevon was the only participant who was mixed-race Black Caribbean British, and he had experienced racism at school and in the community. He was living with his mum, who was on long-term sickness benefits. She used to run her own café and he had helped out there, but he had not managed to get any paid work despite this experience.

Although Kevon described his learning difficulties as ADHD, mild autism, Asperger's and dyslexia, he did not think that would prevent him from getting into the Fire Service. He expressed strong optimism but also a degree of fatalism, related to his Christian faith, and he had not made any plans for what he would do if he was rejected by the Fire Service. He was involved in a youth unemployment scheme and a youth group, which he felt was helping him to prepare for getting paid work.

Sam was 20 and living with his mother and sister in a rented house in an economically deprived city suburb. Sam's mum worked in a café and his dad was a retired factory operator.

Sam had been to mainstream schools, sometimes assigned to special needs classes or with a support teacher at school. He did not make friends easily and had not kept in touch with anyone from school. At college he attained Level 2 qualifications in English and business studies.

Sam had been awarded DLA as a child but his claim for PIP as an adult was rejected. He had not appealed the decision but felt that it was his fault for "*saying the wrong things*". When we first met, he was participating in a youth employability scheme which was supporting him to make a new claim for PIP.

Sam had initially been advised to claim ESA when he left college but had failed the assessment and had to claim JSA. He was expected to look for work for 35 hours a week. He was worried about being able to apply for enough jobs to satisfy his work coach and very aware of the risk of being sanctioned. He felt he was doing everything he could, taking long unpaid work placements, getting work experience in a charity shop, trying to get help from a range of employment support and training organisations, going to jobs fairs and open days.

Sam had been on two traineeships, involving lengthy, unpaid work placements (see Chapter Eight and Chapter Ten). His only "*actual paid work*", was a zero hours contract for a stock-taking company, in which he was only given six shifts in the first month. The contract was cancelled after the second month. Sam was depressed by the response he had had from employers and co-workers in the various workplaces he had been in, especially criticism about his social skills and working slowly.

Sergei was in his early 20s and living with his mother in a city area with below average unemployment. His father worked in an office and his mother was a freelance business consultant. Both his parents were owner-occupiers. Sergei was one of the two participants who were recruited directly rather than through a gatekeeper organisation.

Sergei had experienced mainstream and special schools and colleges, moving schools several times, including two terms at a private school. Sergei described himself as having Asperger's syndrome. He did not make friends at school and preferred to avoid other people with autism. He said that he was never physically comfortable, had great difficulty sleeping, and got bored very easily. He found change and unpredictability extremely stressful.

Sergei had not had any paid work in the three years since he left college. He had recently had an unpaid placement with a government agency, through the Movement to Work programme. He enjoyed it but found the ending of the placement very stressful and had what he called a "*mental breakdown*" on the last day. He had not received the promised acknowledgement of a completed placement or any feedback from the employer, and there was no suggestion of an offer of paid work. Nevertheless, he did feel that doing the placement helped his confidence.

Sergei was claiming JSA. Although he was very positive about his current JCP work coach, he said that she was untypical, and he thought he was being treated better than most other claimants. Previous work coaches had been much less willing to recognise the barriers he faced within in the labour market.

Sergei was quite pessimistic about his job prospects. He thought he might do some freelance accounts work from home but would prefer work that would get him out of the house, give him some contact with other people and provide some structure to his days, as well as an income.

Sergei had remained unable to find paid work. He had started an accountancy degree at university, having passed his college exams, and said he was "much happier" there. He had also recently received a "long overdue" diagnosis of ADHD. He said he didn't think the diagnosis would make any practical difference in the near term as he had been put on a three-year waiting list for therapy.

Ravina was in her mid-40s when we met. She identified herself as Sikh British Asian and was the only British Asian participant. She was very articulate and enjoyed reflecting on her life and her personality. She was also one of only two participants who were recruited directly.

After mainstream school, Ravina went to college to train as a beauty therapist. She worked in salons and then did a business course and set up her own salon, with the loan of a shop premises from her aunt, and some start-up capital from the Princes Trust. Although she ran her business for 20 years, she said she made very little money, often much less than the minimum wage. She lived with her parents and later with her brother during these years, so she was able to manage on a very low income.

Ravina had never claimed any out-of-work or disability benefits, or tax credits and said she was not aware of what she might be entitled to. She had rarely been out of paid work, but since closing the beauty therapy salon, she had had a series of minimum wage jobs mostly in catering, cleaning and care work (see Chapter Nine).

At the time of the third interview, Ravina was employed for 40 hours a week cleaning flats for asylum seekers. Although she said she enjoyed the work, as with other jobs she had previously done, she was worried about the effect it was having on her health. Ravina appeared to be an optimistic person, constantly looking for new ways to challenge herself and improve her prospects. However, her work history showed no progress and even some decline in pay, conditions and level of responsibility.

Ravina was still cleaning flats for asylum seekers and said she was “not getting a chance” to do a supervisor/housekeeper job, when vacancies came up. She was finding the 40-hour week and unsocial hours very tiring and thinking about looking for something else. Discussing the research, she said: “you expect people in the workplace to understand, but they don’t”

Robbie was 20 when we met. He talked very openly and with humour about his situation. He lived with his mum and his younger sister, both of whom had health problems, in a council house in an area of the city with above average unemployment. His mum was not in paid work but was able to claim carer's

allowance because Robbie was getting the qualifying rate of DLA (see Chapter One for details of disability benefits). Robbie was also claiming ESA (WRAG).

Robbie said he had dyslexia, dyspraxia and an autistic spectrum condition. He had severe psoriasis visible on his face and arms, which was a reaction to stress. He described his mild learning difficulties in relation to social interaction, especially handling unfamiliar situations and uncertainty, but also knowing the right and wrong things to say, and when to stop talking.

Robbie went to mainstream schools and had additional support in secondary school. He had only had one job in the 18 months since he left college (see Chapter Nine).

At the time of the third interview Robbie was on a four- to six-week full-time retail-skills training course. The course had been arranged through his Jobcentre and it was unclear whether it was a condition of continuing to receive ESA.

Robbie was frustrated by the lack of recognition for his relatively invisible disabilities. He felt he needed help to boost his confidence, and work experience. Robbie remained committed to trying to find work in retail. However, he was worried that he might not find anything. Although he was trying to stay optimistic, he talked about “a wasted life”, sitting at home playing video games.

Robbie had not had any other paid work but had completed two unpaid work placements and was about to start a temporary, part-time pre-Xmas contract in a supermarket. He had left one of the placements early after being rudely criticised for taking time off due to ill health. His DLA claim had stopped but he had not qualified for PIP. His ESA claim was also stopped after an assessment, but he had not made a claim for UC and he was hoping that the supermarket job would continue after Xmas. Discussing the research and his experiences, he said “I’ve got plenty of motivation... it is the complete lack of respect”.

Ryan was in his late 20s and lived alone in an economically deprived area of the city, where he grew up. His parents had died in the last few years and Ryan had no family support, having fallen out with his brother. He had married at 22 but divorced three years later.

Ryan left mainstream school at 17, having experienced years of bullying. He did not think he had any qualifications. After three years of looking for work, Ryan

gained his only experience of paid work which was a four-week Christmas-period contract with Royal Mail.

Ryan struggled to concentrate in the interviews and was reluctant to talk about the details of past events, despite his wealth of experience of employability support, voluntary work and unpaid work experience placements. He was very frustrated by the lack of recognition for the work (paid and unpaid) that he had done. He was getting some one-to-one support through a programme set up by his housing association landlord, but he was not optimistic about this, as none of the other programmes he had participated in had led to anything tangible. Ryan did not have any clear goals, except to find paid work. He spent most of his time helping out at a local community centre.

Ryan was offered a paid job working in the dispatch department of a clothing company and was expecting to start on a four-week training course when we met. At the second interview he bitterly reported that the job had not materialised and instead he had been “*messed about*”.

At the third interview Ryan said he was about to enrol on a university course. He was unable or unwilling to give me any details about the course.

Phil was in his mid-30s and had never had any paid work. He had been looking for work since he left college about 15 years ago. Phil had non-specific learning difficulties which made it difficult for him to read and write. His speech was not very clear, although he was expressive of his opinions.

Phil had been to several special needs and mainstream schools and colleges in the area. He lived on his own, but he had lived with his mum until she died about five years ago, and before that with both parents. He was in regular contact with one of his sisters, who was also unemployed.

The complexities and frustrations of Phil’s experiences of claiming benefits is explored further in Chapter Eight.

Phil had worked for a day or two a week at a charity shop since he left college. He had hoped that this experience would help him to get paid work in retail, but that had not happened. He had been referred to a range of employability and support agencies but had not found them helpful. He was not allocated a disability employment specialist work coach at his Jobcentre.

Phil said he was keen to get any kind of paid work, as long as it would offer him some variety and a chance to meet new people and learn something new. He also hoped to go back to college and work on his literacy and maths skills.

Although Phil had gained an interview for a job in a bingo hall, it was only a temporary contract for 12 hours a week. He had been advised by a welfare rights adviser that he would be substantially worse off if he had to move back on to benefits after taking this kind of work, because he would have to move to UC and lose his disability premiums under JSA. He felt he needed to wait for full-time, permanent work. In the meantime, he was volunteering at various local job clubs and enjoying meeting new people. Discussing the research, he said “people do need help sorting out the benefits side... but the Jobcentre don’t see it like that”.

At 19, **Tyler** was the second youngest participant. He lived in an economically deprived area of the city. Tyler had been brought up by his grandma, because his mother was drug dependent. Other members of his extended family also lived in the house from time to time. His grandma worked part-time as a dinner lady.

Tyler left college in the summer of 2017, having attended mainstream schools. He had been permanently excluded from one primary school. He said he tended to react violently when he felt threatened or frustrated, although he did not get into fights or self-harm. He had gained a Level 3 BTEC at college but did not apply for university or an apprenticeship. He said this was because he “*messed up*” but also that he “*didn’t get much support*”. Tyler said he had been diagnosed with Asperger’s.

Tyler claimed UC when he left college but found paid work almost straight away. However, he left the first job after a week, finding that the very early start, long hours and working conditions were making him ill, through lack of sleep and not eating properly. His experience of being sanctioned under UC is discussed further in Chapter Eight.

The second job was a cash-in-hand cleaning job lasting two weeks. The third job was in a distribution centre of a major supermarket chain, at above the minimum wage for his age group. He enjoyed this job and thought it was going well but he was not taken on at the end of the probation period. He thought that was because he had been “*messing about*” on his phone, but he was also working hard and doing what he was asked to do.

The UC sanction left him with no income and in debt to repay the UC advance payment. Tyler felt that his job prospects were more limited than his peers because of his difficulties handling uncertainty and working with other people. He was hoping to find local warehouse work, where he could work by himself and “knuckle down” to something very routine.

Tyler had not found any other paid work and remained on UC. He said it had been “a tough year”, dealing with a bereavement as well as being unemployed. He had started to expand his job search to retail because he hadn’t been able to find warehouse work. He said his Jobcentre work coach had been “lenient” and had suggested jobs to apply for, but he was not accessing any other support because he wanted to “do it on me own”.

Nick was a softly-spoken and intense man in his early 30s. He spoke in a deliberate manner and a serious tone, with lots of long pauses. Nick split his living arrangements between his parents’ house, in a prosperous suburban area, and sharing a house (owned by his parents) with his brother in the city.

Nick was diagnosed with Asperger’s at a very young age. He said his autism made it difficult for him to learn new skills, and made him work more slowly than others might, but it also made him more accurate, thorough and focused in his work. However, he also linked being autistic to his mental health conditions including depression and suicidal feelings.

Nick had achieved academically beyond GCSE, gaining a level 4 accountancy technician qualification (above A-level), with one-to-one support throughout school and at college, but he was not confident about progressing beyond that. He had experienced minimum wage and temporary paid work in a supermarket and as a data entry clerk. His long-term aim was to be an accountant. To that end, he had been working for many years as an unpaid volunteer at various charities, but he had been unable to gain any accountancy-related paid work. Nick had been getting help with his job search from a community-based employment advice centre but had just heard it was closing down (see Chapter Eight).

Nick’s search for a girlfriend was as important to him as his search for paid work. His lack of success in looking for work and for a relationship, and the loss of the community centre, had left him feeling very low.

Nick got another temporary contract for part-time data entry work and then a permanent contract. He was glad to be in paid work but “fed up” that the location meant he was unable to live independently of his parents. He continued to do voluntary work. He had obtained a work trial at an accountancy firm but had been “let go” because one of the other employees “didn’t take” to him. He said, “it hit me quite hard... but it was a bit of wake-up call”, making him consider giving up on accountancy. About the research, he said “maybe my experiences can help other people”.

Reflections on the pen portraits

My own understanding of the participants’ situations was informed not only by my meetings with them but also by my pre-PhD experience of working in further education and community education. This experience helped me to be alert to the ways that mild learning difficulties might be reflected in participants’ communication, particularly in their speech patterns which were often difficult to follow. It also meant I had to take extra care when reflecting on how the participants talked about the visibility of their mild learning difficulties to other people and the extent to which they were likely to be identifiable to people with little or no knowledge of mild learning difficulties. What might be an ‘obvious’ sign of mild learning difficulties to me, might not be obvious to their work colleagues or employment adviser.

Writing the pen portraits also brought to the fore that there were few similarities in the demographic profiles, educational background, and socio-economic position of these participants. What they had in common, above all, were their difficulties in finding and keeping paid work, and one other factor: most of the participants had experienced bullying during their childhood and teenage years, especially but not exclusively at school or college. The frequency of bullying experienced by children with SEN and disability, and its long-term effects into adulthood, were highlighted in Chapter Three.

It should also be noted here that although the sample included people from black and ethnic minority communities, their numbers were too low to enable conclusions to be drawn about differences between experiences that might relate specifically to the intersection between ethnicity and disability. Women were also under-represented within the participant sample and this constrained the extent to which the analysis was able to explore the intersection of gender and

disability. Reflections on these limitations of the research are included in the concluding chapter.

Chapter 7 Notions of disability

This chapter focuses on addressing the research question:

How do people with mild learning difficulties relate to concepts of disability and how does that affect their expectations in their search for paid work?

The policy focus of this research is government policy relating to the employability of disabled people and the disability employment gap (DEG), as discussed in Chapter Five. The analysis in Chapter Five highlighted the extent to which government policy misrecognises disability as a straightforward term of identification and positions the DEG as an effect of a lack of individual motivation and aspiration. This thesis argues against that misrecognition, starting with the literature discussed in Chapter Three, but drawing principally on the experiences of the participants, how they spoke about those experiences and how they engaged with questions about labels, disability and being disabled.

This chapter explores how the participants talked about their mild learning difficulties, how they talked about disability and how consistencies and inconsistencies between these might aid understanding of issues of misrecognition and maldistribution arising in their search for paid work, referring to Fraser's concepts as discussed in Chapter Two. The participants were recruited to the research on the basis of self-identification with the term 'mild learning difficulties' rather than 'learning disabilities' or 'disabled'. In doing so, the intention was to include people who would *not* consider themselves disabled, as well as those who would, in order to explore that aspect of their self-identification and what impact it might have.

As discussed in Chapter Three, mild learning difficulties, learning disabilities and being disabled, and related phrases, remain labels with negative connotations, "reflecting dominant discourses of tragedy and inferiority" (Swain et al, 2003:15). Any discussion of participants' responses to questions about their mild learning difficulties, diagnoses and labelling needs to acknowledge that these responses will have been influenced by the social meaning of these labels. Interview-based responses will also have been affected by the relationship between the participant and the non-disabled researcher, as discussed in Chapter Four.

It should also be noted that identity is not a static characteristic and people may have multiple reasons for expressing uncertainty about their mild learning difficulties and their emotional responses to that (Beart 2005; Rapley, 2004). This chapter does not claim to represent precisely what the participants thought about their own mild learning difficulties but to explore the influences affecting identification with certain labels. In doing so, it demonstrates that a diversity of views was expressed, even among only sixteen people, and explores some of the possible reasons for this diversity.

Three themes are delineated here to explore the way participants talked about their own conditions and about disability. Within each theme, sub-themes have been also been used to explore the wide range of views and experiences discussed by participants. The sub-themes are effectively “themes–within-a-theme” (Braun & Clarke, 2006: 92). These are set out in Table 7.1.

Table 7-1 Summary of themes and sub-themes

Themes	Sub-themes
A. Am I disabled?	A.1 What does disabled mean? A.2 I’m somewhere in-between
B. My mild learning difficulties	B.1 Stress and anxiety B.2 Literacy, focus and memory B.3 Social interaction B.4 Slowness
C. What difference does it make?	C.1 Telling employers C.2 Comparing myself to siblings and peers C.3 Rights

Theme A: Am I disabled?

Chapter Three explored critiques of the notion of disability as a binary concept, challenging the idea of non-disabled as a non-identity or 'normal' (Clare, 2017). Disability was situated as fundamentally political (Kafer, 2013) and not "a universal, unmarked category" (Kafer and Kim, 2017:128). The implications of these arguments were explored in relation to government policy in Chapter Five. This section turns to the participants and considers how they spoke about the idea of disability as a label and as an identity, the extent to which they referred to their own impairments in the language of disability and the ways in which their understandings of disability could be varied and fluid.

All the participants had a strong sense of what they frequently referred to as "*struggles*" with a range of embodied conditions which affected not only their interactions with others but also dealing with their daily lives: eating patterns, sleep patterns, managing their own physical and mental health. Nevertheless, this did not necessarily translate into an association with the term 'disabled'.

Towards the end of the first interview, and usually after talking about their mild learning difficulties, participants were asked about whether they viewed themselves as disabled (see Table 7.2). Participants also referred to being disabled or having disabilities at various other points during the interviews, in relation to their experiences of being in work, looking for work and claiming benefits as well as more generally in relation to their social lives and family relationships.

Theme A.1 What does disabled mean?

The participants used the term disabled and disabilities in a variety of ways, in reference to themselves and other people. This was explored not only through direct but abstract questioning ("what does it mean to be disabled?") but also through analysing the way participants talked about themselves and about other people that they might refer to as disabled.

The five participants who strongly identified as disabled expressed a sense of being different from other people:

Disabled ... means having a mental or physical... impairment... something that separates you from other people [Sam]

They were also more likely to refer to disability as a legal status, to refer to concepts of rights and discrimination or administrative labelling and the receipt of disability benefits. These connections are explored further in theme C.3.

Most of the participants, like much of the population at large, considered 'disabled' to be *"a physical thing"* [Ravina], especially relating to mobility:

I automatically think "wheelchair", because that's just the symbol it gives, but I'm not in a metal contraption [Jack]

I'm not exactly disabled...I can walk around everywhere [Ryan]

The association of disability with physical and sensory impairments is deeply-rooted culturally, most commonly illustrated by the wheelchair or guide-dog symbols used to identify facilities and services for disabled people. This essentialist and debility-oriented view of 'disabled' is closely linked to the medical model of disability discussed in Chapter Three. Government policy claims to be driven by a social model view of disability (see Chapter Five), in which disability is a product of social barriers rather than (and separate from) impairment. However, this does not translate into the way that employment, employability support, or out-of-work benefit provision is presented and perceived. Participants' talk about disability as physical or sensory impairment was consistent with their experience of being denied access to services and disability benefits.

The language of disability labelling and terminology is frequently qualified with comparative terms such as 'mild', 'severe' or 'profound', or with references to a position on a 'spectrum' (see Chapter Three). The participants all associated with a label using the term 'mild', and many expressed a sense that the term 'disability' was associated with a greater intensity or severity of impairments, using phrases such as *"how severe it is"* [Lillian] or *"a lot worse than myself"* [Jack]:

real autism... unable to look after themselves... not people like me [Tyler]

These responses could be interpreted as attempts by the participants to distance themselves from a stigmatised label, but this is not the only possible interpretation. Monteleone & Forrester-Jones suggest "poor comprehension of disability terminology" and "self-degradation stemming from negative judgements of others" combine to block "healthy" identification with disability (2017:313).

However, it is also possible that participants did not perceive the “taken-for-grantedness of the stigma attached to ‘being intellectually disabled’” (Rapley, 2004:111). The tone of the responses and the language used by many of the participants was more suggestive of an empathetic response towards people that they perceived as ‘really disabled’ and a sense that they did not *deserve* either the label or the level of support that they would expect disabled people to receive.

Doubts about deservingness were compounded by experiences of welfare benefit re-assessments which resulted in the loss of disability-related benefits, experiences which are explored further in Phil’s story in Chapter Eight. This reluctance to identify themselves as ‘really disabled’ is also consistent with media and political narratives of ‘fake’ disability (see for example, Ryan, 2019; Elgot & Osborne, 2017) and these were occasionally reflected in comments which contradicted the participants’ own experiences of difficulty in claiming disability benefits:

It's really not hard to say to someone: “oh I got a disability”, act like an absolute lunatic and then get money for it [Tyler]

In Tyler’s case, his guardian had been in receipt of DLA while he was a child, but the benefit had been stopped after an assessment when he turned 18. Several other participants had either had disability-related benefits stopped, following re-assessment, or were concerned that this might happen to them in the near future. Theme A.2 explores connections between these experiences and how people spoke about their own disability status. Theme C.1 returns to this issue of ‘fakery’, in relation to disclosure of mild learning difficulties. Connections between self-identification, labelling, entitlements and deservingness are explored further in the concluding chapter.

Theme A.2 I’m somewhere in-between

Most of the participants were ambivalent about identifying themselves as disabled, although only one rejected the identification out of hand. Table 7.2 summarises participant responses to direct questions about whether they would describe themselves as disabled. It shows that only five of the 16 participants identified themselves as disabled without any caveats. This contrasts with the

way participants talked about the impact of mild learning difficulties on lives, as discussed in Theme B.

Table 7-2 Am I disabled?

	Definitely Yes (5)	Definitely No (1)	Ambivalent or unsure (10)
Anthony			•
Emily	•		
Jack			•
Jeff		•	
Kevon			•
Lillian			•
Louise			•
Nick			•
Peter			•
Phil	•		
Ravina			•
Robbie	•		
Ryan			•
Sam	•		
Sergei	•		
Tyler			•

Only one participant, Jeff, did not use either 'disabled' or 'disability' with reference to himself. This may be connected to Jeff's age, as the oldest person in the sample, as well as his long work history and experience of living independently. As another participant commented, referring to an older family friend with learning difficulties, there is:

a decreasing trend to recognise people...as we go back in time...just labelled as a being a bit thick...he's not thick by any stretch of the imagination, but that was what people often got billed as in days gone by [Peter]

Although Jeff had attended a special school as a child and had only lived independently from his parents since his mother was moved to a care home after a diagnosis of dementia, he was not aware of having ever been in receipt of disability benefits and had a long history of paid work, albeit very part-time and low paid. Jeff's stories of employment are explored more fully in Chapter Nine. His association of disability with a sense of "*if a person can't do it*", and his rejection of the association for himself, suggested a strong connection between his identity and his experience in the labour market, particularly in maintaining long-term paid work contracts. Despite recognising that he "*can't read properly*" and that he struggled to "*understand things*", Jeff did not think of himself as disabled because he was able to do what he wanted to do, which was primarily to find and keep paid work.

The only other participants who came close to expressing this kind of connection between experiences of work, attitudes and expectations about work and the rejection of a disabled identity were Tyler and Kevon, who were the two youngest participants and had been looking for work for the shortest time. Both expressed relatively high levels of optimism about being able to find suitable work, even though in Tyler's case he had experienced job loss and a benefit sanction at the very start of his search (see Chapter Eight), and Kevon had yet to find any paid work despite looking for nearly six months.

It is also notable that all three of these participants were male. As discussed in Chapter Three, there are connections between sexism and the negative conceptualisation of disability which might add a gendered dimension to a reluctance to identify as disabled.

All but one of those who said 'yes' to being disabled were in receipt of non-means tested disability benefits (DLA or PIP) or had recently been in receipt of them and were in the process of re-applying. All had received support from employability support services who specialise in supporting people with disabilities. The connections were either explicitly stated:

Me: And would you consider yourself to be disabled?

Well I get, if I get DLA then, yeah [Phil]

or implied less directly:

I am legally considered disabled [Sergei]

It is perhaps to be expected that those who had been awarded disability benefits would identify themselves as disabled, but this was not always the case. Both Anthony and Louise were in receipt of PIP and ESA but appeared to view these as more closely associated with Louise's ill-health than with both participants' mild learning difficulties. Jack and Lillian were also receiving ESA and Lillian had been awarded a disabled person's bus pass. Nick had been in receipt of Working Tax Credit on the basis of qualifying for the disabled worker element. All expressed some ambivalence about identifying as disabled:

You have severe learning disabilities [Louise to Anthony]

Whatever you want to call it....I wouldn't class myself as disabled [Anthony]

If I need to use it, I'll use it, but if I don't, I'll discard it [Jack, in response to being asked if he would say he was disabled]

I suppose disabled is quite a, I don't know. I have a disability, but to be disabled, I'm not sure, I'm, I'm, I'm unsure where I fit [Lillian]

For these participants the idea of being labelled as disabled conflicted with their strong sense of the term as referring to either to physical or sensory impairments or to people with more severe cognitive impairments. They were not at all ambivalent about the barriers that they faced in their search for paid work or about the impact of their mild learning difficulties on daily life. Jack, for example, expressed great anger and frustration at what he perceived as a failure by employability support services to provide the support he needed.

Lillian, who used the phrase “*somewhere in-between*” was the only participant who drew a distinction between *having a disability* and *being disabled*. This suggested she wished both to assert a claim to recognition of the significant barriers that she faced in daily life and in the workplace, but also to assert her independence and capability, especially in comparison to a disabled friend. Other participants did not do this so directly, but nevertheless indicated something similar in their ambivalent comments, and this was also reflected in the way participants talked about disclosing their mild learning difficulties to others, including to employers, as discussed further below.

This ambivalence could be interpreted as uncertainty about the significance of their impairments or about the barriers that they face. Such uncertainty fits with the social context of devaluing, neglecting and stigmatising disability in general and cognitive disability in particular, as discussed in Chapter Three. Such institutional misrecognition reinforces the exclusion of disabled people from economic and social resources. However, it also reinforces and is reinforced by the rationing of resources to those who are deemed ‘disabled enough’, as discussed in Chapter Five. In that sense, the participants’ ambivalence also suggested an acceptance that the label ‘disabled’ should exclude them because they did not *deserve* to be included within a term that was associated with entitlements to services and benefits. This acceptance was reinforced by their actual exclusion from these entitlements and the withdrawal of entitlements following welfare state assessments. Such interactions between individual and institutional misrecognition and maldistribution are explored further in the concluding chapter.

Theme B: My mild learning difficulties

Most of the responses discussed here relate to questions asked about participants’ mild learning difficulties, along the lines of “*tell me about your learning difficulties*”, with follow up questions to probe participants’ responses and to scaffold more detailed responses where participants did not articulate a response to open questioning, or where their response was too broad to aid understanding, for example “*I have trouble with a lot of things*” [Jack].

Most participants talked in negative terms when asked how they felt about having mild learning difficulties. Some made directly and deeply negative remarks such as:

It sucks, I hate it, cos I wish I was like, you know, normal, instead of being counted as a weirdo.[Jack]

my autism's a curse [Nick]

Most of the negative comments were about how they felt towards themselves, rather than about how their conditions might impact on other people. These were epitomised in the use of words and phrases such as “*something wrong*”, “*limitations*”, “*liability*”, “*setback*” and “*what I may have lost*”.

This kind of talk was not universal, however. Six of the participants consistently used much more neutral language when talking about having mild learning difficulties, referring to being different, but also denying difference. For example, Anthony indicated an acceptance and even some sense of pride about his mild learning difficulties:

I'm fine with it...it's who I am, it's me ... I can't change who I am [Anthony]

Kevon also commented “*it just makes me who I am*”, but later added:

It don't make me different to, being to do what I need to do [Kevon]

Other participants indicated a more guarded assessment, as shown here by use of the word ‘shouldn’t’:

it doesn't really bother me ... as long as you can get on with your daily life, ... what you need to do, it shouldn't really... affect people [Phil]

These more neutral comments could be interpreted as downplaying the significance of mild learning difficulties in the participants’ lives, indicating resistance to a disabled identity and a refusal to be “categorised on the basis of bodily difference” (Watson, 2002:525). The comments might also reflect the greater significance of other aspects of their social identity, such as age or social class, which were not directly discussed. These participants were regularly participating in social groups of people (with and without mild learning difficulties) looking for paid work, such as job clubs and youth groups, where they might meet people without mild learning difficulties who were experiencing similar barriers to finding work.

Turning to consider in more detail their daily lives, and how mild learning difficulties affected them day to day and in their search for work, participant responses largely fell into four categories:

- stress and anxiety;
- concentration, memory and understanding;
- social interaction;
- slowness.

Table 7.3 overleaf summarises who talked about each of these areas, either in direct response to these questions or during conversations about their experiences. This is followed by an exploration of each of these areas.

As discussed in Chapter Three, this thesis takes a social model of disability as its starting point for understanding what disability means. It is not the intention here to suggest participants are defined by or reduced to impairments or functional limitations. However, by focusing on the way participants talked about each of these areas, there is an intention to respect and attend to the significant and serious impact that having mild learning difficulties can have on individuals' everyday lives, as well as on their notions of disability, and to recognise that this impact is not well known (Emerson & Glover, 2012).

Theme B.1 Stress and anxiety

Most participants referred to experiencing some form of stress or anxiety as part of their mild learning difficulties, and this was not only as a response to experiences and interactions with others. Participants referred to high levels of anxiety experienced in childhood as well as into adulthood, often worsened by dealing with uncertainty, “*changes in schedules*” [Peter], or newness, and manifesting as fear or in some, “*panic attacks*” [Lillian]. Stress and anxiety were also exacerbated by a sense of frustration or dejection about their own limitations:

if I can't do what anything I want to do [Emily]

the amount of pressure that was building up...I would freak out [Lillian]

not knowing where I'm supposed to be going or...what I'm supposed to be doing, that freaks me out summat fierce, like damn near a phobia [Robbie]

Table 7-3 How mild learning difficulties affect me

	Stress & anxiety (13)	Literacy, focus and memory (13)	Social interaction (9)	Slowness (8)
Anthony	•	•		•
Emily	•	•		•
Jack	•	•	•	
Jeff		•		
Kevon	•	•	•	•
Lillian	•	•		•
Louise		•		•
Nick	•	•	•	•
Peter	•		•	
Phil		•		
Ravina	•	•		
Robbie	•	•	•	•
Ryan	•	•	•	
Sam	•	•	•	•
Sergei	•		•	
Tyler	•		•	

Robbie's use of the phrase "*supposed to*" draws attention to a sense that there are things he should be doing, that he may have not registered or forgotten (see also theme B.2). He talked about how it fails to "*click in my head*" that certain things are important. The participants frequently described anxiety in relation to this sense of missing out on something, or fearing that they had missed something, whether it was a work task, a Jobcentre Plus appointment, or catching a bus, or related to a social interaction such as missing the meaning of an instruction or a joke.

Robbie described how his anxiety manifested itself in a "*flare up*" of psoriasis that would regularly disrupt his sleep. Participants also used phrases such as "*nervous breakdown*", "*mental breakdown*", "*meltdown*" and "*brain freeze*". These are metaphors of crisis and destruction, emphasising the negative impact of anxiety.

Those who talked about anxiety indicated that they felt they over-reacted to worrisome situations:

when I get panicky, I get really, really panicky [Jack]

I care so much, I don't do anything [Sergei]

These responses signalled awareness that the levels of stress and anxiety that they experienced were unusually high. Participants spoke of it not being "*normal*" to experience such levels of stress and anxiety. There was also a sense that they compared themselves unfavourably with other people, in how they were able to deal with the stress and anxiety:

...my inability...not being able to handle stress [Lillian].

Five of the participants also directly referred to episodes of depression, and this fits with research which suggests a higher risk of mental health problems among "adults with mild intellectual disabilities" (Emerson & Hatton, 2014:59). Nick talked most openly about this, using words and phrases such as, "*suffer from depression*", "*mood swings*", "*obsessions*", "*suicidal*". Other participants were less direct, but nevertheless indicated periods where their mental health had deteriorated significantly, most often linking it to a lack of progress in finding paid work, but also linked to family troubles such as illness and bereavement.

Many of the experiences the participants talked about had exacerbated feelings of stress and anxiety. These included bullying at school and college, assessments for disability-related welfare benefits, and repeated and long-term lack of success in applying for paid work. However, there was also a strong indication that their higher than average stress and anxiety levels were deeply-rooted, arising in childhood as well as manifesting during adulthood, rather than being purely a product of adult life experience. This is consistent with population-based studies (Emerson & Hatton, 2014).

It is important to acknowledge the deep-rootedness of this anxiety, in order to understand that participants did not only experience it in the labour market, whether as actual or potential employees. Anxiety was not only the *effect* of interpersonal interactions, working conditions or benefit conditionality, but was a pre-existing factor influencing those interactions and experiences. For example, Sergei's experience of a work placement in which he felt well supported, where he enjoyed the work and found the co-workers friendly and welcoming, nevertheless ended in what he described as "*emotional breakdown*".

As discussed in Chapter One, where stress and anxiety are considered, they tend to be viewed as outcomes in relation to 'stressful' working environments, with employers urged to support employee 'resilience'. The failure by employers, support services and government policy makers to recognise the nature and significance of stress and anxiety in the lives of people with mild learning difficulties is a central feature of the social context within which the participants' experiences were located. This is discussed further in the concluding chapter.

Theme B.2 Literacy, focus and memory

The connections between concepts of mild learning difficulties, specific learning difficulties, and communication skills are discussed in Chapter Three, exploring how each of these involves different levels of stigma. Eleven participants initially focused on difficulties with reading, writing and spelling when asked about their mild learning difficulties. This included participants who had passed academic and vocational exams at above GCSE level. Comments about reading or spelling were sometimes qualified:

struggle reading difficult words [Jack]

I can't read properly [Jeff]

I can't read things really high up [Phil]

The addition of the words “*difficult*” and “*properly*” and “*really high up*”, may have been intended to signal competence at a basic or functional level, reinforcing a sense of the stigma of being unable to read. It was apparent from the kinds of work that the participants were pursuing, or the ways they were looking for work, or what they were doing outside of work, that all of the participants were able to read and write at some level. For example, Jeff was able to follow written instructions for building model cars. However, many of the participants had received additional support in school to help with reading and writing, which would have reinforced the sense of a connection between the label mild learning difficulties and their literacy skills.

The references to literacy skills could be seen as an attempt by the participants to distance themselves from stigmatised ideas about learning difficulties and disabilities. By focusing on their literacy skills, they could also be making a connection to a much broader section of the population since difficulties with reading and spelling ‘difficult’ words are far from uncommon and may be something shared with family and friends. This claim to “commonality of membership with ordinary folk” (Rapley et al, 1998:825) may be reinforced by family and support workers aware of the stigma associated with mild learning difficulties. The risk of this claim to commonality is that it may not only underplay the extent to which the participants struggle with literacy but may also imply that mild learning difficulties can be remediated straightforwardly by educational programmes. This is connected to the institutionalised misrecognition discussed in Chapter Five, in which disability employment policy prioritises individual skills and confidence over demand-side barriers.

When talking about specific experiences of work or looking for work, many participants also referred to being forgetful, finding it difficult to concentrate and having problems understanding instructions:

I have a job to understand things... I keep, you know, forgetting things [Jeff]

say “do three things”, I remember number one [Lillian]

sometimes it makes focusing and concentrating incredibly difficult [Sam]

Participants also made connections between concentration, memory and anxiety:

When there's too many tasks involved, it's just too much [Ravina]

*...when I get stressed I get muddled, and when I get muddled I get stressed
[Robbie]*

Participants indicated an awareness of the stigma associated with these difficulties, relating to a sense that they signalled lower intelligence. As discussed in Chapter Three, the concept of 'intelligence' as a characteristic that can be clearly tested is readily open to critique but nevertheless remains highly influential, and the idea of below average intelligence remains strongly stigmatised:

I won't say anything, cos I think, oh god, they'll think you're thick [Louise]

I don't always take instructions very well...I pretended I knew what he was talking about, but I never [Ravina]

I don't want people to take the mick out of me and say "oh he's got learning difficulties, oh he can't do this, he can't do that" [Ryan]

Participants were not only aware of the stigma associated with misunderstandings and forgetfulness, but also indicated some appreciation of their significance to employers. However, participants generally did not dwell on these aspects of employability when discussing what they thought they might need to do to gain or retain work in the future, referring more to matters relating to teamwork and getting along with other people. This suggested a mismatch between participants' priorities and concerns and those of employers given, as discussed in Chapter One, that communication skills, memory skills, skills in interpreting instructions and responding to ambiguity, are increasingly seen as essential by employers, even for relatively 'unskilled' work such as cleaning.

Theme B.3 Social interaction

Nine of the participants mentioned difficulties broadly relating to social interaction, notably about the way that they talked and conversational cues. Five of the participants said that they talked 'too much', and that this resulted in a negative reaction from others:

I never shut up half the time. People tell me all the time, "shut up, Jack, you're talking too much" [Jack]

I did waffle on quite long, did kind of get on everybody's nerves [Robbie]

Others talked about repeating themselves, and again emphasised the impact on others:

I'm conscious of irritating people, over the repetitive asking [Lillian]

These comments indicated that these participants were aware of the conversational 'rules' but were often unable to prevent themselves from breaking them, despite probable negative consequences. In a similar vein, some participants referred to difficulties with humour, jokes and banter, both in terms of understanding and of being understood. The examples they gave related to work environments where they were expected to work as part of a team and where they were dependent on the goodwill and support of co-workers, supervisors and managers. Getting it 'wrong' in these environments resulted in exposure to complaint and bullying, as the stories in Chapter Nine illustrate. As Sam put it:

every time I don't engage in social interaction I feel left out, but every time I do, it's the wrong thing to do

As already noted, most participants highlighted issues relating to teamwork and getting on with co-workers and supervisors as priority areas for employers. However, those with the most work experience had gravitated away from work involving high levels of social interaction towards work that they could do in relative isolation, mostly cleaning. Such work tends to be low paid, offering few hours and unsocial hours, on precarious contracts, as highlighted in Chapter One. Participants' experiences of this is explored in more depth in Chapter Nine.

By identifying the impact of mild learning difficulties as individual functional limitation (personal and social skills), the participants effectively appeared to accept a degree of personal blame that was in line with institutional misrecognition of disability as individual deficiency to be addressed by offering training courses and confidence-building exercises. The personally maldistributive consequences of this (loss of paid employment, restriction of employment opportunities to low paid, temporary and part-time contracts) further entrenched its negative impact, reinforcing participants' sense of isolation and their exclusion from workplace interaction with non-disabled colleagues.

Theme B.4 Slowness

Eight participants directly referred to concerns about being slow, or slower than others:

I'll still do it, but it might take me a bit longer [Kevon, talking about work on a bad day]

We just going to be slower...we can do it, at us own pace [Louise]

Bar work's too fast for me [Ravina]

It is important to acknowledge that the significance of this emphasis of slowness goes beyond the idea of completing tasks over a longer time period. As discussed in Chapter One, speed is increasingly significant within the labour market, related to a long-term rise in “work intensity” (Green et al, 2018). Its significance is also linked to the development of computerisation and automation, building on a sense that “speed and mental ability should correlate” (Goodey, 2016:126). Many participants indicated that being ‘too slow’ was a major obstacle to gaining or retaining paid employment. Nevertheless, those who mentioned their slower speed of working suggested that this should be incorporated into working life, despite their experiences of negative reactions from employers, supervisors and co-workers. The result, in some instances, was continuing rejection by employers, or even individual offers to work extra time for no pay to ‘make up’ for slowness. Institutional misrecognition of slowness as a personal deficit or failing did not result in any distributional benefits, as participants were unable to negotiate any ‘reasonable adjustments’ to their workloads except at their own cost. As will be discussed further in the concluding chapter, this form of institutional and cultural misrecognition effectively diverts attention away from employer decisions about work intensification with negative consequences not only for people with mild learning difficulties but across much of the labour market.

Theme C: What difference does it make?

Participants were asked various questions to explore how they felt their mild learning difficulties might relate to their experiences of employment and unemployment, and what effect identifying or not identifying as disabled might have on these experiences. These included questions about whether or not (and

why) they would tell employers and potential employers about their mild learning difficulties. Participants were also asked how they felt their experiences differed from their siblings and peers who did not have mild learning difficulties. Their responses are considered here as two sub-themes, drawing out further nuances in the way that recognition and misrecognition of mild learning difficulties interacted with the maldistributive impact of unemployment, benefit conditionality and precarious employment. The final sub-theme is rights, considering both how participants referred to rights and discrimination and reflecting on how the language of rights was used and not used by participants.

Theme C.1 Telling employers and employability service providers

Half the participants saw disclosure as preferable or even necessary, as shown in table 7.4 overleaf. Eight participants said they would tell employers about having mild learning difficulties. There were three broad reasons given for this: a desire for openness, a hope for support and a wish to manage expectations.

Three participants related disclosure to a need for openness:

I can't lie about it [Ryan]

This related to their earlier affirmative comments about mild learning difficulties being part of who they were:

that's just me, I'm an honest person [Anthony].

For these participants, disclosure was signalled as part of their personality and essential to their relationships with others. This was not necessarily because they felt their mild learning difficulties was 'obvious', although none of these participants had experienced other people overtly denying their mild learning difficulties.

Secondly, participants related disclosure to consequences, particularly the prospect of gaining support either at work or from employability service providers. Participants indicated that they were more likely to disclose to employability service providers, some of which were offering specialist services to disabled people:

Table 7-4 Would or did I tell an employer I have mild learning difficulties?

	Yes (8)	Only if asked (2)	No (3)	Unsure (3)
Anthony	•			
Emily*	•			
Jack	•			
Jeff			•	
Kevon				•
Lillian*	•			
Louise				•
Nick		•		
Peter			•	
Phil*		•		
Ravina*	•			
Robbie*	•			
Ryan	•			
Sam*	•			
Sergei*				•
Tyler			•	

* participants who strongly identified as disabled or as having a disability

...my disability adviser was my regular job coach, so I'd be seeing her to sign on and also to talk about any issues... she was the one who put me on the Work Choice programme [Sergei]

Disclosure to Jobcentre Plus work coaches might result in a direct referral to a specialist support service offering supportive advice and a greater probability of finding paid work experience, although some felt it made no difference:

I think they were just following the rules... it's all about ticking boxes [Nick]

The risk of negative consequences following disclosure to such service providers might be expected to be much lower, compared to disclosing to potential employers. Service providers were generally expected to take a sympathetic view of the barriers that participants were facing, and to offer support and encouragement. However, this was not always the case:

She was forcing me ... where I was doing everything by myself ...I would try and explain to her I had learning disabilities and need help but "no, he's a big boy he can do it himself" ...she just didn't care whether you had a disability or not [Jack]

As both these quotes illustrate, whether experience was positive or negative, participants not unreasonably *expected* disclosure to service providers to result in significant practical support. In contrast, participants appeared to have much lower expectations about the effect of disclosure to employers and co-workers:

I thought they'd be, go a little bit easy on me [Anthony]

because I... told them, and then they tell me what to do... they show me what to do [Emily]

Thirdly, those participants who said they would disclose their mild learning difficulties to employers and co-workers mostly related disclosure to managing the expectations of *others*, rather than in expectation of practical support:

It's acceptance... that they have the ability to work round my disability [Lillian]

I always say I've got it... so they don't think I'm being weird [Ravina]

more covering my own backside than anything else, cos if there's a problem because of it and I haven't told them... [Robbie]

Without an expectation or demand for support, this kind of disclosure appears to signal that the person with mild learning difficulties is anticipating that they will not meet the expectations of managers and co-workers. Disclosure becomes a way of forewarning of this shortfall. By disclosing, they were effectively signalling 'do not expect too much of me', or even 'I am a liability'. It is therefore unsurprising that many of the participants decided against this kind of disclosure.

Of the eight participants who said they would not voluntarily disclose, only one directly identified as disabled (see Theme B.2). This was also the only participant who actively sought to distance himself from association with other people with mild learning difficulties, linking this to negative experiences of specialist schools:

I try to distance myself from people with learning disabilities...cos I have one and I don't hold myself in high regard [Sergei, interview 1]

Any person I ever tell is surprised... good, means I hide it well [Sergei, interview 3]

However, although Sergei's views were expressed in the strongest language, seven other participants also indicated a preference for hiding or minimising their mild learning difficulties, saying either that they would not disclose, or that they were unlikely to, or would only do so if directly asked:

I tried to hide it...because I didn't want them to know cos I didn't want them to make fun of me [Louise]

if I didn't [tell them] then they might, I might have a good chance of being taken on [Phil]

if I put that down, they tend, they would probably tend to think of it as a negative [Tyler]

These participants were clear that disclosure could make them less likely to be hired, because employers would see mild learning difficulties as a negative factor; or make them less likely to thrive in the workplace, because co-workers would be unwelcoming. They recognised the barriers to employment that they faced in relation to their mild learning difficulties, including the difficulties

discussed in Theme A, and all were open to the idea of additional support albeit at different levels of intervention. However, their rejection of the idea of disclosure appeared to indicate a sense that employers' and co-workers' prejudice about what it means to have mild learning difficulties was the biggest barrier of all, outweighing any potential benefits from disclosure. These participants were effectively saying that they were *correctly* recognising the prejudice of others and how this could act as a barrier to recruitment and job retention, rather than misrecognising disability by refusing to disclose.

Participants also linked non-disclosure to concerns about not being believed or exposing themselves to accusations of being fake. This concern about being considered fake was also reflected in experiences of mild learning difficulties being denied or doubted. In the most extreme case, one participant had repeatedly been told that she was not disabled, leaving her feeling afraid to work with others:

...people don't believe me when I tell them about my disability...it serves no purpose, so I don't tell people [Lillian, interview 1]

...it was the fear that they weren't going to believe me...the fear of discrimination [Lillian, interview 2]

The stories participants told about looking for work and being in work highlighted many examples of more subtle and passive forms of denial and neglect by employers and co-workers, from failing to make minor adjustments to allowing people to be socially isolated to ignoring or failing to address disrespect and bullying. A minority of participants directly connected these forms of denial to stereotypes of disabled people or unemployed people:

...you get these idiots nowadays who try and fake it... I tend to keep it to myself just for that reason [Tyler]

As discussed in earlier chapters, this link between the way disabled and unemployed people talk about themselves and the dominant media "scapegoating of the disabled" (Ryan, 2019:3) and discourses of "scroungerphobia" (Patrick, 2017:145) has been widely documented. The connections between these media and policy discourses and the way the participants spoke about their experiences is discussed further in the concluding chapter.

When employers and co-workers hear claims for reasonable adjustments and additional support from people with mild learning difficulties, which have financial and redistributive consequences, they are likely to evaluate these, in the absence of detailed personal knowledge, by “social generalization about the epistemic trustworthiness” of the speaker (Fricker, 2009:32), drawing on stereotypes. As discussed in Chapter Three, stereotypes of people with mild learning difficulties historically involve characteristics that are prejudicial to being considered competent, authoritative or credible. Thus “[a]ffirmative redistribution can stigmatize the disadvantaged, adding the insult of misrecognition to the injury of deprivation” (Fraser, 1995:86).

In the UK, this idea of ‘affirmative redistribution’ is largely limited to social security payments or workplace adjustments, rather than affirmative action such as quotas or targets for the employment of disabled people, although such approaches have been attempted in the past. Only one participant related the issue of non-disclosure to a wish to avoid being subject to potential affirmative action:

Part of the thing is that I want a job cos of what I can do, I don't want a job, out of the need to fill the quota to employ someone who's technically disabled, I want a job cos I'm quite capable of doing lots of things [Peter]

It was notable that no other participant made similar references to a negative sense of being singled out for preference in recruitment. Although the Disabled Persons' (Employment) Act 1944 included a quota system for the employment of disabled people by larger companies, it was rarely enforced and increasingly ignored, fading into obscurity by the 1970s. The UK quota system ended in 1994, followed by the 1995 Disability Discrimination Act which adopted a new approach to discrimination as a legal issue (Sargeant et al, 2018). This was also part of a strategic “shift of emphasis from the state back to the individual” (Warren, 2005:310).

There is little remaining in DEG policy that could be characterised as affirmative action, although there are various government-funded schemes involving major employers offering work experience or temporary placements to disabled people, as well as to other people facing multiple barriers to employment. One of the participants (Robbie, discussed in Chapter Nine) was recruited to such a temporary contract through an arrangement with a disability specialist

employment support service, but there was little evidence of other participants being aware of or accessing similar services. Participants would be unlikely to consider disclosure in this light because they are effectively excluded from 'affirmative' disability-related services after leaving full-time education, and because such services are increasingly thin on the ground.

The way the participants talked about disclosure illustrates an ever-shifting balance of consequences. People with mild learning difficulties are constantly faced with the risk that disclosure, whether intentional or unintentional, is met with prejudice, discrimination and exclusion.

Theme C.2 Comparing myself to siblings and peers

Almost all of the participants felt that it was harder for them to find paid work than for their non-disabled or non-mild learning difficulties peer group or siblings. The two that did not feel it was harder were the oldest participant, who had the strongest paid work record, and the youngest participant, who had only recently begun his search for work. All of the other participants recognised that their mild learning difficulties were connected to a series of obstacles to fulfilling their life goals, not only achieving paid work, and they discussed this largely in very individualistic terms:

...gaining independence, finding love, getting a job is much easier for them, cos they don't have a condition holding them back [Nick]

... difficult to make people understand that, how difficult it is because I've got so many caveats, say, I can't work more than a certain amount of hours because I won't be able to cope with it [Robbie]

it just makes me realise what I may have lost because I'm autistic... makes me realise that maybe my life would have been better without it [Sam]

Although participants clearly associated their mild learning difficulties with less favourable outcomes than their peers and siblings, they tended to focus more on their individual conditions and what they saw as individual limitations and failings, rather than collective experiences or social arrangements. This negative, individualistic focus also largely underpinned the way participants spoke about their expectations that they might get extra help and support. Only two of the

participants offered an alternative focus, suggesting positive contributions people with mild learning difficulties might offer employers:

... it's been quite a gift... because I can understand what it's like to have it
[Ravina, talking about working with people with learning disabilities in residential care]

Ravina's use of the word "gift" was also echoed by Nick, who talked about autism as a "curse" but then also said it was a "blessing", explaining that it meant he was more "focused" and "driven" than someone without an autistic spectrum condition. However, in general there was little indication that the participants enjoyed a positive appreciation of disability as "brilliant imperfection" (Clare, 2017:57).

Theme C.3 Rights

The majority of participants were at most ambivalent about claiming that they were disabled and most of the talk about disability had an individualistic focus. However, most of the participants also made some reference to rights and discrimination, implying some recognition of a social dimension to the barriers that they faced. Given the conclusions drawn in Chapter Five about the policy focus, and the absence there of commitments to enforce, protect or extend rights, it is also pertinent to consider what was *not* said about rights.

During the second or third interview, participants were specifically asked about policy proposals, recently reported in the national media (Bloom, 2017; Morris, 2014), that disabled people might justifiably be paid less than the National Minimum Wage. Participants largely used the language of deservingness as a defence against such an idea, but also drew on a discourse of rights and discrimination. In doing so, participants highlighted a sense of mild learning difficulties as a condition or set of conditions outside their personal control:

...we're struggling more than everybody else, so we deserve, like, more rights
[Emily]

I was born with that disability, I didn't choose to have it, so it's discrimination isn't it? [Lillian]

...why should I be paid less for something I cannot control? [Robbie]

Participants used the language of rights with ease to reject out of hand the hypothetical idea of being paid less than the National Minimum Wage, highlighting the maldistributive consequences of recognising a disabled identity under such a proposal. However, this contrasted with an almost complete *absence* of talk about their rights in relation to their *actual* experiences of barriers to paid employment, loss of welfare benefits or job loss. Only one participant had negotiated a change in her working conditions with direct reference to her mild learning difficulties, but this had involved adaptations *by her*, rather than by the employer, effectively ‘allowing’ her to spend more time on her work than she was contractually paid to do. Yet in view of her past experience of being denied even this form of adjustment, she noted:

...my bosses are far more understanding than they ever were at the last couple of jobs I’ve had [Lillian]

It was notable that the only person contacted during the research who had achieved paid work on a comparable basis to non-disabled colleagues and with legally binding reasonable adjustments in place, was eligible for adult social care and therefore outside the sampling frame for this research (see sampling section of Chapter Four). None of the participants had formally negotiated reasonable adjustments in a workplace, made applications to the Access to Work fund or sought advice about their employment rights. Only one participant mentioned joining a trade union, and that same participant was the only one to directly refer to legal protections, which he had been informed about by a disability specialist employment support service:

with the like Discrimination Acts... the 2010, they can’t discriminate against me, they can’t say you’ve got autism, go away, don’t wanna hear about it... that’s really boosted my confidence [Robbie]

The absence of talk about rights and legal protections within the stories that the participants told about their experiences, and the individualised focus of their talk about disability, can be constructed as further evidence of misrecognition, in Fraser’s sense of “institutionalized patterns of cultural value” which cast some as “simply invisible” (Fraser, 2000:113).

Conclusion

By applying Fraser's perspectival dualism (Fraser, 2003a), the analysis in this chapter provides new insight into how people with mild learning difficulties negotiate a fine balance between claiming their right to support, including redistributive measures, and defending themselves against prejudice and abuse. This in marked contrast to the policy discourse, its essentialised view of disability and its focus on individual behaviour.

The themes and sub-themes in this chapter show how the participants were continuously trying to manage tensions and contradictions between recognising their need for support to overcome the barriers they faced in attempting to participate in the labour market and defending themselves against actual or potential stigma, prejudice, discrimination and accusations of undeservingness or being fake. The withdrawal or denial of disability benefits experienced by most participants served to undermine self-confidence in their deservingness, compounding uncertainty about identifying as disabled. Their own descriptions of their learning difficulties largely, but not exclusively, reflected wider social perceptions of learning difficulties and disabilities as deficits, rather than as positive aspects of human difference and diversity.

In the following two chapters, participants' stories about looking for work, being in work and losing work are explored through narrative analysis to show how this misrecognition interacts with maldistribution to foster self-blame, increase barriers to employment and even to reduce employability.

Chapter 8 Looking for work

This chapter examines the stories participants told about looking for work, including claiming out-work-benefits, engaging with employability support services and carrying out voluntary (unpaid) work. The chapter contributes towards addressing all of the research questions, but particularly the subsidiary questions referring to the stories that people with mild learning difficulties tell about being unemployed and looking for work. The social justice lens, based on Fraser's concepts discussed in Chapter Two, is used to connect the stories to the tensions and contradictions in the government's policy approach to social security, as discussed in Chapter Five.

As discussed in Chapter Four, the primary approach here is narrative analysis, using Polkinghorne's "storied analysis" (1995:19) guided by prior theory, while also looking for new theoretical insights (Riessman, 2008). The analysis focuses on the meaning that the story holds for the participant, before considering the broader context, including social and economic factors. From the individual story, the analysis moves to explore thematic connections with the stories and experiences of the other participants. The stories presented here, and the analysis of thematic connections, are intended to challenge dominant ideas, or "hegemonic stories" (Ewick & Silbey, 1995:219) about how people experience looking for work, as part of the broader critique of government policy towards the disability employment gap (DEG).

The analysis draws on Fraser's concepts of misrecognition and maldistribution discussed in Chapter Two. To recap, Fraser's bivalent understanding of social justice encompasses "a dimension of recognition, which concerns the effects of institutionalized meanings and norms on the relative standing of social actors; and a dimension of distribution, which involved the allocation of disposable resources to social actors" (Fraser, 2000:116). Using Fraser's sense of the interconnectedness of these two concepts, the analysis examines how addressing maldistribution or misrecognition alone can have counter-productive or counter-intuitive effects, and how the two can intersect and amplify each other, exploring the value of these concepts for understanding the participants' stories.

The stories about looking for work focus particularly on interactions with Jobcentre Plus and DWP, interactions with other employability support services,

and unpaid work experience (including voluntary work). The dividing line between Jobcentre Plus/DWP and other employability support services is at times somewhat artificial, since the DWP has effectively outsourced services that may have previously been (and are still in some areas) carried out by Jobcentre Plus. However, participants also spoke about employability services that are less closely associated with the DWP, such as community advice centres and job clubs.

The stories have been categorised in relation to three ‘gaps’ that summarise the barriers and deficiencies that the participants highlighted when talking about looking for work: support, income and respect. In most cases, the dividing line between these gaps is blurred, but broadly: *support* refers to person-to-person support with job-search, interviews, claiming benefits, training and other service-oriented provision; *income* refers to material, mostly financial, provision and the costs associated with looking for work and being available for work; and *respect* refers to organisational policies and cultures, as well as individual attitudes and behaviours encountered directly in the course of looking for work. Each section presents and analyses a key story from one participant and explores connections with the stories of other participants, using Fraser’s concepts.

Following the discussion in the previous chapter, this chapter continues to explore the complexities of the participants’ relationship to ‘their’ mild learning difficulties, including acknowledging the barriers faced by people with mild learning difficulties, expecting access to sources of compensation, both financial and social, while also rejecting a stigmatised disabled identity.

The Support Gap

Phil’s story

Around a year ago, Phil’s out-of-work benefits changed from ESA to JSA, following a routine assessment. He feels under constant and increasing pressure from his Jobcentre to apply for jobs, but his work coach does not offer him any help with finding a job. A friend helps him to apply online for a pot-washing job, but when he is offered an unpaid work trial, with no guaranteed hours, he turns it down.

Phil was in his mid-30s and had never had a paid job. In our conversations about his experiences, he highlighted the change in his benefit claim from ESA to JSA. In emphasising this event, he indicated the profoundly unsettling impact of the shift in his status as a claimant of out-of-work benefits. The previous award of ESA implied that Phil was “being judged to have a limited capability for work” (Millar, 2018:43), although he might be considered able at some time in the future and he might choose to do a small number of hours of paid work. The award of JSA was conditional on Phil looking for and accepting offers of paid work. However, alongside JSA, Phil was also awarded the enhanced and severe disability premia because he was living alone and without a carer. The names of these benefits and their byzantine claiming rules often appear contradictory. The granting of these disability benefits added to Phil’s uncertainty about whether or not he was disabled in relation to looking for paid work and what that meant about his prospects for finding and keeping paid work:

It changed last August, last year, cos I went for a health assessment, on [street name], and erm, I went, I failed, they said, I failed.

They said I was fit, I got a letter through saying I was fit for work, so they stopped me ESA and I have to apply for Jobseekers. I mean, Jobseekers put me down as severely disabled, which I can’t understand why I’ve got to look for work then.

However, Phil’s situation was part of a bigger story of mismatches between expectations and necessities. These arose from misrecognition of Phil’s disabilities by a range of advisers and support workers, as well as an on-going lack of support. Phil had been actively looking for work since he left college in his early 20s. Having attended special needs schools, mainstream schools and a special needs unit in Further Education, Phil left full-time education with no qualifications and only a couple of weeks’ work experience, one in a leisure centre and one doing some gardening work. Initially he was assigned a disability employment adviser at his local Jobcentre. However, even that specialist support failed to recognise Phil’s needs. The only job they were able to find for him put him in a position where he felt his personal safety was at risk because of the hours of work and the location:

...the hours was absolutely ridiculous for it. It was like five o'clock at night till nine at night, which I weren't willing to risk, especially when you got people on the drinks and all that

Phil's nervousness about having to travel home after 9pm should be understood in relation to his learning difficulties and the expectations about his personal safety that were likely to have been established for him by his mother, who was also his carer until she passed away, and by others in authority over him, such as teachers and support workers at special needs school and college.

Since starting to look for work, Phil had been referred to most of the employability support organisations in the region: national organisations such as Remploy, A4e, Ingeus, and local organisations offering so-called employability training. He had attended a variety of job clubs, including one run by a national charity. When we met, he was attending a local job club run by a Christian charity. The volunteers there had helped Phil to apply for a job at a clothes retailer in the teen/young adult high-street fashion sector. Phil was highly unlikely to meet the recruitment criteria for this type of job, given his age, physical appearance and communications skills, despite his voluntary experience in charity shops. It was unclear whether he recognised this mismatch, but pressure to prove his job-hunting efforts meant his attention was focused on the quantity of applications rather than their relevance:

[Sighs] It's so difficult to be on Jobseekers than it was on ESA, cos I'm having to apply for jobs, left, right and centre, than I was on ESA. I mean, I warn't, when I was on ESA I warn't, I warn't, I didn't have all the pressure on me. I was, I was with, I was nice and relaxed, but Jobseekers is so much pressure on you to find jobs, which aren't out there and not suitable for people.

When I asked him about the support he currently got from the Jobcentre, he said:

...they're not actually helping me, nobody's actually helping me look for the jobs I need

I accompanied Phil to his local Jobcentre when he had an appointment to sign on with his work coach. I sat in the waiting area, near enough to be able to hear the conversation he had with his work coach. The interaction with the work coach lasted 27 minutes. During that time, the work coach did not mention any job opportunities or any activities that might support Phil to find work, although she

did ask him about his transport costs and whether he was accessing any subsidised ticketing. Their interaction was generally light-hearted and chatty, and Phil referred to it as a “natter”, but it included a number of queries from the work coach about Phil’s daily life. I noted in my observation notes:

...she asks who I am, and who someone else was that she saw him with in the week. He mentions about moving and she asks about him moving in with his girlfriend and stresses the importance of letting them know if he does that as it will affect his benefits and potentially mean a joint claim. When he mentions about someone from [local organisation] checking his benefits, she asks about [local organisation], and doesn’t seem to have heard of it. She asks where they are based and how he met his contact there. She asks how he feels about moving out of the area.

Although the meeting offered Phil no help with his job search, it did provide the work coach with an update on his housing, his social and personal life. The tone was one of control and monitoring, rather than support. At the end of the meeting, Phil told the work coach about turning down the offer of an unpaid work trial as a ‘pot washer’ at a local branch of a restaurant chain. The work coach appeared uninterested and there was no suggestion that he might be sanctioned for turning down a job opportunity. The nature of this work coach appointment, with its policing tone, lack of practical support and minimal interest in progress was consistent with findings of other research in this area (Patrick, 2017).

After the meeting, Phil and I discussed the work trial:

I didn’t want to really put my JSA at risk...cos I didn’t know how many hours I physically, physically could have done

Phil explained that he had asked his work coach for guidance about the number of hours he could work without jeopardising his JSA:

Then when I asked her, and in, I could have done 16 hours

Phil understood this to mean that he needed to get at least 16 hours work, so he contacted the employer to ask about what hours he might be offered:

I phoned 'em back and asked 'em, I said I could have done 16, I need 16, at least 16 hours, and he said, we might not be guaran, you might not be guaranteed them, and that what put me off

Phil's primary concern, in his decision to reject the offer of a work trial, was to avoid jeopardising his benefits. His fear of "messing up" at work is combined with an awareness that the benefits system is highly complex, and claims can easily be rejected:

If I [sigh] if I, if I could have done 10 to 16 hours, then I, and I was actually doing it, and I [sigh] and I messed, and I messed it up, then that would of actually, I would've thought to meself, what have I actually physically done? So, without knowing all the rules and regulations on benefits, I cannot do nothing.

Phil rejected the offer but continued to feel it was:

a great opportunity to step, to get a first step onto the job market

Phil's experience of looking for work was one of a lack of support, particularly from state-funded services, whether Jobcentre Plus or associated employment support agencies. As someone with many of the characteristics of those "furthest from the labour market" (Stafford, 2015:80), his experience of insufficient support is consistent with other evidence (Heap, 2015; Stafford, 2015). This lack of support resulted in Phil focusing on applying for jobs in quantity, rather than on the likelihood of being recruited.

Although Phil had gained experience of the retail sector through many years of part-time work in charity shops, this had not led to any paid work. In his most recent position, he had been accused of errors in the use of the till, and confined to working in the stock room, a background unlikely to support his applications to work in customer service in commercial retail shops. Rather than being supported towards jobs that he might be offered and be able to do well in, the focus remained on quantity, isolating Phil in his responsibility for finding suitable work:

I was, we were talking to someone, t-telling me about me review and he said I need to apply for five jobs a week but I [sigh/laugh] but I, but I said to him "there isn't jobs out there" and, they, they just constantly putting pressure on

me to do all of that, so I told [JCP work coach] about it all, and sh-she phoned [employability support organisation adviser] up and, and they're wanting me to ha, do different websites an all, which I'm not happy about...I mean they wanted me to do, do that universal job match, totaljobs.com, there's no jobs on there for me.

In addition, because Phil was unable to get a clear answer to his questions about how taking work would affect his benefits, and because of his negative experiences of making benefit claims and being transferred from ESA to JSA, he was becoming more cautious about his potential for finding paid work. This was most obviously exemplified by his turning down the opportunity of a trial shift. Although he had not been offered any paid work, he talked about the need to build up his hours very gradually:

cos otherwise it's all the faffing about with your benefits and that, especially if you lose your job, you gotta re-sign back on [short laugh], which is a nightmare

Phil told this story as an individual experience, highlighting his 'failure' in the ESA assessment, his individual efforts to secure paid work, and his 'choice' to reject the offer of a work trial. This way of telling his story allowed Phil to reclaim some control over a situation in which his social and financial position was highly precarious and under threat from the state, through his benefit claims. However, the ESA assessment had been designed with the express aim of reducing the number of claimants, driven by "ideological reasons" (Roulstone & Prideaux, 2012:151) as discussed in Chapter Five.

In a sense, Phil's talk about the risk of taking a chance of a paid job was in line with the dominant Conservative view of social security as a 'poverty trap', as discussed in Chapter One. However, Phil was not trapped by his benefit entitlement, although he was constrained by his fear of being treated unfairly or of inadvertently breaching benefit rules. His nervousness about the potential loss of benefits and the risk of not being able to sustain paid work in the absence of support were exacerbated by the shift from ESA to JSA, which reinforced the message that Phil's benefits were highly conditional and unreliable.

Nevertheless, that move arguably corrected a misrecognition of Phil as being not fit for work. Phil's talk about risks focused on recognition of his own personal limitations and his fear that he would not be able to sustain a paid job, based on

his self-knowledge and some experience of voluntary work. However, there is a wider issue of misrecognition here, both by Phil, his work coach and built into the conditionality of the benefits system: the failure to recognise the high likelihood that Phil will be unemployed again, given a DEG of around 70% for people with mild learning difficulties (Woodin, 2015:182).

Phil's recognition as a 'jobseeker' was consistent with his own views that he was capable of paid work and wanted to find a job. However, it was accompanied by a recognition of his disability only in terms of redistribution, through the award of the disability premia. No formal recognition appeared to have been made for the impact of his learning difficulties on his ability to find and sustain paid work, or on his capacity to sustain full-time work. Yet informally some recognition did appear to have been made, as reflected in the casual response of the JCP work coach to Phil's reporting that he had turned down a work trial. Phil was left in a kind of limbo, where he was nominally expected to look for work, and his JSA was conditional on doing this and on taking any paid work offered, but he was not penalised for not doing so. His recognition as disabled did lead to redistributive measures (the direct, individualised payment of disability premia), but not to additional support measures to address barriers to his entry into the labour market. As a result of the misrecognition of his disabilities and the maldistribution of resources towards the individual rather than towards support services, Phil's distance from the labour market was effectively further entrenched.

The Income Gap

Tyler's story

Tyler makes a claim for UC shortly after leaving full-time education at 18. Within a few weeks, he gets offered his first job, 40 hours a week working in a warehouse, starting at 6am. The early start, long hours and lack of breaks make him feel ill, and he quits the job by the end of the week, planning to look for another job. He is sanctioned under UC, losing payments for three months, but the sanction is not put in place until over four months later, by which time he has had other temporary jobs. He concludes that he will be more cautious about taking work he is unsure about.

Tyler's story focused on his experience of being sanctioned, or having his social security benefits suspended, for leaving paid work "voluntarily and for no good

reason" (DWP, 2012a:12). Tyler's story about being sanctioned began as the story of his first experience of paid work, but the work lasted only one week and Tyler highlighted the action to sanction his benefits as the key event of the story, with ramifications going far beyond the week's work experience. Tyler's story has been pieced together from his mostly very short and very rapidly spoken replies to the interview questions.

Tyler was diagnosed with Asperger's syndrome when he was a child and had been excluded from primary school for behavioural difficulties. He had attended mainstream secondary school and college and had achieved a level 3 qualification but said he "*can't concentrate on stuff for a long time*". Tyler's grandmother had been receiving DLA for Tyler until he was 18, when he was assessed as not being entitled to the adult disability benefit, PIP.

As soon as Tyler finished at college, he was under pressure from his family to find paid work and he was keen to earn some money. He looked unsuccessfully for a few weeks and then applied for UC, although he had to wait the then standard six weeks for initial payment. His work coach referred him to a local community-based employment support service, where he was offered support to identify suitable jobs and help making job applications and preparing for interviews.

Tyler and one of his friends successfully applied for a three-month agency contract for warehouse work. The working hours were alternate weeks of mornings (6am to 2pm) and afternoons (2pm to 10pm) and Tyler said he chose to start with mornings so that he could be with his friend. The first day included some initial training and he was expected to attend from 5am. Public transport was not running at that time, so Tyler had to cycle from home, leaving at 4.30am. Although the work shift included a half hour break, the workers had to change in and out of protective clothing in that time, so the effective time available to rest was closer to 15 minutes. Tyler also said:

I had erm, bad fingers, I used to, er, summat, er, wood, like, plastic, hit into em, to, cut my fingers open. So I think on my first day I had, I come back with about five plasters round my fingers, just cos it was, just kind of kept digging into my fingers when I was trying to rush

The pattern of work in those first few days disrupted his sleep patterns, resulting in loss of appetite and feelings of exhaustion:

after Wednesday, I was like, I don't wanna do it no more, just feel, I, I, I just felt negative, I dunno, I just felt negative, I felt, like, not depressed, I'm not, not that, that type of depressed, I like, y-you can feel, I j-just felt down, it's like, sluggish, all over the place.

I was being sick, couldn't eat properly

This experience needs to be understood in the context of Tyler's mild learning difficulties. Tyler used the phrase "the right time" and "a certain time", repeatedly, to refer to his need for predictability and routine for basic activities:

...going to the toilet at the right time, going in the shower at a certain time, having something to eat at a certain time...I don't like going into the kitchen with other people...I kinda get a bit, a bit wind up because of it

When these needs are disrupted, the effects can be severe:

I tend to take it out on other things, and I kind of put a hole in a wall, just by punching something

The effect of disruption to routines for people with mild learning difficulties, and especially for people with autistic spectrum conditions, is likely to be a major increase in stress levels, as discussed in Chapter Seven.

After his shift on the Thursday, Tyler went to the employment support service to ask for advice:

I think it was [advice centre worker], who actually helped me, erm, text it to not sound like an absolute douche-bag, basically, to make it sound professional, and just like {the response was}, "OK, fair enough, at least you gave me the notice. Are you, you, are you coming on Friday?", I went, "Yeah I will, I'll come in on Friday, I'm, I've just come here to let you know".

Tyler's use of words here signals his underlying positive work ethic and his wish to avoid behaving badly ("douche-bag", "professional"). However, he also recounted the episode as a matter of personal choice, that he chose to give up the work. That is consistent with the DWP view of his action as voluntarily leaving

work. At the same time, Tyler's description of the working conditions, including the working hours, suggest a heavy weight of demands for a first job, with no consideration of his autistic spectrum condition, despite the involvement of a support worker. When I asked him if he thought he had been treated fairly in the job, he said:

Yeah, they treated me fairly, they, they understood where I came from, like, when I was there, saying "Oh, erm, I don't, I'm not really, I'm not really used to, I'm not really comfortable meeting new people, kind of, tend to keep individual, on my own", and they was like, "Ok, fair enough, obviously, if you, if you need any help, come and tell us", and just left on me own, just let me do my own thing, basically. I just feel bad, I just, they's like, "We understand, we had a couple of people here had difficulties".

Despite these disclosures, the employer provided no support beyond acknowledging Tyler's request to work by himself. This isolation included no ongoing training, no monitoring of his pace of work or his wellbeing, although a supervisor was always nearby. The long hours and early starts were not only a challenge to Tyler's stamina, but likely to cause additional problems for someone with an autistic spectrum condition because of the disruption to their routine. For Tyler, this meant not eating and not sleeping, and unsurprisingly within a few days he felt very ill.

Tyler appeared to conclude that the failure of the job was entirely his own fault, for not being able to keep up with the pace of the work and for getting ill. Nevertheless, he was shocked by the response from his Jobcentre Plus work coach:

I had to quit, but then the, u, the jobcentre sanctioned me for it...apparently me being physically ill, not able to work is not a good enough reason apparently to leave

The decision to sanction his benefits for three months for a "first failure" indicates that this was a high-level sanction (Dwyer & Wright, 2014:32), confirming that there was no formal recognition from the DWP of Tyler's autistic spectrum condition and he was subjected to the highest level of conditionality within UC.

As discussed in Chapter One, the conditionality and sanctioning system within UK social security has been presented through legislation and government policy

documents as being primarily about behaviour change, based on a view that claimants need to be negatively incentivised to take and remain in paid work. For Tyler, however, the sanction could have no immediate effect because it was not actioned until three or four months after he left the job. In contrast to the policy assumption that he left because he was in some way work-shy, he went on to take other temporary work, including cleaning and warehouse work over the months after leaving his first job.

The sanction was finally actioned at a point when Tyler came to the end of another temporary contract, losing a job because he was not offered a longer contract at the end of an eight-week probationary period. He was both surprised and disappointed to receive a negative appraisal and to be told that the contract would not be extended. Again, his employers had not recognised his autistic spectrum condition. Whether he considered himself to be disabled or not, Tyler clearly identified aspects of his condition, including problems with concentration, an aversion to being with large groups of people and to meeting new people, difficulties handling uncertainty and change, difficulties expressing his emotions, which would put him at a significant disadvantage in the labour market, particularly for entry-level jobs. Yet the response from the social security system to his return to unemployment was a punitive fine for the loss of his first job four months earlier. As Tyler put it:

I was unable to work because of the early hours, I was, I was physically ill, I was unable to eat, I didn't much sleep. And apparently that wasn't a good enough reason.

Not only did Tyler view the sanction decision as unjust, by failing to accept his reason for leaving the job, but he also viewed it as unfair and arbitrary. Tyler's friend, who had started the job at the same time as him and left the job during the second week, was not sanctioned:

...when my mate did it, he put it was because there was, there wasn't erm, it wasn't an advanced role, what I could im, improve to, in a couple of years, and he got away with it, and I didn't

Tyler's friend appeared to present his work coach with an acceptable reason for leaving the job (lack of potential for progression) whereas Tyler presented an unacceptable reason (being ill). This is likely to be a reflection of the discretion

allowed to individual work coaches (Fletcher, 2011), as illustrated in Phil's story and discussed further in the concluding chapter. Tyler's use of the phrase "*got away with it*" signalled a sense of confrontation with a hostile system, in which some are able to outwit the authorities. Tyler concluded that the system was arbitrary but powerfully punitive, and therefore he should take more care over accepting a job offer. Rather than the sanction making Tyler more likely to accept work, it made him feel more reluctant, because it raised the cost of making a mistake. The sanction therefore had a maldistributive effect not only in removing Tyler's only source of income at a time of unemployment, but also in reducing his willingness to take risks in his job search and making him less likely to take future contracts. Like Phil, with his fear that taking a few hours work might jeopardise his benefits income, Tyler concluded that decisions about paid work needed to be weighed carefully against the risk of breaching conditionality.

Tyler's experience of a sanction decision that he concluded was both unjust and arbitrary was consistent with stories of the other participants. The only other participant who had been sanctioned was Emily, who also found that no allowance was made for her mild learning difficulties. She had been sanctioned once for missing a work coach appointment and once for going on a week's holiday and reporting that she would not be available for work during that week. Emily was highly dependent on the support and care of her parents, so she would not have been expected to stay at home during occasional family holidays. Under JSA rules, Emily was expected to indicate that she was available for work at all times, to avoid being sanctioned. This caused a conflict for her when the family was holidaying several hundred miles away from home. Not only was the sanction itself financially and emotionally punitive, increasing her anxiety about her relationship with Jobcentre, but it also increased her sense of powerlessness and she felt forced into a deception:

...so now, so now I put 'yes', every, every time I go on holiday I put 'yes' to it now, I've got no choice

Tyler's response, like Emily's, indicated that the cost of removing benefit income extended far beyond the initial financial impact, undermining confidence in the idea of out-of-work benefits as a safety net, and undermining trust that they would be treated fairly and reasonably. Other participants also indicated a sense that the benefits system was arbitrary and unfair:

Jack: [mimicking his work coach] “that’s not enough Mr [name], Master [name], you need to, you need to do this, this, this, zz, zz, zz and write it all down in your little booklet”, cos if you didn’t, you get a sanction

Ryan: when jobcentre want you to do things, you have to do it [snaps his fingers] just like that! If you don’t do it, that’s it, jobcentre can just, have the power to stop your money, you know.

Sam: well they always give me a caution but of course if you get too many cautions they’ll sanction your benefits, and then of course sanctions, er, sanctioning your benefits is disastrous

The participants who were claiming out-of-work benefits were highly dependent on the income they provided. Only Lillian and Sergei had another source of income (i.e. parents who might be able to support them financially). Their responses to the conditionality and sanctioning system indicated a high degree of compliance and an understandable sense of fear about the cost of making a mistake. The cost implications of non-compliance are clear: benefit income is threatened or stopped. This is the case for all claimants, regardless of mild learning difficulties, whether considered disabled or not. However, for those with mild learning difficulties, the likelihood of unintentional non-compliance is much higher. For example, compliance with the requirement to attend face-to-face appointments on time depends on being able to manage a face-to-face meeting despite high levels of anxiety, remembering dates and times, accessing public transport, understanding and remembering how to report reasons for failing to attend or to reschedule an appointment. Recognition of these factors is either absent or is dependent on the good will of the individual Jobcentre Plus work coach. This is a form of misrecognition with life-threatening maldistributive consequences, where people with long-term illnesses or disability face the same “ratcheted up punishment” as any healthy jobseeker (Ryan, 2019:43).

The Respect Gap

Nick’s story

Nick is looking for work as an accountant. He has been looking for ten years, following completion of a level 4 accountancy qualification. In that ten years, he has mostly worked unpaid for two community savings and loans organisations

(CSLOs). Despite positive feedback from managers, Nick has never found any paid work in accountancy. He has never been recommended for a paid position and there has been no work progression. In between these two unpaid positions, he has had temporary minimum wage work doing data entry. This work ended just before two years, when Nick would have been entitled to additional employment rights. When the employability support service that he attends informs him that they are closing due to loss of funding, Nick decides to return to the data entry work he has done before, since he has been away from it for the required 26 weeks and can be deemed to be on a new contract.

Nick's story of looking for work was a story that challenged the policy narrative that people with drive and skills can find paid work and achieve work and pay progression. Over ten years after leaving school, Nick had achieved a relevant qualification and years of experience in unpaid positions, yet he had been unable to find any paid work in the career he wished to pursue, accountancy, even at a low level. Nick's search for work was driven not only by his personal ambition, but also influenced by his family background. His parents were running their own small company and both of his adult brothers were in paid work. He even mentioned his grandparents, who had emigrated from an Eastern European country, and how their "*hard work and graft*" had enabled the family to buy a house.

Nick's quiet intensity suggested a seriousness and dedication which, he said, characterised the way that he worked, helping him to be "*more focused on the task at hand*". For seven years, Nick worked for a non-profit CSLO (community savings and loans organisation) as a volunteer. With his determination to pursue his ambition of working in accountancy, he was eager to accept opportunities to gain relevant work experience and hoped that working as a volunteer would not only build his skills but also lead directly to paid work. Nick was signposted towards voluntary work by a specialist employability support organisation supporting people with autistic spectrum conditions. During the seven years he won awards for the quality of his work and for his long-standing commitment. Yet he felt he made little progress despite the awards:

...would have been nice though if they could have given me some more finance or accountancy, accountancy work, tasks

Although there were paid positions within the CSLO, Nick did not apply for any of them at any point. He asked about paid work opportunities, but the response was negative:

they said they couldn't get me anything, they couldn't get me anything yet, er, never happened. They wanted to, they wanted to take me on full time but, er, they didn't manage, they couldn't get funding for that

Nick's suggestion, that the CSLO wanted to offer him paid work but that the barrier was funding, indicates that he did not feel he was being treated unfairly by the organisation itself. Yet it is unlikely that such an organisation would have done no recruiting during those seven years. When he finally decided to leave, Nick said his manager said he was "sorry to see you go", but with the lack of progression, Nick felt that he ended up "doing very little".

His parents helped him to find and apply for the data entry job. This work was through an agency and was on a rolling contract for 16 hours a week. Nick talked about having to take a break of at least 100 days after the end of this contract before he could work for the company again. It is likely that what he was referring to here was a measure to avoid the conferral of employee rights. If the breaks were taken every two years, Nick would not gain rights in relation to dismissal, including unfair dismissal. Nick had had two periods of working for the company for just under the two years, and when we met was on the second of the 100 days breaks. Nick appeared to be unaware of the implications of this way of being employed, although he said that some of his co-workers were kept on when his contract came to an end:

I don't understand, I don't understand much of it, and quite honestly, not much, not really interested. I don't really care.

This comment highlighted Nick's vulnerability to misrecognition and exploitation in his search for work. His attitude was unsurprising given his determination to work and the difficulties he had experienced in finding paid work. It meant that the employment agency was easily able to exploit Nick's situation to the employer's advantage.

Nick talked in glowing terms about the employment agency that placed him in the data entry role:

I'm, I'm just, I'm, I'm glad I've got them actually, because they see, they see my potential. Er, there's a I, there's a lovely lady who, er, who's er, who recruits workers at [employment agency], er, she sees the potential in me. Er the one, the woman before that [name], er, no, her name was [name], erm, she gave me, she gave me a chance to prove myself and er, turn my life around, working for [computer company].

What the agency had done was to place Nick in low level work at minimum wage with no prospect of progression. He was required to have a break of at least 26 weeks every two years to ensure he did not become a permanent employee. His positive use of the word “*potential*” and his sense of being given “*a chance*” was so out of step with what the employment agency was doing, that it suggested he was being actively misled by the agency workers.

At the end of the two years, Nick returned to unemployment and looking for work. Frustrated at his lack of success finding accountancy-related work, he decided to volunteer with another CSLO:

I was trying my best to find in jobs in [city], in the [city] area and then I had a brainwave. I decided I'm gonna try [city] [CSLO] so I asked [other CSLO] for a reference and, er, it was a, it's a very good reference and so the [CSLO] taken me on, and I, I do feel real, I do feel valued, well valued there.

Nick's need for validation (“*prove myself*”, “*feel valued*”) left him open to being exploited by both commercial agencies and third sector organisations. When talking hypothetically, he is clear that work should be paid:

I think work experience's a good idea but, er, the employers, er, should be greatly encouraged to pay, to pay them after a while, take them on, give them a chance

When asked why he thought he had found it so difficult to find paid work, Nick referred to the economic recession which began around the time he started to look for work. However, Nick repeatedly indicated that he believed the biggest barrier he faced was being underestimated or misunderstood:

I think a few people who really see, who've known me really well and really understand me, can see, can see the positives, but anyone else would probably see me as a liability

He repeatedly used the word “*chance*”, to indicate a need to demonstrate what he was capable of, both to himself and to others. Although he had received very positive feedback from managers at the CSLOs and the data entry job, this had possibly reinforced Nick’s sense of frustration about his lack of progress in his job search. On the one hand he was being told he was doing very good work, and on the other hand the value of this work was not being reflected in pay or progression.

Nick was prepared to work for years for no pay for a not-for-profit organisation, on the basis that they did not have the funding to be able to pay him. While short periods of unpaid work may not be uncommon among young people looking for work and work experience, it clearly becomes more problematic for people in this position for several years. People with mild learning difficulties, as discussed in Chapter Three, have statistically very low rates of employment, relative to the general population, but nevertheless experience an education system with a strong emphasis on preparation for paid employment. Nick was one of several participants who appeared to have responded to these pressures by working for long periods in unpaid positions in not-for-profit organisations, as discussed further overleaf.

Rather than respecting Nick’s ambitions and potential, the organisations that he came into contact with appeared to exploit his willingness to work for no pay or to give up paid work when asked. At the end of the third interview, Nick indicated that he was so demoralised by his lack of progress in finding accountancy-related paid work, that he was preparing to return to the low paid data entry work that he knew would not offer him progression even into permanent employment.

Everywhere he turned, Nick appeared to be facing disrespect, denied pay or progression for years of work, denied support from employability organisations, denied work in the types of jobs that he had trained for, where he could see there were vacancies. These forms of disrespect were clearly having an impact on Nick’s mental health, and he made several references to depression and feeling lost:

I was so unhappy and despondent when I was unemployed, feeling like nobody wanted to give me a chance [interview 1]

it's very frustrating. In fact, I've, suffer from depression because of it [interview 1]

I feel I have to put myself through, through hell to, er, to get another job [interview 1]

waiting ages trying to find a new job, trying to better myself and at the minute I feel like whatever I do makes no difference whatsoever [interview 2]

now I'm completely lost, I don't have an agency to come, to go to, and give me one-to-one help [interview 2]

I try and stay positive but it's a real struggle [interview 3]

Although Nick's situation was unique among the participants in the type of unpaid work that he had been doing, others had also committed to long periods of unpaid work for not-for-profit organisations. Much of this work has developed as a result of the decline of public services and the restructuring of the welfare state (Taylor R, 2016; also Chapter One). Third sector organisations are increasingly responsible for delivering services to support people on very low incomes (e.g. foodbanks, low-cost loans, job clubs) and fundraising to support such activities (e.g. charity shops), and participants had been involved with a number of these organisations.

Volunteering is frequently seen as a route towards paid work, as an opportunity to develop employability skills, as well as an alternative source of social connections for disabled people (Trembath et al, 2010). Jobcentre Plus work coaches and employability support providers frequently promote the value of volunteering for developing employability. However, there is little evidence that it does improve the employment prospects of people with mild learning difficulties and there are indications that people with mild learning difficulties may be misled about what volunteering can offer and what alternatives are available (Trembath et al, 2010).

Several participants indicated an expectation that charity shop work would provide meaningful work, in the sense of developing work experience and work-related skills that would improve their employability, as well as providing social benefits (meeting new people and making friends). They also talked about voluntary work as providing opportunities to try out new types of work. Their

experiences were generally consistent with findings of other research involving “individuals with limited skills”, where “volunteering for them is a way of securing low to medium-skill work in the mainstream economy” (Amin, 2009:45). It is not the intention here to deny the value of voluntary work in meeting at least some of these objectives. However, many of the participants’ experiences of voluntary work indicated treatment that could be considered disrespectful and ultimately exploitative:

- Phil worked for over three years in a charity shop because he was trying to gain front-of-house retail experience. The shop manager insisted that he remain working in the back of the shop, away from customers, because he may have made a mistake in the use of the till. Phil eventually decided to leave, frustrated that: *“they’re just not learning me absolutely nothing”*.
- Emily worked in a charity shop for seven or eight years, preparing clothes for sale and stacking shelves; when a new shop manager was hired, Emily felt that the management style became very “bossy” and she decided to leave.
- Sam worked for six months in a charity shop, having been signposted to the work by his Jobcentre work coach as way of gaining retail work experience; although he initially enjoyed the work, it offered very little variety and the friendliness of the other staff declined to the point where he felt unable to continue.
- Ryan took a series of unpaid retail work placements as a condition of continuing to receive JSA, including various charity shop placement. The placements ranged from 2 weeks to 6 weeks in duration, but none was valued as ‘proper’ work experience when he applied for a paid job (*“according to their, the, the company, I’ve got no work history”*)

These four participants, despite long periods of work in charity shops, remained unable to find paid work in the retail sector. Several other participants had also undertaken voluntary work in charity shops, encouraged by Jobcentre Plus work coaches, as a way of gaining retail work experience. However, only one of the participants (Robbie) had found paid retail work after doing unpaid charity shop work. In Robbie’s case, recruitment was more likely to have been driven by his

referral to a specialist disability employment support organisation and his story is explored further in Chapter Nine.

For all of these participants, there was a sense that they were being directed towards voluntary work because they were not (yet) employable. The suggestion that unemployed people should do unpaid work as a way to prepare for paid work implies a lack of work-readiness that could be seen to conflict with the notion that they are 'fit for work'. Yet for those who were claiming out of work benefits, such as Emily, Phil, Sam and Ryan, the conditions attached to their benefits indicated that they were indeed assessed as fit for work. Such "inconsistent messages about work-readiness" have been found in other research with disabled people claiming out-of-work benefits (Patrick, 2017:110).

Even after such experiences, most participants remained optimistic about the potential for unpaid work in charity shops to provide them with useful experience and social connections, and several were continuing to do such work. The only exception was Louise, who actively expressed a sense that she was being taken advantage of:

I was left to do all the work myself while other people stood there chatting and talking, and I was like, hold on, where's everybody else? I'm not doing nowt of that

In Louise's case, her resistance to working in a charity shop was tempered by the threat of being sanctioned by the Jobcentre:

I knew what it was about, but I was like, don't really wanna go an work there, cos I don't like charity shops, but I had no choice, otherwise they'd stop the money

Positioning the way that the participants were treated while doing unpaid work in the voluntary sector as a form of disrespect is problematic because volunteering is traditionally viewed as "inherently 'good' and virtuous" (Taylor R, 2016), as is the sector itself. Most participants who worked in these unpaid roles were supported financially by the state or, as in Nick's case, by parents or supplemented by earnings from paid work. They undertook unpaid work in the voluntary sector either as a strategy to improve their employability or as a way of making social connections, or both. However, they did not necessarily do so voluntarily, since several felt pressured by the conditionality rules of their out-of-

work benefits to take on such work. They were directed towards unpaid work and encouraged to donate months or years of their labour towards charitable organisations. Their expectations that this would improve their prospects of getting paid work were unfulfilled. The processes and outcomes involved both misrecognition of the participants' aims and potential and maldistribution, with participants remaining unpaid while their work effectively contributed to the fundraising efforts of the organisations or provided services that these organisations would otherwise have had to pay for.

In terms of direct, personal disrespect, it is important to note that most of the participants did not talk about a lack of respect shown by Jobcentre Plus work coaches or other employability service providers, although most had not found their services to be helpful in locating actual paid work opportunities. Nevertheless, there was a sense in which these service providers could be seen to be lacking in respect for the participants. Several participants had seen employment advisers at multiple agencies:

Louise: ...basically my adviser I got wasn't very friendly, erm, didn't understand where I was coming from, so no I didn't find them helpful, I found them useless

Robbie: we would go down the Jobcentre, say right, here's this, right here I am, I need, I'm unemployed, I wanna find a job, can you help me? It was a case of right, up on this computer, off you pop and they never told us that my mum was supposed to be putting in her details 'cos she was my carer, so we spent six weeks just going round and round in a circle

Jack: I've had all the help I've had, can get, from companies, organisations, Remploy, everything else, all the other ones, I've had help from every organisation, there is nothing anyone can offer me at all, for help wise, I don't think so anyway, because we've been to every single job agency in the county, country, and not one of them could help me get into work. We tried [another youth training charity], that was a complete and utter waste of time

Ryan: I been to A4e, I've been to Ingeus, I've been to, erm, Working Links, I've been to Remploy, [local organisation]...I've been to UK Training about four times. You want to see, you want, you want, you wanna see, you wanna see the list of my er, my, my, my er, my CV, it's horrendous

The participants are quoted at length here to communicate their frustration at being sent from pillar to post through a wide variety of organisations who are part of an ‘employability support’ industry. For the most part, participants did not complain of being treated with disrespect, although some did. I visited Jobcentre Plus offices with seven of the participants and mostly witnessed participants being treated with courtesy but not being offered any practical support for their job search. However, in my observation notes of a meeting between Anthony, Louise and Anthony’s Jobcentre Plus work coach, I noted:

When she talks to Anthony she uses a slightly ‘sing-song’ voice, as if she is talking to a child... She seems to take particular relish asking him whether he is ‘Mr’, whether he is male, female or prefer not to say, and what his sexuality is. I know she is just reading out the form, but it certainly isn’t helping her with building rapport.

This kind of ‘petty’ disrespect has the effect of reinforcing dominant narratives about people with mild learning difficulties who are claiming out-of-work benefits, that they are either to be pitied as lacking capacity or scorned as lazy scroungers (Ryan, 2019). It is directly connected with the narratives around stereotypes of benefit claimants, discussed in Chapter One, and is discussed further in the concluding chapter.

Conclusion

This chapter contributes new knowledge to questions about how people with mild learning difficulties experience unemployment and looking for work. It applies Fraser’s concepts of maldistribution and misrecognition to identify gaps of support, income and respect that undermined the path towards paid work for the research participants. The participants’ stories show how maldistribution and misrecognition interact to block access or push them further away from the paid labour market. This application of Fraser’s concepts helps to uncover the consequences of a social security benefits system that is experienced as arbitrary and prioritises redistribution over recognition, illuminating the inadequacies of the policy response to supporting the employment of disabled people.

Chapter 9 In employment and leaving work

This chapter examines what is happening when participants are in work and how they make sense of work coming to an end. The chapter contributes to addressing all of the research questions, but particularly the subsidiary questions about the stories that people with mild learning difficulties tell about being in work and what these stories reveal, through the lens of Fraser's social justice concepts, about the labour market and the adequacy of the government's policy approach as discussed in Chapter Five.

The dividing line between looking for work and being in work is drawn at the point that a firm job offer has been made. Employment is characterised here as involving a workplace where the majority of workers were paid, and where the participant either was hired as a paid worker or had a work placement intended to give experience of a paid role. Placements arranged by schools are excluded, as is unpaid work in predominantly volunteer-based workplaces, such as charity shops, discussed in the previous chapter.

As discussed in Chapter Four, the primary approach here is a "storied analysis" (Polkinghorne, 1995:19), guided by prior theory while also looking for new theoretical insights (Riessman, 2008). The analysis aims to explore the meaning of the story for the participant before widening the interpretation to consider connections with the experiences of other participants and the broader social and economic context.

The analysis draws on Fraser's concepts of social justice as discussed in Chapter Two and applied in the previous chapter. The analysis examines how maldistribution and misrecognition are exemplified in the participants' experiences, how they may intersect and amplify each other, how attempts to address either alone can have counter-productive or counter-intuitive effects. The concluding chapter considers whether there are aspects of the participants' experiences of injustice that fall outside the scope of these concepts.

None of the participants remained in one job throughout the time of the fieldwork and most were out of work during that time. Those who gained jobs during the fieldwork moved to jobs that were no better in terms of pay or status than previous work they had had, although participants may have considered them preferable for various other reasons. It is therefore unsurprising that the focus

here tends towards the negative, on how in-work experiences do not meet participants' needs or wishes, on job loss and on ruptured plans, rather than on successes and satisfactions. The stories are stories of job loss and are grouped thematically.

The stories have been categorised in relation to the three 'gaps' referred to in the previous chapter, which represent the barriers and deficiencies that the participants highlighted when talking about looking for work: support, income and respect. To reiterate, the dividing line between these gaps may be blurred, but broadly: *support* refers to person-to-person support with job-search, interviews, claiming benefits, training and other service-oriented provision; *income* refers to material, mostly financial, provision and the costs associated with looking for work and being available for work; and *respect* refers to organisational policies and cultures, as well as individual attitudes and behaviours encountered directly in the course of being in or leaving work. In this chapter, two participants' stories are analysed in detail within each gap category.

Before discussing the stories that participants told, however, it is acknowledged that many of the participants also had positive things to say about their experiences. The following section considers these positive comments and what they indicate about participants' attitudes towards and expectations of work. The responses can broadly be categorised into five themes: social interaction and making friends; enjoying tasks; a sense of achievement and purpose; learning; and physical health.

Positive experiences and reasons for seeking paid work

Most people do paid work to earn money for subsistence and consumption, and the choices that having money enables, but those are not necessarily the only or even the main reasons people cite for going to work (Noon et al, 2013). Peter, who had only had a few very short work placements, directly talked about being motivated by money:

I'm not thrilled by the idea of work, I just want some more money, which is what most people want. It's not that they're greatly informed by a desire to pick litter or send invoices or drive lorries across the nation, but they, they really would just rather like some money.

However, when participants were asked about what they liked about the jobs they had had, none directly mentioned their earnings, despite their reliance on these earnings as a significant or main source of income, although in some cases these may have been supplemented by out-of-work benefits, training allowances or tax credits. The paid work discussed was almost invariably paid at minimum wage and it is possible that the level of earnings might have had more significance had it been higher. This is not to say that pay was unimportant: as the previous chapter showed, most participants had undertaken voluntary work in expectation that it would lead to paid work.

Eleven participants mentioned social interaction when asked what they liked about a particular job, a finding that is consistent with other research on the benefits of participating in paid work (Hall & Wilton, 2015). Several mentioned longer-term friendships that developed through work. Their responses were often enthusiastic:

Lillian: I like the people I work with, erm, they're nice and some of the customers are lovely

Robbie: They were lovely and friendly. In fact, I still meet up with one of the people I was actually sent there with, I meet up with her on a regular basis actually, so I did actually get a nice friendship out of it as well

Sergei: I was assigned a buddy. He was, he was sitting next to me the whole time and we had a lot of very similar interests, so we got on really well. I, I'm still friends with him.

Several participants said they enjoyed the tasks involved in their jobs:

Jack: [name] coffee shop, at [country park], that was ace, I really enjoyed that, cleaning tables, taking the food out to the public

Lillian: I'm enjoying the actual work itself, I'm enjoying cleaning

Ryan: I loved, I loved working in the [DIY] store because it was, it was absolutely massive and I loved going in the, erm, the garden centre

Sam: I liked, I liked the, the wide variety of things I was doing

Several other participants, including those referring to voluntary work, also talked about work giving them a sense that they were making a contribution, doing something well and gaining a sense of achievement. This was reinforced by positive comments they received from managers, customer satisfaction surveys and certificates of achievement, providing a sense of satisfaction but also a sense of belonging, as illustrated by this comment from Nick:

Just basically having a purpose, just a purpose, knowing that I'm like every, that I'm like everybody else, that I have a job. I felt I could fit in with society.

Four participants referred directly to learning new skills and taking on new responsibilities. This included Jeff, who was offered a training opportunity that he was very disappointed to have to decline. Ravina repeatedly mentioned her search for new experiences and responsibilities.

The three oldest participants talked about their physical fitness and how this was improved by having paid work, either because of the physicality of the work itself or because of walking to and from the workplace, although they also talked about how the physical strain of work such as cleaning, left them feeling too tired to do anything else outside of work. Nick, Robbie, Sergei and Tyler, all with autistic spectrum conditions, also talked about how work provided some structure and focus to their day, enabling them to get out of the house and to feel more positive about their lives.

Participants' positive comments about work mostly reflected their hopes and aspirations more than their actual experiences, except where they had made new friends through work. This comment from Phil, who had had no paid work despite being in his mid-30s, reminisced (with no sense of irony) about a 2-week placement he had enjoyed when at school:

it just made me think, you know what, this is going to be best thing I've ever done in my entire, entire life

These positive comments about expectations and aspirations provide an important backdrop to the next sections which explore participants' experiences of being in work and losing work.

The Support Gap

Robbie's story

Robbie enjoys his first and only paid job, working on the checkout at a supermarket. He appears to be satisfying the employer's requirements, but his contract is not renewed at the end of his probationary period. The employer tells him they do not think he will cope with increasing pressure in the run-up to Christmas.

Robbie's first and only experience of paid work came to an end after a three-month contract. The progression of the story towards job loss involves an intertwining of maldistribution and misrecognition that began with the recruitment process. The involvement of a specialist employment and skills support organisation (anonymised here as SESSO), to which Robbie was referred by his Jobcentre Plus work coach, signals that Robbie's additional support needs relating to his learning difficulties were recognised from the start of the recruitment process.

Robbie had been out of work for several months after leaving full time education and had no work experience when he was referred to SESSO. Following a brief period of voluntary work in a local charity shop, Robbie was put forward for an interview with a major supermarket. Such interviews were done in advance of any job offer, so that anyone considered acceptable was then effectively on a waiting list for a vacancy. When a vacancy arose, if the person was still available, they could start straightaway. For Robbie, this process took six or seven weeks and then he was offered a three-month contract, which he inferred to mean:

...there you go, on a temporary contract, then if you do a good enough the job, you get the full contract

This recruitment process was confirmed to me during meetings with SESSO staff and meetings with retail employers who engage with SESSO. One of the significant features of the outcome of Robbie's story, is that the employer was aware from the start of the contract that Robbie had some form of disability or health condition. Regardless of whether Robbie disclosed any information about his condition to the employer, the employer would have been aware (through SESSO) that Robbie would have support needs in the workplace. This point was

reinforced by Robbie's comments about "*small adjustments*", such as supervisors taking additional time to explain things to him and checking up on him from time to time. It should also be noted that Robbie had a psoriasis condition, related to stress, which was highly visible on his face and arms. It is therefore probable that the employer hired Robbie knowing that he would need extra support and that he suffered with stress.

The work was on the checkout tills, serving customers, and occasionally collecting and stacking baskets or helping a customer to find something. When asked about what he liked about the work, Robbie said:

Really it was somewhat the simplicity of it, I always knew what I was doing, it was nice, simple, easy to do job, just sat on the tills... that's really what I was looking for, was a simplistic job because problem that I have is, I get confused easily and especially in stressful situations, I get things muddled in my head.

When Robbie discussed how he felt he had performed in the job, he noted that did find some of the customer interactions stressful, but these were not overwhelming: dealing with customers who have misunderstood multi-buy offers; identifying unscannable items on the till menus; sending customers to another till when his till crashed. All of these incidences are common occurrences in till-work, and none caused him to abandon his checkout. He was able to call for help from the supervisor and described them as: "*always willing to lend a hand*".

Although he was nervous before the job started, he said:

I was pleasantly surprised at how easy the job actually was once I got going.

Robbie did not consider that any of the work was too difficult for him. His performance on the job was not only monitored by supervisors but also by the automated processes of his till which produced a regular report of his 'scan rate':

It wasn't low enough that they were worrying about firing me, but it was one of the, it was at the low end of acceptable... they'd send you, like, a letter saying, right, you scanned, your average scan time was this amount per minute, which was like, and they drew like a little graph, where it's unacceptable, poor, decent, and all that sort of thing, which I was at the low end of the good side

Robbie gave one example of manager behaviour that indicated clear recognition of his disability. He recalled an incident where a customer complained because

she had been waiting in the queue while he had been chatting with another customer ahead of her. Robbie referred openly to his tendency to “waffle on” and to find it difficult to gauge when to stop talking. His manager intervened to support him saying “*I know this isn’t your fault*” and offering to remind him in future to “*get on with your work*”. Robbie referred to this as:

“one of the main times...they did sort of recognise my disability”

The recognition was not, however, accompanied by any support. Robbie’s response was not only to feel a high level of stress, but also to blame himself:

...you know, felt like, oh great, really done dope here, but yeah it was that sort of, disappointed in myself, frustrated with myself

When asked about what he disliked about the work, Robbie only mentioned wishing he could have had more hours. The contract was for 12 hours a week and therefore only marginally redistributive in monetary terms. However, the pay rate was at the national minimum wage for people age 25 and over, and therefore above the minimum level Robbie might expect at his age. His pay was docked if he was late clocking in, which he said happened when he forgot to use the clocking in machine because he was rushing to avoid being late. However, he said that only happened in the first week and the manager was “*very understanding*”. Robbie’s attitude to work is also illustrated by his recollection of going in for one shift when he was unwell and having to go home:

I’m handling food and things like that, and with me, having a sort of chest infection, coughing up god knows what, it was sort of, yeah, I shouldn’t be here, doing this, cos people giving me dirty looks and things like that

These kinds of responses are “cultural products” (Riessman, 1990:68) which reflect wider social attitudes and expectations of employer and employee behaviour, including self-surveillance (Grint & Nixon, 2015), as discussed in Chapter One. Robbie’s responses indicate acceptance of the employer’s right to set rules, to arbitrate and to punish. His expression of these attitudes suggests a wish to emphasise his willingness to please and to comply with workplace norms.

When Robbie’s three-month contract came to an end in the autumn, it was not renewed. He said he received an apologetic letter from the employer, indicating

“we don’t think you’ll be able to cope”. Robbie reflected on this several times during the interviews:

...on the run up to Christmas they binned me off in the, I think it was the.. September, because they were worried that I wouldn’t be able to cope with the Christmas rush so, yeah, they didn’t renew my temporary contract, which, I don’t know if that, if my disability had anything to do with that, their decision, but, well, what’s done is done, in’t it [interview 1]

At first, I was a bit miffed about it, but, looking back on it, I do understand what their point was. They didn’t, I wouldn’t, to be honest with you I don’t think I would have been able to cope [interview 2]

Again, Robbie’s response signals self-blame and compliance with the employer’s authority. His experience of work may have been slightly redistributive in monetary terms, but the longer-term impact was maldistributive by weakening his employability. His story indicates a number of ways in which his immediate and longer-term employability was reduced. Robbie was encouraged to ask for help and the empathic response of individual supervisors to the time he spent talking to customers gave an indication of some recognition of his disability. The monitoring information that he was given about his own ‘scan rate’ suggested his productivity was acceptable. Yet this same ‘scan rate’ was later used to ‘prove’ that Robbie would not be able to cope with the pre-Christmas rush.

Recognition of the way that Robbie was disabled in this workplace undermined his position and resulted in the loss of the job, rather than in more appropriate adjustments or the offer of an alternative role. His comment that *“we all got binned off”*, refers to all of the people who were taken on at the same time as him. It is not clear whether they were all put forward for employment by SESSO, but it is probable, given that none of them were retained. It is also probable that other staff would have been taken on to deal with the anticipated Christmas rush.

Robbie remained very disappointed about the decision to ‘bin him off’. The metaphor of the ‘bin’ underscores the sense of the outcome as a highly negative assessment of his performance and capability. Robbie’s phrases *“what’s done is done”* and *“I don’t think I would have been able to cope”* indicate a fatalistic view of the experience and an internalising of the employer’s judgement that he was not good enough.

Robbie's interpretation of the outcome was that he was simply not up to the job. However, there is nothing to suggest from his account that he failed to meet the standards set by the employer at the start of the contract. No doubt he would have found, as would anyone, that the pre-Christmas rush was a more stressful time than during the summer months. Consequently, the outcome can be interpreted as *inevitable*, given what the employer knew about Robbie at the start of the contract, the timing of the contract and the lack of commitment to longer-term support and skill development.

In effect, a group of disabled people were given temporary contracts during a quiet period, with no longer-term commitment to support them. This had several advantages for the employer, who had the unfettered right to end the contract after three months but could also claim to be meeting government policy aims of employing disabled people. The employer could also make wider claims to corporate social responsibility. SESSO's involvement, probably supported by government funding for placing Robbie in a job, may also have facilitated a wage subsidy to the employer (Stafford, 2015).

Only Robbie lost out, carrying the penalty for the ending of the contract. The experience reinforced Robbie's sense that the employer did him a favour by taking him on, and that what happened was his own fault. Not only was his self-confidence hit, but he was also likely to look less employable to other retailers, given that his only paid work experience had ended at the start of the busiest retail period of the year.

Robbie's story resonated with several of the stories told by other participants, where recognition of the need for support appears to reduce the likelihood of sustained employment. Tyler, for example, had a contract with a major supermarket, in the distribution area, loading lorries for home delivery services. Tyler asked his supervisor if he could have an occasional short rest to help him manage the pace of the work but was uneasy about full disclosure of his learning difficulties. The supervisor agreed but no information was given to his co-workers. When I asked about how his co-workers reacted, Tyler commented:

A couple of 'em were curious, "oh why are you not loading?", I was like, "oh, I talked to the supervisor, said it's alright to sit here for a bit", just cos obviously I felt a bit, a bit heated, and a bit exhausted, and they was like, "oh ok, sure, yeah, yeah, yeah, yeah".

Tyler's responses indicated that he felt the supervisor and the co-workers had been broadly supportive and had made minor adjustments, such as allowing him an occasional short break, to enable him to do the job. Yet at the end of his probationary period, Tyler was told that his work rate was not good enough and he would not be moving on to a permanent contract. Misrecognition, by both Tyler (non-disclosure) and his colleagues (failure to assess), in the context of intense working arrangements and precarious contractual conditions, results in maldistribution (job loss). As a result, it is unlikely that personal disclosure would have changed the outcome, and that is the conclusion that Tyler drew.

Speed of working also features in Emily's story, in which there was no indication that the employer was given any information about her disability or support needs. Her story, like Robbie's, illustrates how a lack of support can cause long term damage for the individual.

Emily's story

Emily works in a food packing factory, packing and labelling boxes for a few months. She is paid minimum wage for the job. She is not given any additional support and no adjustments are made for her. Her supervisor is usually nearby to tell her what she needs to do, and Emily enjoys the work. However, during one shift she becomes separated from her supervisor and is told by one of her co-workers to join a group working on a conveyor belt. No-one shows her what to do and she becomes very upset, panicking about the speed of the work and not knowing what to do. One of the managers shouts at her and the other workers for being too slow. Emily becomes very distressed. She is told that she will not have to work on the conveyor belt again. The contract finishes after about four months and Emily is not offered any further work.

Emily's story has been pieced together from her short responses to the interview questions. During her three interviews, she often gave minimal responses to questions, shrugging her shoulders or saying "*mm*". Her speech was often unclear, and I made several attempts to clarify some of the detail. Emily's longest responses were about her experience of working on the conveyor belt. These were also her most emotional responses and she cried about it at one point. From the information she gave, it appeared that this was an incident that happened once, at least four years before the interviews. It remained deeply distressing for her, but she was not reluctant to discuss it: she began talking

about it straight away when asked whether there was anything she did not like about the job and referred to the incident again later when asked whether she thought she had been treated fairly.

Emily made no secret of her need for support and was clear about recognising herself as disabled. At the start of the second interview, she asked me to ring her mother to clarify the purpose of the interview. This clearly signalled her need for reassurance. Emily's disabilities and anxieties were embodied in her person, in the way that she moved, her general nervousness and her speech patterns. However, she highlighted how these characteristics were misrecognised by her employer, supervisor and co-workers as grounds for either ignoring her or criticising her:

I just did what people told me to do and if it, even, even if it wasn't right, I just, I just, I do what I had to do, really, I, I was struggling....I didn't know where she [the supervisor] was, I couldn't ask for help with anything, and I think I just couldn't do it...they just didn't really like say much to me, or anything, like as if I wasn't there

Emily's excuses for the failures of her supervisor indicate her acceptance of their judgement of her as unable to satisfy their demands. Her expression, "*like as if I wasn't there*", seems to epitomise her day-to-day experience in the workplace. This only changed when she expressed panic when working on the conveyor belt:

I think they realised that I didn't like doing it, they said, "well you don't have to do it no more now, because, yeah, er, er, you know, it upset you".

Emily said that there was no discussion about further work at the time that her contract ended. However, she said that the employer did later ask her to make contact to discuss some further work, but when she did so, she was told that there was no further work on offer. She expressed this using the phrase: "*oh, we don't want you to work there anymore*"; the use of the word 'want' conveyed a sense of personal rejection. This was in line with her conclusion that such factory work was too fast for her:

I only tried doing conveyor belt work at [factory] but clearly that did not work out well, at all, too fast, yeah. I can't do fast things.

These comments demonstrate how Emily excused the behaviour of the employer and their failure to recognise her disability and provide adequate support.

Instead, she blamed herself. The ending of the story (job loss), and the misrecognition of her disability, was internalised as a personal failure, being too slow, being too emotional, being unwanted. The “imaginative work” (Riessman, 2008:55) that Emily did in trying to make sense of her experience, drew on her earlier experience of bullying in school and her position as an only child in a household where both her parents were in full-time work. Emily’s lack of experience of independence and need for reassurance, illustrated by her request that I speak to her mother about her participation in the research, were likely to have reinforced her lack of confidence in her own capability, despite having previously held down another paid job for a year.

However, looking beyond these “private troubles” (Mills, 2000:129) to broader social structures, it can be seen that Emily was effectively disabled by the workplace arrangements, the lack of support and guidance and the short duration of the contract, which prevented her from developing expertise and confidence. The failure of the employer to recognise Emily’s learning difficulties and her need for support resulted in the loss of wages, but also had longer term maldistributive effects by reducing her employability as she continued to search for work with lower confidence and another episode of failure on her work record.

In Chapter One, the issue of the pace and speed of working was highlighted as a particular feature of contemporary work, especially low wage work and jobs where low or no qualifications are expected. Like Robbie and Emily, Jeff, Lillian, Nick, Ravina and Sam talked about either finding the pace of work too fast or being told by managers that their pace of work was too slow. Like Robbie, Nick worked in a large supermarket on a temporary contract, although not recruited via SESSO or similar. It is unlikely that the employer was told of Nick’s cognitive condition when he was recruited. Nick was told he was working too slowly but he felt that this was due to his attention to detail. The work ended after two months and Nick was unhappy about that, but his longer-term plan was to find office work using his numerical and accountancy skills.

Ravina mentioned speed of work in relation to catering and hospitality work:

I find bar work’s too fast for me, and I found waitressing could be too much as well

However, she was able to negotiate informally to work at a buffet counter, where speed was less of an issue. Ravina's control over her work and her ability to negotiate and seek out alternatives are discussed more fully below.

Several participants talked about supportive co-workers, supervisors and managers, and some experienced unsupportive ones. None mentioned any in-work support beyond standard arrangements for induction and training, and informal arrangements among co-workers. Participants' limited experience of paid work might suggest that they would not necessarily have been aware of any additional support arrangements being put in place 'behind the scenes', but their experiences suggested that these either did not exist or were inadequate to preventing job loss.

Their stories indicate a lack of *systematic* support, backed by employment policies, both within the workplace institution and from supporting agencies, which not only effectively undermined the likelihood that short term contracts would turn into long-term ones, but also resulted in long-term damage to participants' employability. This failure of support was not the product of misrecognition by individual colleagues: in each case there were indications that the participant's disabilities were acknowledged. Rather, the misrecognition was at a structural and institutional level, associating learning difficulties with a lack of ability to meet the demands of the workplace, and failing to value the participants as peers.

Lillian was the only participant who had participated in a work-focused one-to-one support scheme. This was a local authority funded, long-term arrangement, offering continuity and support to find work, help with applications and interviews, and support in the workplace. Even with this support, Lillian experienced bullying from co-workers and a lack of co-operation from management. She did eventually go on to find other jobs offering a better working environment. Nevertheless, this work continued to have maldistributive consequences, including substantial unpaid travel time and expense and additional unpaid time spent at work to enable her to work at a slower pace. Lillian's experiences are explored in more detail in the section titled The Respect Gap. Before that, the next section discusses issues around pay and related aspects of work.

The Income Gap

Jeff's story

Jeff works as a cleaner in a succession of jobs, some of them overlapping. One of these jobs, at the local branch of a bank, is for an hour and a quarter every evening, and Jeff works there for over 12 years. The job pays minimum wage but is close enough for him to be able to walk there from where he lives. The other jobs, also minimum wage, are a bus journey away. Jeff is also the primary carer for his elderly mother at this time and he decides to give up these other jobs so that he has more time and energy to look after her. He also turns down the chance of taking on more responsibility in one of the jobs. His mother develops dementia and eventually Jeff is unable to continue looking after her. She moves into a care home. The cleaning job at the bank comes to an end when the branch closes.

At the time of the first interview, Jeff had been left with no paid work, despite many years of experience. Jeff had done cleaning jobs for most of the 40 years since he left school. He began his working life working for a national charity warehouse, collecting donations of clothing and household items, and then sorting items in the warehouse. This full-time job lasted for over 10 years but ended when the warehouse shut, and all the workers were made redundant. After a long period of unemployment, Jeff had a series of cleaning jobs, all paying minimum wage. These were in a variety of offices, pubs, schools and stations.

The chronology of these jobs was difficult to establish from the three interviews with Jeff as he was often unable to recall the details of when jobs began and ended or the order in which they had occurred, although he was able to give me the exact date of the start and end of the longest job, in a local branch of a bank. Given the length of his working life, some uncertainty would be expected from most people, but the uncertainty was probably more pronounced for Jeff because of memory problems and communication barriers relating to his learning difficulties (Booth & Booth, 1996). However, Jeff was able to relate in some detail his work responsibilities, which included a wide range of cleaning tasks usually carried out working alone rather than as part of a team:

I was, er, I was upstairs cleaning, cleaning all the toilets, er, the sinks, er, doing the floors, filling all the machines up with toilet paper, paper hand towels, er, hoovering up there, er, went in the kitchen, what, that's what they called the restroom, er and I used to do all the hoovering in there, er, mop the floor in there, mop the step in there, er, and then I used to do the top, the kitchen top, I used to do all that, the sink, clean the microwave out, er, and then I done all the doors and then, come down, and then get all the rubbish out, for them, that was up there, take it all downstairs, chuck that in the bin, and when I finished all that lot, I used to go downstairs and do, mopping, hoovering, dusting, doing the windows, the glass in the doors.

Jeff talked about two periods when he had another cleaning job, while he continued to work at the bank. The first of these was cleaning at a train station, five days a week for two hours each day. The second job was in another office building. Both of these jobs involved work in the morning, so it was possible to combine them with his evening hours at the bank. Talking about all of these cleaning jobs, Jeff commented that he never had any complaints about being too slow or about not getting the work done as expected. On the contrary, he gradually became quicker at his work, *"I picked it up and picked it up"*, and was sometimes given extra responsibilities, such as locking up at the end of his shift:

And then when I finished, I, then I used to say to 'em, I used to, when it was time for me to go, I used to say "I'm off now", cos, er, if I didn't they would have locked the doors and I would have still been in there [laughs] and so I done that, and that was it and so, in the end, I, I was responsible of locking the place up as well.

Despite his years of employment and his increasing responsibilities, Jeff only received the minimum wage in all of these jobs. He initially explained his decision to leave the job cleaning at the train station by referring to a request by his manager to work seven days a week instead of five. Jeff described this as *"getting a bit heavy"* and *"getting too hard"*. He said he had to *"let that go"* and that he *"could not manage"*. Jeff also indicated a lack of awareness of his entitlement to breaks and holidays. Talking about a cleaning job he had in a pub, he said:

this manager, barmaid, come down, er, and she says to me, said [change in tone of voice] "you're due for a holiday now, aren't you?". I said, I said, "to be

honest with you I-I-I just don't know". She says, er, I think she says, "you been here about a year", and she said, "you're entitled to have a day off"

Jeff took on a cleaning job at a printing company, because he needed *"a bit more money to help me mam as well as meself"*. This job lasted *"a while"* but then *"they said they was laying people off"*. In the first interview, Jeff described how he was offered a way to stay in the job:

They asked, the woman, the boss there said, er, "I got to lay somebody off, d'you want to be taken, d'you want to be, to be taught how to use the printing machine?"

In the second interview Jeff referred to this incident as an offer of promotion and explained why he had to turn it down:

I had to look after me mam as well, anyway, on that, I had that job, that was in the morning, job, then I had another job at, in the evening, at night, and that was the bank.... I thought I couldn't do any more cos of me mam being that bad

Jeff's use of language and tone of voice when he told this part of the story indicated his optimism about the employer's intentions, that taking on additional responsibilities was an improvement to the job and a promotion. He did not indicate whether he would have been offered more money or more hours. He highlighted the content of the work and the opportunity to learn something new, emphasising his view of work as a source of personal satisfaction and development. Although it is possible that the 'promotion' was simply a way of extending the cleaning tasks to include some maintenance of specialist machinery, there was no suggestion of this from Jeff's responses. In refusing the employer's offer, he became the 'somebody' laid off.

Jeff misrecognised the outcome as a consequence of his decision rather than the result of a lack of employer support, and particularly a consequence of low pay. Jeff blamed his capacity to juggle his paid work and caring responsibilities as justification for being made redundant. It is possible that the new role demanded a higher level of literacy than was needed for the cleaning job, and that Jeff's own or the employer's concerns about the adequacy of Jeff's literacy may also have influenced the outcome. However, neither Jeff nor his employer appeared to recognise his learning difficulties or acknowledge his right to any support to

enable him to remain in the job. Jeff emphasised his disappointment at having to turn down the opportunity for promotion:

I couldn't do it, and that, and that's sort of, got me dead.

Throughout the interviews with Jeff, when discussing this period of his life, he presented his work experiences in a positive light, saying he had been treated fairly, even when there were problems. He did not appear to recognise any connection between his learning difficulties and precariousness of his contractual conditions or the low level of remuneration. He did not appear to find any of his working conditions exploitative or unreasonable. Returning to the matter of why Jeff ended up with no paid work after all these experiences, his interviews indicate that he understood this as a mixture of personal decisions (based on his priority to care for his mother) and remote market-oriented decisions (the closure of the bank branch).

There were multiple indications of maldistribution within Jeff's story, not only because low pay and few hours combined to severely restrict his income. For example, when talking about the cleaning job at the station and at the printing company, he referred several times to the cost of travel:

I had to keep going backwards and forwards all the time, and I could not afford it...I kept catching, having to catch a bus every day, down here, and then it was, it was costing me too much

Jeff also referred to transport costs several times when we were discussing issues relating to looking for work. Cleaning work provides very little income for people working an hour here and two hours there, even if they are working every day of the week. Even cleaners with no disabilities are unlikely to find enough hours to be full-time in one place. Travel to other locations involves expense that is not covered by employers. For Jeff, a daily bus ticket would have cost him around £4, equivalent to more than a quarter of his earnings for two hours work at national minimum wage. His income, net of travel time and costs, would therefore be substantially lower than the equivalent legal minimum wage for the hours he worked.

How many hours of physical labour would it be reasonable to expect Jeff to be able to do, given his health and his age (late 50s at time of interviewing)? Jeff indicated that three hours a day of this kind of work was "*hard*". Despite his long

years of experience, his dedication to his work and his record of meeting his employers' requirements, he remained on the National Minimum Wage and was unable to envisage this work leading to any higher paid work. In addition, when out of work, he was only considered entitled to claim JSA rather than disability-related out of work benefits, reinforcing his sense that a lack of recognition for his learning difficulties was routine.

Jeff's experiences of multiple, low wage contracts were similar to the experiences of Ravina and Lillian who had also had several periods of paid employment. Neither of them had been paid more than the National Minimum Wage, except when Ravina received a slight increment for working overnight shifts in a care home. This was despite many years of work experience. Neither expected that situation to change.

Only three participants reported receiving a wage rate above National Minimum Wage (Louise, Robbie and Tyler). Louise and Tyler had received a higher rate for very short term cash-in-hand work, although Louise had also experienced cash-in-hand work at a rate below minimum wage. Robbie and Tyler indicated that they had received the main adult rate of minimum wage in their work for major retailers, and not the lower minimum rate for their age group.

Almost all of the jobs discussed by participants were part-time rather than full-time and this is characteristic of the types of jobs involved. In many cases, participants felt they were only able to contemplate part-time work because of their health conditions.

Lillian: Yeah it was every day, it was only two and a half hours, erm, and I get in there, that took about 45 minutes, so, 45 minutes there, 45 minutes back, two and a half hours at work, I was sleeping something ridiculous like 15 hours because I was so exhausted from it

Robbie: I can't work more than a certain amount of hours because I won't be able to cope with it, so it's about 20, 21 hours is my upper limit

Although only Jeff talked about working for a long elapsed-time with no holidays, several others talked about lack of breaks or lack of time for breaks during the working day. So, for example, Robbie said he had no break because his shift was only for four hours. Sam said he would get a 20-minute break if he worked over six hours on a shift. Tyler said that although he got a half hour break, by the

time he had changed his clothes (to avoid contamination from the warehouse) and allowed time to change back, the time left was about 15 minutes.

Some participants did not want to work part-time but were offered few hours. Sam talked about the ending of a zero hours contract doing stock-taking work in warehouses:

Sam: towards the end they only contacted, only contacted me once a month, which was re, which was really unsustainable for work.

Me: So when they contacted you once a month, what was that for?

Sam: Er, well they just asked me if I was able to do, if I, it was re, it was a text or email saying if I could do it, yep

Me: And what was your response?

Sam: Well I said yes, but they never got, got back to me

Similarly, Ravina talked about why she left her first job in a hairdressing salon:

There was not enough hours and I wasn't making any money, I was, I was just, like maybe doing three days a week, and I think I did ask for more, for more hours, but I didn't get them

Ravina, in her 40s, had a long and varied work history. The following story, related to more recent work, illustrates how support and reward issues can combine to undermine job sustainability.

Ravina's story

Ravina gets a full-time job in a residential care home working with adults with severe autistic spectrum conditions, paying minimum wage. She leaves after six months, finding the work too challenging, and moves to a part-time job in a residential care home for adults with learning disabilities. Her pay remains at or only slightly above minimum wage. She stays there for a year but finds the shift work very disruptive to her health. She eventually leaves to take up full-time cleaning work for a building renovation project.

Ravina's decision to leave the care sector and look for work elsewhere was driven by health concerns, exacerbated by low income. The workplace

arrangements made it difficult for her to manage her diet within her budget and appropriate to her health. The pay was minimum wage or very slightly above for unsocial hours and shift work.

Ravina started this period of her working life in her early 40s, after 20 years working as a self-employed beauty therapist. During those 20 years, she said she had managed her own beauty therapy business, with help from her family, as well as training to teach beauty therapy skills. She was unable to make enough money to support herself from the business, so she sold her client list and spent a year doing various temporary jobs, mostly bar work. She started some voluntary work with students with learning disabilities and decided to apply for a paid job in the care sector. The work was full-time and at National Minimum Wage.

Ravina found the skills she had developed as a beauty therapist, as well as her own learning difficulties, helped her to connect with the people she was caring for. However, when she reflected on her struggle to meet her employer's demands, she focused on her own shortcomings rather than the way that work was organised or the lack of support provided:

...you have to be quite alert and I found that too difficult. I was good at it, but when it came to restraint, I wasn't fast enough...and I had to be careful cos of my epilepsy. So it was hard, cos it was a full-time job, I wanted to, I wanted to work, it was a full-time job, it was good hours and I was learning a lot, [but] because of my health I thought it was too much of a risk

Through word-of-mouth, Ravina found out about another vacancy in care work which she thought might be more manageable, especially as it was located nearer to where she was living. The new job was 26 hours a week, rather than full-time, but included night shifts. Ravina remained in the job for about a year and was in post when we first met. I asked her what she liked about the job and she said:

...you get to go out with them and you hope that's going to make a difference, that's what the, the company's values are, you know, to make a difference. And you can actually work and think, "oh I'd like to do this with such-and-such", so it gives you that freedom and independence

Ravina clearly found her new responsibilities more enjoyable and more manageable than in the previous job. However, the shift work pattern became increasingly difficult for her, especially around the issue of managing her diet and the additional cost of bringing in food:

...like today I'm on a night shift, I've got my, I've got my night clothes, that, cos we sleep down the stairs, and er, we have to bring in our own food, so it can be quite expensive, cos like you'll take maybe noodles, so you can eat quite unhealthy as well, you end up eating chocolate cos it takes a lot out of you [laughing] so I think that side of it, I don't like, because I've kind of trained to eat, I've always trained to eat healthy and exercise and it's g-good for my health, and I find I'm so tired that my life balance has shifted and I've put on a lot of weight.

Although the job was part-time, the workload was high and involved a complex range of responsibilities:

...you've gotta be like [listing voice] the cleaner, the cook, the, taking them out, you know, the budgets, the, it's too much for me, like I feel my health is er, [sharp intake of breath] you know, and I'm having to, like, the evenings I'm tired, so I'm eating a lot and I think with the condition I have, it is quite challenging, it, to kee, I do keep up, I fight to keep up.

Ravina seemed to be quite isolated in the job, saying “*you're doing everything by yourself*”. Her change of pronoun from “I” to “you” communicate a sense of alienation or distancing (Riessman, 1990:100) from the person she felt her employer expected her to be. When I asked her about management support, she did not identify any misrecognition of her disabilities or support needs but was quick to say:

The company don't have a lot of money, er, they're there if you need 'em, but most of the time, you know...

These quotes from Ravina typify the way she talked about the many jobs she had tried during her working life, excusing the lack of support from employers and focusing instead on her personal circumstances and health. At the time of the third interview, Ravina explained how the job came to an end:

I've left my, my job as a support worker and, and, I was enjoying it but I left because it was part-time, and the shifts were, er, I found the shifts and that, working the nights and working different patterns, er, on the week, er, was making, was not helping my well-being, er, eating, cos I was eating at different times, and I was putting on weight, and, and, I thought that was having an effect on my health, cos I'm [age – mid 40s], I don't wanna be overweight, and, erm, and taking more medication, as well, cos I, I realised I had high blood pressure as well, so I thought, you know, I need something that's nine till five, where I have, where I get breaks. I just wanted a normal life, you know

Ravina's interpretation of what happened appeared to focus around issues of managing her weight and eating a healthy diet. She offered this reflectively as a reason why she could not stay in the job and had to look for something else. To that extent she blamed herself, highlighting her individual health conditions and her personal choices as root causes. However, her comments also indicated an awareness of the connection between the difficulties she faced and her material circumstances. When talking about having meals at work, she emphasised the cost aspect of this and how it was cheaper to eat less healthy foods such as chocolate bars. She was clear about the trade-off between part-time hours and pay and was struggling to live on a very low income.

Pay at or around national minimum wage is typical for care work, which is a highly gendered sector associated with low pay, as discussed in Chapter One (Grint & Nixon, 2015; Grimshaw & Rubery, 2007). Ravina's experiences highlight a paucity of support and a management failure to provide a workplace in which her personal and social skills could be nurtured. Consequently, her ability to prioritise and maintain her health were effectively undermined by the conditions of work and the structure of the workplace, including unsocial hours and isolation. As such the work was maldistributive beyond being low paid, with Ravina experiencing maldistributive 'costs' of declining health and social exclusion.

Ravina could be seen as something of an outlier in this research for a number of reasons. She was one of only four women in the sample, the only British Asian person, the only person with a higher education qualification, and the only person who had been self-employed. She was also one of the most articulate participants and was confident enough to make direct contact with me, rather

than being recruited through a gatekeeper. Ravina was the only participant who had never claimed any social security or disability benefits or tax credits, although she said she had a formal medical diagnosis which included learning disabilities.

Despite all these differences with the other participants, Ravina's stories resonated with many of the other participants' experiences. Although she did not talk about losing work, her decisions to leave were often driven by concerns about her health and the negative impact that work was having on her health. This was a point raised by Jeff, Lillian and Tyler. Despite having a clearly diagnosed and widely recognised long-term health condition, as well as learning difficulties, Ravina was offered no adjustments to her working conditions, workload or work responsibilities, or support to manage them, like many of the other participants. Her earnings remained low and static despite years of experience, increasing responsibilities and shift work, as did the earnings of Jeff, Lillian and Nick. Although the participants were not always clear about how much they were paid for the work they did, most of the jobs they talked about were likely to pay National Minimum Wage: cleaning, low-end retail and hospitality, packing and loading in warehouses and factories, entry level work in offices and on construction sites.

Ravina was isolated from co-workers and found it difficult to make social connections through this work, regardless of her social skills and outgoing personality. The maldistributive aspects of Ravina's work history can be seen to contribute to her conflicted attitude towards identifying as disabled. At times she was assertive about having a disability and about learning difficulties being a positive aspect of her personality. At other times, she questioned whether she was disabled and indicated that she had not disclosed her learning difficulties to employers or potential employers to avoid being judged as lacking in capability. Such unease about identifying as disabled was consistent with the responses she received from employers, supervisors and co-workers, and her frustration at continuing to face barriers to progression, both in terms of pay and responsibility, at work.

Although Jeff and Ravina's stories have been categorised here to highlight the income gap and how it undermined their employability, their stories, like those of

Robbie and Emily, contain multiple examples of a lack of respect that is a fundamental part of misrecognition with maldistributive consequences.

The Respect Gap

Anthony's story

Anthony is finishing at college and is approached by a member of the college staff, who offers to arrange some off-the-books work for him on a construction site. Anthony finds the work hard and tells his co-workers about his disabilities, hoping for some support. His co-workers respond by teasing and bullying him, and Anthony quits. Later the college staff member contacts him, using disparaging language to criticise his decision to disclose his disabilities.

Anthony related this story with great emphasis on the remarks of the person who effectively brokered the job. By doing so, Anthony indicated his sense that this experience had meaning for him beyond the workplace, reinforcing his mistrust of authority figures outside his immediate family.

Anthony's story was about his only experience of paid work. Bored at college after several years of foundation level courses, he was offered a cash-in-hand job on a construction site by a member of the college staff. Anthony said this was one of his teachers, so they are referred to here as a teacher, although it is possible it was a support worker or administrator in the college. This person had known Anthony for some time and was therefore likely to be aware of his support needs, especially as Anthony had attended a special needs school prior to college. Anthony did not have the minimal training that is usually expected on construction sites so he would have been unlikely to gain this work through a formal application. He indicated that he had been told that the teacher had family connections to the employer.

This was Anthony's first experience of paid work, and he was worried from the start about whether he would be able to cope with the physical demands of the work. Towards the end of his second week on the site, he talked to the site workers about his learning difficulties in the hope that *"they'd go a little bit easy on me"*.

Anthony recounted how the disclosure triggered a range of negative behaviours among the site workers:

Once I'd said that, that was it. They just picked up that and started, made me do things that I couldn't understand, erm, give me, you know the, like the, builders' jokes and everything that I didn't get straightaway, I think, it was like I'm a idiot.

Anthony worked the rest of his shift but refused to return to the site and felt unable to continue with the work. The negative impact of this experience was compounded by the response of the teacher, who contacted him after he had left the site to demand an explanation of what happened:

Anthony: Well he, he come out to me in person, he goes, [teacher voice] "I wanna sit down talk to you, why did you leave?", "Cos I'm fed up of, after I've told them this". He says, he goes, [teacher voice] "well you're an idiot, you're an idiot for telling 'em that". "Well, why am I an idiot? I'm honest. I'm going to tell them", you know, at the time. [Teacher voice] "If it was me, I'd have kept it to myself".

Me: So he, he, he thought you, he was saying "you're an idiot", for doing what?

Anthony: For telling them that, the, the other workers what's wrong with me, the disabilities I have, come out, says, [teacher voice] "You, you're just an idiot, you're stupid, you shouldn't have told them that, you, not at the time". "I don't know", I go, "it's the first time I ever been in the building trade".

Anthony dramatised the parts of the story involving the teacher by using direct speech and appropriating the voice of the teacher. This was positioned as the ending of the story, focusing attention within the story on the behaviour of the teacher, rather than that of the site workers. In fact, Anthony was unable or unwilling to give any specific examples of the behaviour of the site workers. His avoidance of it could be seen as making his story less plausible but could also be interpreted as reinforcing his comments about not understanding what was being said. He knew he was being mocked by the tone of the laughter and the tone of the comments, but he could not re-tell what he did not 'get'.

By directly reporting the teacher's words, Anthony directed my attention to the derogatory intent that Anthony had interpreted from the teacher's behaviour and words. It is notable that Anthony used the word 'idiot' both when he was talking about how the site workers made him feel, and in the reported speech of the

teacher. It is likely that this word is one that had been frequently used as an insult within Anthony's social circle. It is not coincidental that this is a term that was used to refer to people with learning difficulties in legal and medical discourse in the 19th and early 20th centuries (Porter & Lacey, 2005) and now has highly pejorative connotations.

These performative aspects of Anthony's story reinforce a sense of longer-term negative consequences, including feelings of exclusion and mistrust of authority figures:

I felt terrible, specially as it was from a, a teacher that, that knew where I come from a special needs group from the college and he worked in there and everything and, we, I just wouldn't eat and I felt terrible, I thought well, you worked with me for two years, you know I've got learning difficulties and you know problems and everything, and then he comes round and he said "you're an idiot". I see, I see another side of him, obviously, than he's shown in college.

Anthony spoke of years of intense bullying in and outside school during his childhood. Such experiences can establish a "cycle of bullying" (Mishna, 2003:344) with far-reaching psycho-social effects. He talked repeatedly about the role his mother played in defending him from bullying and in dealing with its aftermath. Anthony's response to the events on the construction site followed a similar pattern of retreating from the location of the bullying to the protection of his mother. He may have expected a similar response from the teacher. Anthony strongly expressed his belief that disclosure to his co-workers was the right thing to do. When I asked him how he felt about his learning difficulties he said:

I'm fine with it, it's, it's who I am, it's me. If you can't accept who I am no more, that's it. That's how I look at it now, it's me, I can't change who I am.

During the interviews Anthony expressed strong associations between social interaction and bullying, and between family and protection, which would have wider implications for the effectiveness of support services attempting to help him to look for sustainable work. At one level, his story can be interpreted as one of multiple forms of disrespect and lack of support. Anthony's teacher failed to recognise that he might need additional support to do the job he arranged for him. Anthony's co-workers also failed to recognise that Anthony might need

additional support and used his disclosure as an opportunity for disrespect. Anthony took this as confirmation of his inadequacy for sustaining paid employment. This reinforced the maldistributive impact, widening it far beyond the immediate material effect of the loss of cash-in-hand work.

The way Anthony described the work indicated that he felt the employer was doing him a favour: his use of the phrase *“they took the risk”* underlines his own negative judgement of his capability. Yet it is more likely that this situation meant Anthony could be underpaid and under- or un-insured. It seems plausible that having mild learning difficulties meant Anthony was less willing or less able to question what he was risking by taking on this kind of informal work, but he was possibly also more trusting of his teacher’s support than someone without mild learning difficulties might be, having experienced several years in special needs education. There was no indication in Anthony’s telling that the employer or the teacher might have even considered the site to be disabling for him. Rather, it is implied that the job would not have been offered in the first place and that the job loss was Anthony’s fault.

Consistent with the data reported in Chapter Three, nearly all of the participants mentioned being bullied during their school years. This is mostly related to learning difficulties, but Kevon also talked about experiencing bullying relating to his ADHD and his mixed-race Caribbean-British identity. The only participants who did not mention being bullied were Ravina and Tyler. Ravina was the most outgoing participant and her strong social skills were clearly reflected in her work history in beauty therapy and care work. In contrast, Tyler emphasised his dislike of large groups of people and his need for solitude, but he had been excluded from school several times on behavioural grounds and indicated that he was probably protected against bullying by his reputation for anger:

I wouldn’t class me getting bullied, because I think people learnt that, if I got angry then, it wouldn’t be a good time for ‘em

With a history of bullying through childhood, adults with mild learning difficulties may be more likely to interpret a breakdown in social relations in the workplace as personal bullying, rather than, say, the consequence of failure by the employer to make reasonable adjustments or to offer adequate support. It could be argued that this individual misinterpretation of what is going on, underpinned by a culture of disrespect towards disabled people, is a product of misrecognition

by employers of bullying as “pathological workplace behaviour or unhelpful responses to workplace stresses” rather than the result of a failure of managerial practices (Fevre et al, 2012:221). Lillian’s story illustrates this further.

Lillian’s story

Lillian works in a large supermarket for five years, finding it increasingly stressful to deal with the working conditions and the behaviour of managers and customers. She moves to a job in a smaller supermarket, hoping it will be better. She finds the working conditions worse and she leaves the job.

Lillian highlighted her ease with the job recruitment process at the start of this story, and in her other stories of being in work. Lillian did not disclose her learning difficulties or health problems during recruitment, and these may not have been identifiable by the employer at that point. Although Lillian has some facial characteristics of a particular genetic condition, it is unlikely that these would be familiar or obviously identifiable to someone without specialist knowledge. Lillian spoke clearly, without the regional accent of the area and used a varied vocabulary. Her voice thereby signalled her class origins and in the local area she would be labelled ‘posh’: Lillian was well aware of this and used that description at our first meeting. She indicated a strong belief that it helped her during the recruitment process but subsequently hindered the recognition of her disabilities among her co-workers, who assumed she was undeserving of additional support. She repeatedly referred to incidences in which co-workers and managers effectively refused to recognise that she was disabled.

Lillian emphasised the range and complexity of the tasks involved in the first supermarket job:

You had to learn [whispers, for emphasis] so much, you know, it wasn’t just putting things through the till, it was gift cards, credit cards, erm, people come with vouchers, you know, and it really did highlight a lot of problems.

Other aspects of the job include tasks related to closing the till at the end of her shift. The size of the store added to the complexity of the role, for example when asked to find an item for a customer:

It's that huge, whacking great one, er, so finding stuff, you know, if people asked you, you say yes because you're, like, "I'm a nice person", you know [smiles], and then you think "I can't find it, I can't find it" [sounding worried], so the stress involved in, in, the inability to find something, you know

When asked what she liked about the job, Lillian focused on the people, and being able to walk to and from the store:

I liked the customers, erm, some of the staff were lovely, erm, and I liked the fact that I could walk there and walk home again, you know, the, I, I liked, I kept quite fit then

However, Lillian made it clear right at the start of the story that the negative aspects of the job far outweighed the positives, concluding that she *"hated it"*. Exploring this further, Lillian indicated a complex combination of factors that created a highly stressful environment. For example, she described a situation where a customer attempted to pay with a large quantity of small change. This created a lengthening queue while Lillian attempted to sort out the coins. As the queue lengthened, she called for help from the supervisor but got no response. The waiting customers became impatient and sometimes abusive.

Any problems at supermarket checkouts are managed by the checkout operator staying at the till and calling for help from the supervisor. This puts the supervisor in a position of power over the operator's performance and effectiveness. This may provide opportunities for support where the need is recognised, as illustrated in Robbie's story. However, in Lillian's story, misrecognition or denial of her learning difficulties leaves her exposed:

...they wouldn't answer their phones, they, you'd ring them and they just ignore you, if they didn't like you, if they were pissed off with you, they would [higher pitch] ignore you... there were a couple of people who, you know, who were bullying or just plain not very nice, so they would just talk behind your back, you know, you could hear them [sharper voice] "ner, ner, ner" in the corner...there was some favouritism, you can always tell, you know, so, and if you were liked by the staff, by the managers, then you get treated quite well, and if you weren't, if you were considered annoying or a bit of a pain in the arse, then you weren't

As an example of something that might have made Lillian unpopular with the supervisor, she talked about refusing to work a night shift:

I said, "I've got diabetes, I", you know, "I, I can't work out my insulin, I just can't do it". And she said [raised voice] "Oh you ought to be able to, blah, blah, blah" and, you know, she, she made me feel really small and really un-co-operative and that was hard, you know...

Lillian also gave examples of abusive behaviour by customers:

I, I can't, I, erm, just making me feel upset just thinking about it, erm, so, erm, and they do, and they were, I had people effing and blinding and swearing and, you know, and I had some very abusive people

The behaviour of supervisors in this situation reflects not only their discretionary power but also the context of the monitoring of employee productivity and the precariousness of working conditions highlighted in Chapter One. In that environment, Lillian's refusal of certain shifts and her calls for help when dealing with challenging situations were easily misrecognised by the supervisors as poor productivity or a lack of capability, although this may also have been exacerbated by culturally-sanctioned negative attitudes towards people with learning difficulties.

Talking about why she decided to move to a smaller supermarket, Lillian referred primarily to stress and said: *"it wasn't worth minimum wage"*. This reference to the maldistributive aspect of such poorly paid work, reflects the lack of progression opportunities and the ongoing precariousness of contractual conditions. It also suggests that Lillian associated work, and being paid, with a sense of endurance or acceptance of unpleasant and challenging conditions, although not to an unlimited extent.

Lillian hoped that working in a smaller supermarket would be less stressful, but also less repetitive and more interesting, and she would be able to focus on doing what she felt she was good at: *"assisting people as best I can"*. However, in the smaller supermarket she was assigned to work at the kiosk which:

...was not repetitive enough, there was always something different, someone wants a different cigarette or you'd have to work out how to do, the, the

money, erm, the scratchcards, erm, so there was always something would flag up, that I wouldn't be too sure about, and you'd be left on your own, you'd be left to flounder.

Again, Lillian found herself on the wrong side of supervisors and co-workers. The situation came to a head when she returned a day late after a holiday because she had had to attend a relative's funeral. She had rung to tell the manager and:

I got a very abusive conversation down the phone....And I got some really dirty looks, some real bitching behind my back, when I got back, er, from the person in question, and their mates in the store and that was the point I went, ok, I'm not doing this anymore

Lillian's telling of her stories focused on two main factors: pressure associated with multi-tasking and personal abuse. Primarily she sought to focus on her personal relationships with co-workers or not having the "emotional capacity" to manage stressful situations. This implies a strong element of self-blame. When I asked Lillian whether she thought she got more abuse from customers than other staff did, she said, quite forcefully:

No, I just didn't handle it very well.... at Christmas you just get nasty customer after nasty customer [laughs] but erm, but you know, you would get that, and I just know that I just don't have the ability to deal with that. I don't have the emotional capacity to just, you know, although I did have a certain level of resilience, when you're doing it for six hours, you know, that resilience, it gets to the point where you, you know, you can't cope any more

However, despite blaming herself for not having the "ability to deal with that", Lillian did also highlight the misrecognition and denial of her learning difficulties as a complicating factor:

I, on the surface, you know, it's like a, a duck, you know, on the surface you're gliding on happily, underneath you're [pedalling motion with hands] [laughs] so, so I think that's what it is, and if I turn round and say, "oh, by the way I have a mild learning disability", but if I try to describe it, like I say "I've got memory problems", [change in tone] "oh everyone has a memory problem". So I, I'm up against a brick wall there because everybody does forget things.

Again, this conflicted way of talking about her learning difficulties suggested an element of self-blame, that she considered that her disability was not severe enough or that she was too well-spoken to be worthy of recognition. In this way, Lillian internalised the judgement of others that she was not deserving of support or that she was personally annoying: she not only concluded that retail work was not for her, but also that working with other people was itself problematic and best avoided. The redistributive element of the paid work was offset by the personal cost to Lillian in self-blame and stigmatisation.

Shortly after these supermarket experiences, Lillian applied to a support scheme and was assigned a support worker, who helped her to find other work. She spoke much more positively about a subsequent move into work as a cleaner, where she was able to work alone and at her own pace. With the support worker's help, she was able to achieve employer recognition of her disabilities and health conditions. However, even with this support, she found it difficult to retain work. Despite her many years of work experience, she remained on minimum wage.

Lillian's interpretation of her story was that she was not able to cope with the demands of paid work in a retail environment. This was a similar conclusion to that drawn by Robbie and Emily. Lillian was more ready to criticise the behaviour of managers and customers, but only in terms of individual interactions and personal disrespect. In contrast to the others, she had a higher degree of financial security based on support from middle-class parents and entitlement to disability-related benefits. This would have underpinned her confidence to quit jobs when she had had enough, giving her story a sense of agency and resistance. Nevertheless, she talked about coping with episodes of depression and mental exhaustion, suggesting a high level of emotional cost resulting from her attempts to sustain paid work.

Lillian eventually appeared to conclude that the solution was working alone, rather than with other people. This was indicated by the way she talked about the cleaning job she had at the time of the first and second interviews:

There's no expectations, there's no people telling me, telling me I haven't got a disability, so there's none of the aggro that I've suffered in all my previous jobs and, you know, I'm happy to do bits on my own, you know, even if I don't see people very much.

Lillian's experience of one-to-one support, which began later in her working life, illustrated how intensive support and minor adjustments could enable her to fulfil employer requirements. In her work as a cleaner in a community centre, she was not only able to complete her cleaning responsibilities effectively but also to demonstrate her caring skills through her sympathetic and sensitive social interactions with the centre users. These are the kinds of skills that supermarket managers say they want from their staff (see Chapter One), yet Lillian's story indicates that she was often effectively disabled from delivering them, in that environment. Lillian's work history was one of increasing social isolation, counter-intuitively moving her from work with a high degree of social interaction, drawing on her strong interpersonal skills and empathetic character (tourism and retail), towards lone and physically demanding work (cleaning).

Although it is understandable that Lillian interpreted her experiences as that of one individual struggling with social interaction and personal relationships, there are a number of factors which suggest, as for the other participants, wider social implications. Lillian was repeatedly disabled by the workplace arrangements and priorities which neglected her needs and obstructed her work. Her ability to manage the queue at her checkout and the variety of transactions with customers was highly dependent on her supervisors and their availability to offer support not only depended on staffing levels, but also on Lillian maintaining good personal relations with them. In this way, interpersonal ill-treatment was inextricably linked to the contemporary organisation of work.

It is easy to see how someone preferring repetition and predictability, someone needing regular periods of rest to manage a health condition, could be resented by supervisors and managers working within organisations which prioritise multi-tasking and working at speed. Reducing such conflicts means taking active steps towards "fair and responsive treatment of *all* employees" (Fevre et al, 2012:215, emphasis added) as well as recognise individual support needs and encouraging the disclosure of disabilities and health conditions. Otherwise, supervisors and co-workers on the shop floor may judge resistance to expectations about multi-tasking and speed of working as matters of (poor) attitude and behaviour, or adjustments as "special treatment" (Fevre et al, 2012:215) and respond with hostility and resentment. Having been judged in this way, it becomes almost inevitable that the individual will fail to meet expected standards of customer service.

It is plausible that participants themselves were aware of this, to some extent, and that this might account for some of their reluctance to disclose information about their learning difficulties. This could be seen as an assertion of personal agency or resistance within largely disempowering environments. It is also possible that blaming personal behaviour and relationships is less alienating than blaming what might be seen as immutable structural barriers. These factors add further layers of complexity to the recognition and misrecognition of disability, for the individual, the employer and at the level of policy.

The respect gap focuses on issues around ill-treatment in the workplace or “trouble at work” (Fevre et al, 2012). Most participants did not tell stories about overt ill-treatment at work. However, during participant observations of four participants I was aware of them being mocked or laughed at, but two of those participants did not comment on this themselves. It is possible that participants’ strong desire for paid work motivated them to overlook all but the most blatant forms of disrespect, as in the case of Lillian, or that their learning difficulties limited their understanding of such behaviour, as was suggested by Anthony. There were also indications that some experiences were simply too traumatic to talk about. This is illustrated by the following exchange with Ryan:

Me: But do you think they treated you fairly there?

Ryan: No

Me: No

Ryan: Nope. Not at all.

Me: Can you say anything about why not? What happened that wasn’t fair?

Ryan: It’s just [shrugs]

Me: It’s just it would be really helpful to understand a bit more about what that means, in a, in a work situation.

Ryan: Erm

Me: For somebody

Ryan: The just [sighs] it, it's very diff, it's very difficult, difficult to say right now, not in the, right frame of mind, I just want to, I just, just want to, I just want that to, I just want to put that behind me now.

Me: I know, yeah, I appreciate that.

Ryan: It's, it's, it's, it's not the fact that, I'm glad that, I'm glad I did a job like that, but, I, I don't, I don't look toward, I don't look at the past anymore, I look at the future. The future for me right now, is getting a job, and being set, and, and, and knowing that I'm going, I'm going to be stable in it.

What makes this kind of experience even more difficult to talk about is that there is a sense in which the language available is simply inadequate to describe what has happened. The term 'bullying', as defined by Einarsen et al (2011) to include regular, sustained behaviour with hostile intent, is inadequate to cover workplace experiences such as "incivility, abuse, mistreatment, social undermining" (Fevre, 2012:7). This goes beyond misrecognition or maldistribution towards a form of epistemic injustice, in which people have "at best ill-fitting meanings to draw on in the effort to render them intelligible" (Fricker, 2009:148). The effect, again, is to excuse or obscure the role of the employer in creating or enabling an environment where people with learning difficulties can be misrecognised and abused.

The maldistributive aspect of the stories in this chapter is primarily about individual job loss and a reversion to an income based on out-of-work social security benefits or financial support from close relatives. However, there are other maldistributive aspects: the jobs discussed here were all low wage and participants experienced no progression in terms of pay or pay-related conditions even after years in post; they were mostly part-time, temporary contracts; breaks and holidays may not have met statutory requirements; employers may have offered minimal or no adjustments; the participants were unaware of what adjustments might be possible or unable to persuade or enforce their implementation. The participants were effectively exploitable and exploited because of their eagerness for paid work and their lack of alternatives. The support many of them received from parents and close family was part of what made it possible for them to subsist on the very low level of wages that they earned in these jobs.

Many participants chose not to disclose their conditions and differences because of fear of negative consequences. In Anthony's story, where he did disclose, the consequences were indeed negative, and he was unable to continue in the job. However, non-disclosure may not be up to the individual, as in Robbie's story or in Emily's, and disclosure may result in denial, as in Lillian's story. Jeff and Ravina made few demands on their employers and withdrew, blaming themselves, when they felt unable to meet employer expectations.

Conclusion

This chapter contributes new knowledge to questions about how people with mild learning difficulties experience unemployment and looking for work. It applies Fraser's concepts of maldistribution and misrecognition to identify gaps of support, income and respect that undermined the path towards paid work for the research participants. The participants' stories show how maldistribution and misrecognition interact to block access or push them further away from the paid labour market. This application of Fraser's concepts helps to uncover the consequences of a social security benefits system that is experienced as arbitrary and prioritises redistribution over recognition, illuminating the inadequacies of the policy response to supporting the employment of disabled people.

This chapter highlights multiple forms of injustice experienced by those participants who had participated in the paid labour market. Using Fraser's concepts of maldistribution and misrecognition, the analysis shows how gaps of support, income and respect result in exploitation and the worsening of individual employability. Whether there is disclosure of learning difficulties or not, the participants' stories reflect failures of support which negatively impact on material resources and personal respect. The chapter highlights how this research contributes new knowledge about the experiences of people with mild learning difficulties within the contemporary labour market. The analysis also provides contrasting evidence to the policy claims discussed in Chapter Five, exposing the inadequacies of the policy response to supporting the employment of people with learning difficulties.

Chapter 10 Conclusions

“Some people nowadays go oh if you do this you’ll get a job afterwards and then they’ll screw you over, go, sorry, not successful” [Tyler]

“I always worked harder than everybody else, cos I had to” [Ravina]

“I kind of feel like I’m not entitled to a good job” [Nick]

“I just get to breaking point, and I just snap” [Lillian]

“if I end up on the street, I end up on the street” [Jack]

“I’m throwing myself out there but they’re not giving me anything” [Sam]

People with mild learning difficulties are being denied social justice in their everyday encounters with the labour market and the systems of support available to help them find and keep paid work. This thesis argues that the injustices that they experience arise from a combination of maldistribution of resources, largely through exclusion from paid work but also due to the restricted and conditional social security system, and misrecognition of their equal humanity and right to dignity and respect, whether identified as disabled or not disabled. These failings interact in a number of complex ways to undermine the effectiveness of the support that is made available and to cause significant harm on an individual level. However, they are also part of a wider failure of social justice affecting disabled and non-disabled people claiming out-of-work or disability-related benefits and those in low paid, precarious work.

This concluding chapter draws on the evidence presented in the thesis to show that people with mild learning difficulties who are looking for work are not receiving social justice, and that this is a product of: the miscategorisation of disability as a fixed and essential individual characteristic; the individualisation of responsibility for employability, manifested in the design and delivery of social security; and an ideological commitment to a form of a competitive labour market that prioritises work intensity and worker flexibility.

Each of these issues is discussed in this chapter, following a recap of the way that social justice has been used and explored in this thesis in relation to policy and individual experience. This recap and discussion demonstrates how the

concepts of social justice used in this research contribute to understanding the position of people with mild learning difficulties who are looking for paid work. The chapter concludes with some reflections on the limitations of the research and questions for the future.

Addressing the research questions

The research was about people who self-defined as having mild learning difficulties, who were not eligible for adult social care and who might or might not consider themselves to be disabled. It explored how their experiences, rarely the focus of research about employability or disability, expose flaws in the approach to social justice embedded within government policy since 2010. The injustices experienced by people with mild learning difficulties are not a matter of people ‘falling through the cracks’, in some passive, unexpected way. To a large extent they are a consequence of government policy, the structure and regulation of the labour market and the design and delivery of social security.

Recognising the limited and limiting nature of political discussion about the employment of disabled people, and the hidden-ness and misrepresentation of people with mild learning difficulties in research, the research set out to answer the following question:

How do people with mild learning difficulties experience looking for paid work?

This question has been addressed in the research by drawing on multiple interviews and participant observation carried out in 2017 and 2018 with 16 people with mild learning difficulties who were looking for paid work. People with learning difficulties are under-represented in social research, as discussed in Chapter Three. The design of the research was shown to be successful not only in reaching participants who were hard to reach and sustaining their involvement in the research to enable multiple interviews and interactions, but also in gathering in-depth narratively-oriented data suitable for the application of narrative analysis methods. The research makes a significant contribution to demonstrating the applicability of narrative research methods to people with learning difficulties and communication difficulties.

Chapters Eight and Nine report directly on the participants' experiences of looking for paid work, following on from, and in the context of, the analysis in Chapter Seven of the ways in which they spoke about disability. These chapters not only provide an original contribution to knowledge about the complexities and ambiguities of self-identifying or being identified as disabled, but also provide substantial new evidence of a failure of support, inadequate income and a lack of access to material resources, and a dismal catalogue of incidences of disrespect and abuse.

Combined with the analysis of government policy presented in Chapter Five, the findings of all the data chapters address each of the subsidiary research questions:

1. *What are the tensions and contradictions in government policy towards supporting the employment of people with learning difficulties and promoting social justice?*

This is directly addressed by Chapter Five and informs the analysis in Chapters Eight and Nine.

2. *How do people with mild learning difficulties relate to concepts of disability and how does that affect their sense of their rights and entitlements?*

This is directly addressed by Chapter Seven and informs the analysis in Chapters Eight and Nine.

3. *What stories do people with mild learning difficulties tell about unemployment, looking for work, and being in work?*

This is directly addressed by Chapters Eight and Nine.

4. *What do these stories reveal about the labour market and the social security benefits system?*

This is directly addressed by Chapters Eight and Nine and discussed further in this concluding chapter.

5. *What do the stories of people with mild learning difficulties who are looking for work reveal about the adequacy of the government's policy approach to supporting the employment of disabled people?*

This is directly addressed by Chapters Eight and Nine and discussed further in this concluding chapter.

6. *Are concepts of social justice useful to understanding the position of people with mild learning difficulties who are looking for paid work, and if so, how are they useful?*

This final subsidiary question is addressed in the next section of the concluding chapter, bringing together the analyses from Chapters Five to Nine.

How is social justice approached and used in this research?

The operationalising of the idea of social justice in this research was discussed in detail in Chapter Two. The analysis of government policy, discussed in Chapter Five, which focused on the way policy problematised the relationship between disability and unemployment, included consideration of the Social Justice White Paper (HMG, 2012). Social justice is not a term that has historically been associated with Conservative governments, and there is some evidence to suggest that the Conservative Party's use of the term during the 2000s was part of a strategy to "portray a more compassionate, socially inclusive image" in response to the electoral successes of New Labour in the 1990s and 2000s (Hayton & McEnhill, 2015:144). The Social Justice White Paper (HMG, 2012) was built on foundations developed by the Centre for Social Justice (CSJ), a think-tank established by Iain Duncan Smith, who was Secretary of State for Work and Pensions from 2010 to 2016 and previously leader of the Conservative Party. The White Paper and the work of the CSJ claim poverty is a consequence of family breakdown, addiction, lack of paid work, and other factors linked to individual behaviour, rather than the result of low disposable income (Hayton & McEnhill, 2015).

In this partial conception of social justice, low income is primarily a "symptom of deeper problems", relating to individual decision-making and behaviours. The government's role in improving these behaviours is a matter of "incentivising"

(HMG, 2012:5) people, largely through restructuring the social security system. The White Paper and the CSJ do acknowledge the need for social provision of support to enable and sustain behavioural change but insist that these need to be delivered by the private sector, charities and local community groups, to produce “social and financial returns” (HMG, 2012:11). These two characteristics of the route to Conservative social justice (individual behaviour change and the marketisation of support services) are consistent with neoliberal claims that “the market rather than the state embodies freedom and welfare” (Turner, 2008:149). The neoliberal ideal of the free individual, the “autonomous, self-actualizing subject who ‘gets out’ what they ‘put in’” (Gedalof, 2018:33) is unrestrained by concerns about inequality or the concentration of wealth and power in elite groups and corporations (Harvey, 2005).

As expressed by the government’s social justice strategy and the publications of the CSJ, this is not a philosophy of social justice but a form of ideological discourse that excludes “collective action, universal provision or democratic organisation” (Littler, 2018:68) in favour of the idea that “we are now beyond inequalities of class, race and gender” (Littler, 2018:68). This ideological discourse was highlighted by Theresa May, Conservative Prime Minister from 2016 to 2019, when she referred to individuals going “as far as their talents will take them” (May, 2017) and talked of “burning injustices” while promoting selective education and grammar schools (May, 2016). It is part of a wider ideological commitment to a form of meritocracy, positioned as ‘equality of opportunity’, that has been promoted through policy since the 1950s, but with increased intensity since the 1980s (Littler, 2018).

The social justice framework applied in this research draws on the work of Nancy Fraser who proposes “fair democratic deliberation” (Fraser, 2003a:44) as the basis for dealing with diverse and sometimes conflicting interests and identities within contemporary society. Fraser develops the concept of “participatory parity” in social life as a fundamental pre-condition of democratic deliberation and democratically-agreed changes that are consistent with “the equal moral worth of [all] human beings” (Fraser, 2003b:231). Parity of participation in social life may be undermined by socio-economic, political and cultural barriers or inequalities.

Fraser’s approach maintains the importance of addressing socio-economic inequalities and considering the fair distribution of resources, common themes

among theories of social justice (Burchardt & Craig, 2008). In Fraser's work, these are represented by the concept of maldistribution, which includes a focus on material inequality, marginalisation and exploitation, as well as deprivation. However, Fraser proposes that parity of participation is also dependent on addressing issues of inequalities of respect and esteem relating to "institutionalized patterns of cultural value" (Fraser, 2000:113). This is represented by the concept of misrecognition, and focuses on cultural subordination, nonrecognition and disrespect. This concept of misrecognition is deliberately defined to exclude individual attitudes and self-esteem: Fraser's focus here is on *social* arrangements not "ethical self-realization" (Fraser, 2003a:29).

This research has shown how the lives and experiences of people with mild learning difficulties are constrained and damaged by the effects of Conservative policy on social justice and on tackling the disability employment gap (DEG). The participants' stories highlighted maldistribution and misrecognition, working together or in conflict, to create and reinforce overlapping gaps in support, income and respect. The interaction of maldistribution and misrecognition, and the gaps of support, income and respect, are visible in the stories analysed in Chapters Eight and Nine. The following outline of one participant's story provides examples of how these gaps overlap and interact.

Sam had been labelled as 'special needs' in school and had received Disability Living Allowance as a child. In his last year at school he had a 10-week, full-time unpaid work placement but at the end of the placement he was told that his work was too slow and that his co-workers had complained about his behaviour.

After leaving school he was unable to find paid work and made a claim for out-of-work benefits. He was refused ESA, the out-of-work benefit for people unable to work due to sickness or disability, and only entitled to claim JSA, with its stringent conditions, including spending 35 hours a week looking for work, and the risk of sanctions (loss of benefit, at that time for up to three years) for non-compliance.

Sam took another work experience placement which lasted 14 weeks, at three days a week in work and one day in a classroom. This work was also unpaid although he continued to receive JSA. Sam felt that this work went well but he was not offered any paid work. In the two years since Sam left school, the only paid work he gained was a few hours on a zero hours contract. In the short time

that he spent in a paid workplace, Sam experienced hostility and social exclusion from co-workers, and a lack of support from managers.

Misrecognition and categorisation

Sam's story, like the stories discussed in more detail in Chapters Eight and Nine, highlight how a label of disability can have profound consequences for access to benefits and services, but is no guarantee of justice. The very processes of categorisation and labelling of people as disabled or not disabled have been shown to undermine social justice. The DWP's assessment process for determining eligibility for disability benefits and ill-health-related out-of-work benefits has been linked to an increase in claimant fear, anxiety, mental ill-health and suicides (Grover, 2019; Mills, 2018; WPC, 2018b; Barr et al, 2016).

The scandalous, ongoing failure of social security disability and ill-health assessments to fairly "assess if claimants' impairments are genuine, to assess whether they are capable of work, and to assess what requirements can fairly be placed on them" (Baumberg Geiger, 2018:20) demonstrates how maldistribution and misrecognition are intertwined. Attempts to withdraw financial support from people on the basis that their impairments are 'not severe enough', and the high success rate of appeals against these attempts, undermine the legitimacy of the assessment process. They also expose assumptions that disability is an "always-present essence" rather than "situational" (Bjornsdottir et al, 2014:89). If those who have been claiming disability-related benefits are subsequently assessed as not disabled, the implication is that the categorisation process has identified them as fakes or frauds. This form of misrecognition has been reinforced by stigmatising media portrayals of disabled people (Ryan, 2019; Grover & Piggott, 2013a).

There are also subtler and more insidious implications of building social policy around differences between people based on impairments, relating to issues of deservingness. This is exemplified by the language of vulnerability, through which disabled people are misrecognised into a hierarchy of deservingness largely based on the visibility of their individual, medically-defined conditions ('the most severely disabled'). Unsurprisingly, people with less visible conditions, such as those with mild learning difficulties, are likely to be found at the lowest point of this hierarchy (Roulstone & Prideaux, 2012).

Linking the provision of state support to categories of supposed deservingness, based on a limited and often arbitrary assessment of so-called vulnerability, can have catastrophic maldistributive consequences for those deemed undeserving, especially in the context of ‘austerity’ measures such as the £5bn cut in spending on disability benefits since 2010 (Butler, 2018). Many of the participants in this research had been effectively re-categorised from ‘disabled’ to ‘not disabled’ as a result of their age (i.e. child to adult) or from ‘not disabled’ to ‘disabled’ as a result of challenging a DWP decision at an independent appeal tribunal. Yet their impairments were experienced as unchanged or worsening.

The policy analysis in Chapter Five also revealed some of the contradictions and tensions arising from the categorisation of social security claimants as distinct from taxpayers. This notional separation of those having “a life on benefits” from “the hardworking taxpayers who paid for it” (Duncan Smith, 2015) deliberately fosters misperceptions about “a stagnant population of *them*” (Hills, 2015:249), sweeping aside evidence that the majority of the population receive means-tested benefits or tax credits (Hills, 2015).

These forms of misrecognition produce cultural subordination by associating people who claim disability or out-of-work benefits with derogatory tropes of scroungers and fakes. Inevitably these associations are also internalised, as Chapter Seven highlighted in the discussion of ambivalence among people with mild learning difficulties about disclosing their impairments or asking for support. The maldistributive effects of a denial of support, whether financial or not, are extensive and unjust.

Individual behaviour, talent and aspiration

Claims that underemployment or unemployment are a consequence of lack of skills or experience or behavioural traits are promoted through policy documents ranging from the Social Justice White Paper (HMG, 2012) to the business case for UC (DWP, 2018c). They suggests that a vicious circle of lack of experience, low personal expectations and lack of motivation is *producing* and *produced by* exclusion from paid work. This is reinforced by reference to a concept of personal resilience that suggests such exclusion is beyond the scope of government action (Amery, 2019), except in ‘incentivising’ people through financial punishments or the threat of them.

The solution, according to this view of unemployment, is for individuals to “work on *themselves*” (Cromby & Willis, 2013:256, emphasis added) to develop the character traits and behaviours expected by employers, based on moralistic claims about the links between “certain character traits”, such as self-awareness and self-control, and employability (Taylor N, 2018:402). This instrumentalising of character, with its assumptions about human nature as essentially lazy and impulsive, is connected to the wider influence of behavioural economics and ‘nudge theory’ (Taylor N, 2018; Leggett, 2014). In this view of human nature, poverty and unemployment are positioned as outcomes of character, despite evidence to the contrary (Berkman, 2015).

The DEG has been problematised by policy-makers partly by drawing on these behaviourally-oriented and moralistic discourses to position unemployment as an individual failing, summed up in phrases such as “choosing not to work” (HMG, 2012:38) and “a life of dependency” (Duncan Smith, 2015). Using the language of entrepreneurialism and meritocracy, individuals are urged to take responsibility and punished if they do not play by the rules (Littler, 2018). Within this, disability is reformulated as a category of identity, dominated by and conflated with mental health and/or musculoskeletal conditions, because these are the most commonly reported causes of sickness absence from paid work.

Drawing on a distorted version of the social model of disability, government policy indicates that anti-discrimination laws, the funding provided by schemes such as Access to Work and the obligations of employers to make “reasonable adjustments” (DWP & DoH, 2016:50), provide economically efficient and sufficient ways to allow the disabled individual “the chance to fulfil their potential” (Duncan Smith, 2015) through open competition in the labour market. The implication of Scott’s story, and the other case studies referred to in the government’s Disability Confident literature and positioned as inspirational stories, is that what disabled people need, above all, is self-belief and motivation to go “as far as their talents will take them” (May, 2017, unpaginated). At the same time, as Chapter Five discussed, these claims are contradicted by suggestions that disabled people are under-productive and employers need to be subsidised to employ them.

The participants’ stories of being in work and leaving work exposed the failure of policy to reduce the DEG or to ensure work is the promised route out of poverty.

Where paid work was gained, participants were offered insufficient support to ensure that work was either sustainable or properly rewarded. Those participants who experienced direct hostility or bullying in the workplace had no recourse to any redress. They were excluded from the limited legal protections offered by anti-discrimination legislation: either not being recognised or not recognising themselves as disabled; or facing the high costs and complexities associated with taking legal action.

Participants' efforts, either in work or in looking work, did not 'pay off'. On the contrary, when in work they were confined to low paid jobs or unpaid jobs, which did not lead to higher paid positions. Being in work was not a chance to develop their talents, be rewarded adequately for hard work or "transform their lives" (HMG, 2012:38). For most it was a very short-term and stressful opportunity to earn the minimum wage, often accompanied by either neglect or abuse from supervisors and co-workers. For several participants, a single bad experience of paid or unpaid work undermined their confidence in their ability to work with other people at all.

The research also highlighted how the government's focus on lack of motivation, skills and work-oriented behaviour as the main obstacle to people remaining 'workless' exposed people with mild learning difficulties to an increased risk of exploitation. Several participants worked for years in unpaid jobs for charitable organisations in the hope that this 'experience' would develop their skills and demonstrate their motivation and work-oriented behaviours to prospective employers. These participants were clearly showing that they were *not* "choosing not to work" (HMG, 2012:38). Nevertheless, there was no clear path from unpaid work to paid work for them.

Policy delivery and the role of the welfare state

Misleading rhetoric about people who claim out-of-work or disability benefits not only stigmatises claimants and deters people from pursuing claims for support but also provides political cover for drastic cuts to the funding of public services and undermines confidence in the concept of a welfare state. Policy statements using terms such as "the cycle of worklessness" (HMG, 2012:37) or "the culture of worklessness" (ibid:38) encourage popular misperceptions that most people claiming out of work benefits are "on the fiddle or sitting around idly when there is actually plenty of work available" (Hills, 2015:250).

The analysis presented in Chapter Five showed how the government's social justice strategy was bound up with ideological commitments to cut state spending on social security and on public sector services, and to reduce the power of the public sector to deliver services. One of the most obvious effects for disabled people has been the cuts to health and social care funding. In a recent survey, over a third of people with intellectual disabilities in England reported a loss of care since 2008, with some being referred to local charities as alternative sources of support (Forrester-Jones et al, 2020).

The participants in this research were not eligible for adult social care and their eligibility to support from the charitable sector depended on the availability of resources in that sector. Several of the gatekeeper organisations contacted during the fieldwork closed or reduced their services in response to reductions in funding over the period. It is clear that increased demand for third sector support from people previously supported by adult social care, and reductions in funding of public sector and third sector services, has a negative impact on the services available to people with mild learning difficulties.

A press release issued in November 2018 entitled "Millions awarded to help people with health conditions stay in work" (DWP, 2018d), outlined planned funding of £4 million to 19 projects to "support people to manage their health conditions at work" (ibid). Although any of those 19 projects might employ or support the employment of people with learning difficulties, the £4 million was a transfer from the state to these privately-run organisations, not to disabled people. This is consistent with a neoliberal view of the role of the state as determining policy priorities while enabling and funding competing private and charitable sector providers to deliver their implementation (Birch, 2015, Littler, 2018).

This thesis has demonstrated that the delivery of government-backed measures to reduce the DEG by private and charitable sector organisations can have maldistributive and misrecognition effects for people with mild learning difficulties. The participants' stories showed that, even where organisations acknowledged the needs of people with mild learning difficulties for additional support, this could still result in detrimental effects since there were no obligations on these organisations to train, pay or protect the participants from disrespect or exploitation.

Injustices were also evident in the stories of paid placements. Even when the gap between the employer's requirements and the participant's ability to meet them was pre-assessed, the support needed to bridge that gap was not provided. This raises questions about accountability and the prospect that government funding for such schemes might provide greater benefit to the organisations involved in their delivery, either as brokers or as employers, than to disabled people themselves.

The government's approach to social justice (HMG, 2012) relies on policy delivery by private sector providers and through philanthropy, driven by ideologically-based beliefs in the innovative potential of the market and the equation of merit with wealth. Community-based approaches, rather than those provided by local authorities, are promoted as developing "local control and responsibility" (HMG, 2012:64). In practice, this may mean funding is wasted pursuing approaches that are already known to be ineffective (Greig, 2018), with little or no accountability or transparency.

The participants' stories of claiming out-of-work and disability-related social security benefits contradicted the claims of Conservative social justice that punitive conditionality provides necessary financial incentives to motivate people to choose work. The participants experienced conditionality, through the threat or actuality of sanctions, as highly stressful and demotivating. This is consistent with other recent studies of sanctions and conditionality (Ryan, 2019; Welfare Conditionality Project, 2018; Patrick, 2017).

While the threat of sanctions did sometimes make participants more anxious about complying with instructions from Jobcentre Plus work coaches about attending appointments, there was no indication that these threats moved the participants any closer to paid work. On the contrary, participants indicated that sanctions or the threat of sanctions made them *more* cautious about taking paid work because of the potential impact of failure. The negative impact of conditionality continued to be exposed throughout the period of this research (Mehta et al, 2020; Welfare Conditionality Project, 2018; Patrick, 2017) and continued to be ignored by policy makers (Bulman, 2020; Mehta et al, 2020). Conditionality remains highly detrimental to people with learning difficulties, who face an above average risk of being sanctioned (Mehta et al, 2020). The re-imposition of conditionality after a three-month suspension during the Covid-19

lockdown will have a disproportionately adverse impact on disabled people (Pring, 2020).

The participants' stories showed how their efforts to find paid work could be helped or hindered by the structure and delivery of social security, depending on their individual relationships with work coaches and employability services. Individual work coaches have discretion to refer claimants for additional support if they consider that they deserve such support, or to judge that their work search activities are insufficient and they should be sanctioned. Some of the participants praised the dedication of particular individual work coaches, especially disability employment advisers, who went beyond the official remit of their role to seek out job opportunities and support for their clients. However, participants also indicated experiences of a lack of support and, in a few instances, disrespect from work coaches.

More generally, participants were distrustful of the administration of social security, displaying scepticism about handling of applications and assessments, the timeliness and accuracy of payments and the threat of sanctions. The deterioration of the reputation of the DWP, arising from the "inherent tension" (Pollard, 2018:13) between attempting to offer employment support and policing the rules of the social security system, has led to suggestions that support for "harder-to-help" groups should be transferred away from the DWP entirely (Pollard, 2018). The evidence of this thesis supports that conclusion, but any alternative service would need to address other weaknesses in the provision of employability support beyond the tension with policing social security rules.

The labour market

The right to work, and decent conditions of work, are enshrined in Article 23 of the Universal Declaration of Human Rights (UN, 1948) and in Article 27 of the UN Convention on the Rights of Disabled Persons (UN, 2006). These are acknowledgements of the potential for work to contribute to the enjoyment of "full and effective participation in society" (UN, 2006). However, these rights are of little benefit to people with mild learning difficulties facing the gaps in support, income and respect described in Chapter Nine, because they are either largely unaware of their rights or have no means of claiming them.

The participants' experiences were often consistent with reports from wider studies of "poor work" (Patrick, 2017:101) which highlight highly stressful working environments, uncertain or unsocial hours and low pay (Bloodworth 2019; Crouch, 2019; Bailey, 2016; Shildrick et al, 2012), but also the social benefits, such as increased self-esteem, friendships and a sense of belonging, derived by some people who do those jobs (Patrick, 2017; Shildrick et al, 2012). For people with mild learning difficulties, these social benefits are harder to gain and harder to retain. The stories in Chapter Nine highlighted participants' exposure at work to isolation, neglect, bullying and abuse. This resulted in participants sometimes choosing to leave work to protect their own mental health or concluding that they were not 'cut out' for work with other people, despite the maldistributive consequences that they knew they would face.

Their stories highlighted the interaction of misrecognition and maldistribution through which participants experience disrespect and dismissal that is frequently turned inwards as a form of self-blame. Recognition of their learning difficulties or of being disabled was no guarantee against misrecognition of their "common humanity" (Lister, 2004:188). The participants' stories highlighted gaps in support, income and respect that obstructed their route into sustainable, fairly paid employment, increased the likelihood that they would experience poverty and left them at greater risk of exploitation and discrimination at work.

By focusing on the costs of the employment gap, particularly social security costs, and on the motivation and skills of the individual, government policy fails to provide the support that people with mild learning difficulties need to enjoy meaningful work that provides a decent standard of living. In emphasising the relative number of disabled people in employment, through the focus on the DEG, the government avoids addressing issues around the "nature of employment that disabled people are in... and whether it protects them from poverty and social exclusion" (Grover & Piggott, 2015:7).

Chapter One discussed changes to the labour market highlighting the impact of technological change, the dominant position of the service sector and recent trends in service sector work, and the increase in intensification and precarious contractual conditions for low paid and so-called low skilled work. The evidence presented in this thesis has shown how these trends have had adverse effects on the employability of people with mild learning difficulties. The participants' stories

showed how technology was used as a tool of managerial surveillance to focus on the intensification and speed of performance, rather than to support participants in their work. They demonstrated how demands for flexibility exacerbated participants' anxiety without offering any compensatory advantages such as more suitable working hours, higher wages or skill development. Participants discussed how their "image and performativity" (Roulstone, 2012:216) was mocked by co-workers or misinterpreted by work coaches.

The growing precariousness of the conditions of paid work, exacerbated by the decline in trade unionism (Crouch, 2019; Pettinger, 2019; Gallie, 2017), increases the complexities involved in determining appropriate responses to the support needs of people with mild learning difficulties. The thesis has shown that it is possible for recognition of their need for support to result in a deterioration of their employability, with maldistributive consequences.

Employers have little incentive to support the development of workers' skills or productivity, or to reward "their accumulating experience", in the gig economy (Crouch, 2019:92). Given the obstacles and injustices experienced by the participants during a period of falling unemployment, the prospects for them post-Covid are bleak. However, the experiences of most workers in low paid, low skilled and precarious work during the pandemic has highlighted how a lack of support, income and respect is experienced by a much larger section of the population than people with mild learning difficulties, intersecting with issues relating to the misrecognition of class, gender and race (Vickers & Hutchings, 2020; Pettinger, 2019; Littler, 2018).

Limitations of the research

People with learning difficulties are under-represented in research and neglected by policy-makers for a number of reasons discussed in this thesis. Their experiences of injustice may have implications for a much larger group of people who are looking for good work. However, the scope of the analysis carried out by this research was limited by the number and the demographic diversity of participants recruited.

Recruitment to the research was limited by the resources of the research project itself, the focus on a group that was, by definition, hard-to-reach, and the use of multiple interviews as the main method of data collection. The methods used

proved effective in building rapport with the participants, enabling engagement and producing rich interview data. However, the recruitment strategies and the resources available proved insufficient to recruit enough participants to support an intersectional analysis (Crenshaw, 2014) that might have revealed insights into the different experiences of men and women, and of people from Black, Asian and other minority ethnic communities. It was notable that gatekeeper organisations were more than twice as likely to identify a male participant than a female one, and this raises questions about whether and why men are more likely than women to engage with these organisations, but these could not be addressed by this research.

Discussions with gatekeeper organisations indicated that Black, Asian and other minority ethnic communities might have different ways of supporting or including people with mild learning difficulties, but little headway was made to address questions about what this might mean in practice. Similarly, there were not enough Black, Asian and other minority ethnic participants to enable exploration of how “an economic system that is deeply racialized” (Bhambra, 2017:S227) might affect the experiences of participants from different ethnic groups. While these issues should be of interest to any researchers working in this field, neglect of such questions is exacerbated by the under-representation of Black, Asian and other minority ethnic people in academia and the neglect of issues of ‘race’ in social policy curricula (Craig et al, 2019).

The analysis of government policy documents and the accounts of the participants raised a number of questions about the role of employers in improving opportunities and outcomes for people with mild learning difficulties which are not addressed here. During the fieldwork period, three interviews were carried out with supervisors and managers at two large employers running work placement schemes specifically focusing on the recruitment of disabled people. These interviews indicated a willingness to engage with the research questions. They also raised a host of questions about the impact of these schemes on work practices and workplace relationships, as well as questions about funding, costs, pay and progression. Given the emphasis within the policy documents on government expectations about employer action, and the claims of many employers to a commitment to employ disabled people, this would be another potentially fruitful area for further research.

Concluding remarks

People with learning difficulties are represented in a very limited way within government policy, such as the single story in the White Paper on Work, Health and Disability (DWP & DoH, 2017) about “a talented young man who has a learning disability”, named Scott, who is offered an apprenticeship following an extended work experience placement (ibid:20). Scott’s story, set out on its own and representing success, serves to narrow perceptions and reinforce the view that personal attributes determine progress in the labour market. In representing his success, reference is made to Scott’s talent and to being hardworking, and he is presented as grateful for the opportunity to have had a year’s work experience with no pay (Tarlo, 2019). This places Scott in an elite category, implying that those who do not share his experience are *not* talented, *not* hardworking and *ungrateful* (Fernandes, 2017).

The experiences documented in this thesis illustrate that the results of being viewed in this way are unjust. The effects are damaging financially, socially and psychologically for individuals with learning difficulties and their families. This finding is important not only for those individuals: it has much wider implications at a time when increasing numbers of people are reliant on income from precarious work and/or a punitive and unfairly conditional welfare state within which provision is not matched to need.

The concepts of social justice used in this research have highlighted the complexities of the situation faced by people with mild learning difficulties who are looking for work, but also exposed undeniable injustices inflicting personal and social damage. The participants’ stories and the social security and labour market issues discussed here directly contradict the government’s claim to be promoting social justice and to be supporting disabled people and unemployed people into good work.

Fraser’s concepts of maldistribution and misrecognition have been applied in an original way to explore under-researched experiences of people with mild learning difficulties. These social justice constructs have exposed contradictions between government claims to be promoting fairness and opportunity and the impact of the direction of policy on the lives of people with mild learning difficulties, the provision of support and income to meet need, and protection and redress against disrespect and abuse.

Fraser's distinctive sense of misrecognition has proved to be challenging to apply in this research because of its ambiguous everyday meanings. Institutional misrecognition of disabled people is exemplified by the cultural devaluation of disabled people in the media, in the construction and delivery of conditionality within UC and other out-of-work benefits, and in the assessment and restriction of entitlement to disability. However, in this research, the participants were more likely to discuss the effect of this *institutional* misrecognition as forms of *individual* misrecognition. This was manifested in the behaviour and attitudes of individuals towards themselves (for example, in self-blame) or towards others (for example, bullying or exclusion). These are forms of misrecognition that are a combination of social practices and self-consciousness, supporting criticism that Fraser's approach underplays the significance of the "psychological dimension of misrecognition" (Lister, 2007:165).

Many of the injustices highlighted in this research are connected to people with mild learning difficulties being uncouneted (Cobham, 2020), whether in research, in policy discussions, in political debates or in wider public and media platforms. This hidden-ness is not entirely addressed by reference to the concepts of maldistribution or misrecognition. The obvious lack of political representation of people with learning difficulties is symptomatic of being overlooked, but their marginalisation is underpinned by epistemic injustice, in the sense that people with mild learning difficulties are not valued as "giver[s] of knowledge" (Fricker, 2009:5) and their experiences are "inadequately conceptualized and so ill-understood, perhaps even by the subjects themselves" (ibid, 2009:6).

These injustices relate to deeply rooted prejudices against people with cognitive impairments (Goodey, 2016) which underpin misrecognition. They expose the negative implications of binary and essentialist thinking about who is or is not disabled or impaired, which leave people with mild learning difficulties in a liminal position around the borders of these categories: sometimes deemed to be *not* disabled and therefore ineligible for support; sometimes accepted as disabled but as lacking sufficient individual merit and aspiration.

This thesis has documented how people with mild learning difficulties have faced an *increasingly* challenging environment, exacerbated by the years of austerity. Government claims that people are better off in paid work have been substantiated by maldistributive policy action to restrain social security benefits,

such as the benefit freeze (2015-2020) and the failure to up-rate legacy benefits (which long-term out-of-work claimants are more likely to receive) in line with UC during the Covid-19 lockdown. Claims about work as a route out of poverty are contradicted by evidence of in-work poverty, with more than half of those living in poverty being in a family where at least one person is in paid work (JRF, 2020).

The participants' stories have provided testament to social injustices related to the intensifying of conditionality within social security, the tightening of eligibility criteria for disability rights and support, and the rising precarity of the kinds of work that people with learning difficulties are likely to be directed towards by those offering employability support. They have been stories of injustices relating to a widening gap between provision and need, embedded within the structure of the social security system such that most are excluded from gaining paid employment, and the yawning gaps in support, income and respect experienced by those who have succeeded in engaging with the paid labour market. The injustices documented here are connected to shifts in 21st century western societies towards "an increasing polarisation in labour markets between a well-remunerated, high skills core and a large, hypercasualised, often part-time, low paid periphery" and undermining "twentieth century welfarist categories" (MacNicol, 2015:3) such as disability and unemployment.

The relationships between policy and experience discussed in this research frequently illustrate how "individualizing, victim-blaming discourses" mask structurally-produced injustices (Fraser, 2012:45). These injustices have been documented during a period of global economic expansion and falling headline unemployment. People with learning difficulties who are looking for work now face a new set of challenges in the era of Covid-19, including an expected sharp increase in unemployment and a deep recession, as well as the devastating impact of the pandemic on health and social care. There is a high risk that the unjust ways in which people with mild learning difficulties are treated by the welfare state and the injustices they experience in the labour market will be further exacerbated under these circumstances, with devastating consequences for their quality of life. These injustices are complex and multi-faceted.

Transformational change and redress is needed to address them, including recognition of the diversity of human experience rather than binary labelling; redistribution of resources through the welfare state on the basis of need, not

arbitrary calculations of deservingness; and collective action to defend the equal humanity of everyone in and out of paid work.

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Appendix 1 Research ethics approval



**University of
Nottingham**
UK | CHINA | MALAYSIA

**Faculty of Social Sciences
School of Sociology & Social
Policy**
University of Nottingham
University Park
Nottingham
NG7 2RD

16/06/2017

Reference: 135-16-17-PGR

Dear Ruth

Your application for ethical approval from the School of Sociology and Social Policy

On behalf of the Research Ethics Sub-Committee, I am pleased to confirm that your project "Working and unemployment: experiences of people with mild learning difficulties" has been reviewed and approved and you are now welcome to begin your data collection.

If you propose to make any amendments to the approved project or supporting documentation, you must first send details of the amendment along with any supporting documents to the Research Ethics generic email address, LQ-ResearchethicSSP@exmail.nottingham.ac.uk for approval. Please do not use any unapproved or amended documents or procedures before these have been reviewed and approved by the Ethics Sub-Committee.

If you have any queries during your project, please contact either the Research Ethics administration team or your academic supervisor(s).

Good luck with your project!

Kind regards

A handwritten signature in black ink, appearing to read 'Alison Mohr'.

Dr Alison Mohr
Research Ethics Sub-Committee Officer

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Appendix 2 Participant information sheet



Work and unemployment: experiences of people with mild learning difficulties

Information sheet for participants

What is the purpose of the research project? The purpose of the project is to find out about the experiences of people with mild learning difficulties. We are learning about their experiences of being unemployed and employed.

Why am I being asked to take part? You are being asked to take part in this project because you are an adult with mild learning difficulties who is in work, or looking for work, or will be looking for work soon.

Do I have to take part? No. You decide whether to take part or not. If you decide to take part, you can change your mind at any time. You do not have to give a reason for changing your mind. You will not be in any trouble if you decide to stop taking part at any stage.

Who is doing the project? Ruth Tarlo is doing the project as part of her university PhD study.

If I take part what will happen to personal information about me? Your name will not be shown in any reports of the project and people reading the project reports will not be able to tell it is about you. Any information you give Ruth will be kept securely. Any recordings of your voice or written record of what you say will be kept securely and only Ruth will listen to the full recording. Anyone listening to or reading clips of what you say will not be able to tell that it was you that said it.

What will happen if I choose to take part? If you do take part, Ruth will arrange at least 3 meetings with you. She will talk with you about your experiences of work, looking for work and being unemployed. You may like to take some photos on your phone about looking for work and talk about the photos. Ruth will not take or keep copies of any photos you take. If possible, Ruth would also like to spend time with you doing something related to work or looking for work, like visiting a jobcentre or a job club or going to work.

What are the benefits of taking part? You will not be paid for taking part in the project. You will get the chance to tell Ruth about your experiences and views, about what has gone well and what has gone badly. This may help others to understand more about what life is like for people with mild learning difficulties and what could be done to support people who are out of work.

Appendix 3 Participant consent form

**School of Sociology and Social Policy
University of Nottingham**

Participant Consent Form

Work and unemployment: experiences of people with mild learning difficulties

I sign this form to show that:

- | | | | | |
|---|-----|--------------------------|----|--------------------------|
| 1. I have read the Participant Information Sheet or someone else has read it to me. | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| 2. I understand what the research project is about | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| 3. I have had the chance to ask questions. | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| 4. I understand that I can choose to stop being part of the research project at any time. I do not have to give a reason and I will not be in any trouble if I decide to stop. | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| 5. I understand that the interview will be recorded using electronic voice recorder. | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| 6. I understand that recording of my interviews will be looked after and kept safe. Only the researcher will listen to the full recordings. Short clips from the recordings may be included in reports and presentations. People listening or reading will not be able to tell that the words are mine. | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| 7. I understand that any information I give is confidential (except see below). My name and other personal details will not be in any reports of the research. | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |

8. I understand that the researcher may have to report to social services any significant harm to a child, young person (up to the age of 18 years) or adult at risk, that she becomes aware of during the research. The researcher will not be able to keep confidentiality where there is harm to a child, young person or adult at risk. Yes ☐ No ☐
9. I agree that what I say in the interviews may be quoted in reports written about the research. These reports may be published. People reading the reports will not be able to tell that it was me that said it. Yes ☐ No ☐
10. I understand that I may contact the researcher if I need more information about the research. Yes ☐ No ☐
11. I agree to take part in this research project Yes ☐ No ☐

_____ My name (BLOCK CAPITAL)	_____ My signature	_____ Date
_____ Researcher's name (BLOCK CAPITAL)	_____ Researcher's signature	_____ Date

Appendix 4: Policy document sample (see Chapter 5)

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
Social justice and rights		
HMG (2012) Social justice: Transforming Lives	<p>Key legislative document on Conservative Social Justice Strategy. White Paper delivered under the Coalition Government by Secretary of State Iain Duncan Smith and strongly influenced by his thinktank, Centre for Social Justice.</p> <p>Covers five areas: families, young people, work, supporting the most disadvantaged adults, and policy/programme delivery.</p>	Refers to learning disabilities in list of disadvantages including mental health conditions, drug and alcohol dependence and homelessness (63)

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
DWP (2013e) Fulfilling Potential: Making it Happen	<p>Key Government statement on strategy for supporting disabled people</p> <p>The Coalition government's view of a society "where disabled people can realise their aspirations and fulfil their potential". Includes 'inspirational' stories of disabled people and their achievements.</p>	Mentioned in section on mentoring and advocacy services for offenders and ex-offenders "with learning disabilities and mental health conditions" (13)
HMG (2014) Think Autism	Only statement of policy specifically about Autism. Update produced by Coalition government, as required every 5 years under the 2009 Autism Act (enacted by New Labour government). Formal review of strategy was expected in 2019 but not published.	Throughout. Includes recognition of diverse ways that autism is experienced (e.g. "can often", "may also"), including communication difficulties, isolation, and hypersensitivity or lack of sensitivity

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism
DWP (2018a) Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland	Government response to the UN's first review of the impact of government policies on the rights of disabled people in the UK. This report was published one year later, giving time to reflect on recommendations, including recommendations on work and employment. Published during fieldwork.	Acknowledges need to take "learning or cognitive issues into account" when determining what is "appropriate and reasonable to expect claimants to do as "work-related activity" (19)
<i>Disability and Employment</i>		
DWP (2011) Specialist disability employment programmes	Policy statement marking shift in policy away from public provision of specialist disability employment services. Response to the Sayce Report (Sayce, 2011), which recommended closure of Remploy factories and removal of Remploy Employment Services from the public sector.	Only reference to learning disabilities is in relation to a claim that work is underway to increase take-up of Access to Work among under-represented groups and people (8)

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
DWP (2013g) The Disability and Health Employment Strategy: the discussion so far	Sets out government proposals for improving employment support for disabled people and those with health conditions	<p>In relation to Work Choice, that 28% of participants have a learning disability</p> <p>Recognises ‘extra support’ needed for some young people including those with “learning difficulties and hidden impairments such as autism” (29)</p> <p>Vocational pathway may be more attractive for people with learning disabilities (29)</p>
DWP (2014a) Disability Confident 1 year on: breaking down the barriers to employment	Review of Disability Confident progress (as communications campaign, see 2018b), before it became an accreditation scheme (see 2019a).	Claims a doubling of number of people with learning difficulty or disability completing apprenticeship in the last decade (3)
DWP (2015a) 2010 to 2015 Government Policy: employment	Summary of government policy during the coalition	None

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism
DWP & DoH (2017) Improving Lives: the future of work, health and disability	Key legislative statement on disability, unemployment and welfare reform. White Paper on disability, ill-health and employment, follows consultative Green Paper.	<p>“People with neurodiverse conditions, such as those with learning disabilities or autism” (9)</p> <p>Reports an employment rate of 24% for working age disabled people with a reported main health condition of a learning difficulty (from LFS Jun2016, as reported in the Green Paper)</p> <p>“poor employment outcomes for young people with learning disabilities can be the result of lower aspirations and inadequate support” (20)</p> <p>“the overwhelming majority of people with learning disabilities want to work and can work, with the right preparation, opportunities and support” (20)</p>

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
DWP (2015b) Equality Analysis for the Future of Access to Work	<p>Analyses impact of proposed changes to the main source of funding awards to disabled people in work, including impact of capping the size of “high-value awards” to increase number of awards</p> <p>Four biggest recipient groups by condition are: hearing, seeing, dyslexia and back/neck (55% in 2013/14).</p>	<p>There is a reference to “under-represented groups” of people with “hidden impairments.. including ..learning disabilities” in reference to the idea of capping and thereby being able to make more (but smaller) awards (10)</p>
WPC (2017) Disability Employment Gap: Government response	<p>Government response to review by the cross-party Work and Pensions Committee (WPC). Includes WPC recommendations and government response.</p>	None

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
DWP (2018b) Response to WPC re Disability Confident	<p>Overview of Disability Confident as accreditation scheme.</p> <p>Letter from the Minister for Disabled People, Health & Work to WPC chair about Disability Confident. Clarifies that DC was formally launched in November 2016 and was previously only a communications campaign.</p>	None

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
DWP (2019a) Disability Confident Aims and Objectives	Key statement of DC Aims and Objectives, originally published in 2015 and updated in 2019.	None
DWP (2019b) Employing disabled people and people with health conditions	<p>The most comprehensive statement, within the DC documents, of guidance for employers to increase understanding and “enable” recruitment and support.</p> <p>Published in 2013 and updated 18 times between 2013 and 2019.</p>	<p>Provides advice on “hidden impairments” including “autistic spectrum conditions”(9), ADHD (p10) and learning disabilities (11)</p> <p>“Many people with a learning disability are in work and with the right support can be hard-working and reliable employees.” (11) Suggests some adjustments to recruitment practices, in-work support and presentation of information.</p>

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
<i>Unemployment-related social security</i>		
DWP (2012b) Universal Credit Impact Assessment	<p>Government assessment of impact of flagship change to work- and unemployment-related social security benefits during period.</p> <p>Produced during Coalition Government, as required under the Equality Duty, in relation to the Welfare Reform Act 2012</p>	None

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
DWP (2013a) Government Response to the House of Commons Work and Pensions Select Committee's third report of Session 2012-13 Universal Credit implementation – meeting the needs of vulnerable claimants	<p>Statement of government position on concerns about Universal Credit and claimants with complex needs.</p> <p>Response to a report from the Committee highlighting concerns about claimants with complex needs, such as people with disabilities, homeless people and those that struggle to manage their finances</p>	None
DWP (2014b) ESA and Work Capability Assessments: response to the Work and Pensions Committee	Coalition Government response to a report from the WPC which includes a call for a fundamental redesign of the assessment process. This is largely ignored.	Rejects WPC recommendation for more responsiveness to “those with mental, cognitive and behavioural difficulties” (30)

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
DWP (2015c) Government response to the Work Capability Assessment (WCA) independent review year 5	Government response to the fifth and final of a series of reviews by independent advisers to DWP. Produced under the Coalition government. The report closest to the fieldwork period.	<p>“better support for people with learning disabilities” noted as an area for further exploration (4)</p> <p>Learning disabilities referenced in relation to improving communications materials about WCA including Easy Read formats (17)</p> <p>New provider has plans for more “assessors with detailed knowledge of specific health conditions such as learning disabilities” (18)</p> <p>Unspecified plans to “explore” “the best form of support” for “young people with learning disabilities” who are leaving education (22).</p>

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
DWP (2015d) 2010 to 2015 government policy: welfare reform	Summary of 'welfare reform' measures enacted under the Coalition	None
DWP (2015e) Welfare Reform and Work Bill: Impact Assessment to remove the ESA Work-Related Activity Component and the UC Limited Capability for Work Element for New Claims	<p>Government impact assessment of cut to additional support for out-of-work benefit claimants in ESA WRAG (and equivalent under UC).</p> <p>New claimants lost a supplement of £29 a week, reducing their benefit to the same level as JSA (£73.10 a week).</p>	None
DWP (2017a) Government response: SSAC report on decision making and mandatory reconsideration	Government statement on benefit claim decision making by DWP, responding to report raising concerns about the decision-making process and the high level of (often successful) appeals.	None

Document Title	Reason for inclusion and brief description	References to learning difficulties, learning disabilities or autism (page)
DWP (2017b) Penalties for social security fraud and error	Policy statement on the handling of fraud investigations and enforcement actions.	None
DWP (2018c) Universal Credit programme full Business Case summary	<p>Government statement of the business case for UC, the flagship policy reform of social security during the period.</p> <p>Published after the full business case was approved by the Treasury.</p>	None