

The (Un)Intended Consequences of Employment Policy for People with Learning Disabilities

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Dedication

I dedicate this thesis to my Mum, Wendy. Some 20 years ago, you told me that I was a perpetual student – how insightful you are. Never did I expect to be where I am now, but I would not be here without your faith in me, and your love and support. I also dedicate this thesis to my children, Harriet, and Ned – for your sunshine, smiles, inquisitive minds, inspiration, and cwtches.

Preface

Part of this thesis has been presented in the following publications:

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Summary

People with a learning disability, who are in receipt of social care, often have a precarious relationship with paid work – less than 6% of working-aged people within this demographic are in any form of employment. In a society that privileges ‘productivity’, employment can recast individuals into a role that holds value and meaning. The ‘welfare-to-work’ policies for learning-disabled people follow a similar trajectory to mainstream policy that locates the barriers to employment with the individual and specialist work programmes prioritise those who have a mild/borderline learning disability. However, little research captures the experiences of people who wish to engage with work who have a more complex diagnosis.

This thesis is based on ethnographic research from a community organisation that responded to the underserving of work preparation support for people with higher forms of interdependent need. Additionally, three further sites of data collection complement the ethnographic study. Together, this research explores not only the impact of paid work on the lives of people with learning disabilities, but also the complex, persistent and prevalent barriers to employment inclusion. In doing so, this thesis unpacks the nuanced, multifaceted reality of everyday life for learning-disabled people struggling to access paid work.

Further, when employment and learning disability policy is scrutinised with my empirical analysis, this research exposes a central paradox between ability, expectations, and realistic job prospects. Consequently, structural job discrimination and unconventional experiences of work that falls short of national minimum wage legislation are commonplace. Yet, more subtly, ethical and moral considerations of value and worth are brought to the fore. As such, much of this thesis considers the grey, blurred lines, challenging not only the conceptualisation of what work is but also how it is rewarded, when faced with tension within the broader labour market structures of how employment is organised.

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Chapter 1

Introduction

This study explores the relationship that some people with a learning disability have with work preparation and employment. Research presented in this thesis includes an ethnography, drawn from a newly funded job club set up by a third sector care provider in England. To complement these data, three further research sites in Wales strengthen the study to demonstrate how people with a learning disability, who are in receipt of social care, are underserved by employment policy, and how this is prevalent across geographical boundaries. Further, this study sketches out some of the consequences of employment exclusion. As such, much of this thesis engages with the blurred lines of what work is, and how it is rewarded, which, as the discussion presented next demonstrates, is nuanced and contextual.

During the 2019 election campaign, Sally-Ann Hart, a Conservative candidate in the Hastings and Rye constituency, was heckled by the crowd at a constituency hustings, for suggesting that people with learning disabilities should be able to earn less than the minimum wage, because, ‘they do not understand money’ (Busby 2019). When challenged, Hart responded to the crowd that, instead of focusing on the financial gain of work, it was, ‘about them being given the opportunity to work because it’s to do with the happiness they have about working’ (Busby 2019). In response, the Labour Shadow Disabilities Minister, Marsha de Cordova, branded the comments as ‘hateful’, suggesting that anyone with such views had ‘no place in Parliament’ (Stone 2019). Moreover, Ciara Lawrence, a Campaign Support Officer with Mencap, commented:

People with a learning disability, like me, can work and make really fantastic employees with the right support. We have the right to be treated and paid equally – it’s the law. I’m proof that... all is needed is for employers to make small and cost-effective reasonable adjustments in the workplace to open up doors to employment for people with a learning disability’ (Stone 2019).

While Lawrence and de Cordova adopt a response that reinforces equality for all, less than 6% of working-age adults with a learning disability, who are in receipt of social care, have any form of employment. As such, discrepancies are exposed on both how to increase the prevalence of employment inclusion for people within this demographic, and also, to consider the multifaceted experiences that are experienced by people with learning disabilities themselves. While the position adopted by Hart (Busby 2019) may be considered 'hateful', it does shine a light on an underexplored area of research – that is, what is the relationship between people with learning disabilities, and employment?

Before I delve into this with reference to my research, it is essential to consider the definitions at play within a health and social care context and, also, to sketch out the contemporary landscape for learning-disabled people and their relationship with employment. Unpacking such notions holds historical ramifications that are still relevant today and, consequently, broader considerations of social exclusion and marginality must be contextualised. Indeed, it is a little over 100 years, since learning-disabled people were perceived to be a threat to society and segregated by institutionalisation and asylums (Mental Deficiency Act 1913).

During this period of segregation, individuals in this demographic were considered not to be a responsible citizen, and their welfare was transferred to the state. Moreover, with the fear of 'feeble-mindedness' being hereditary, population control was restricted to prohibit the 'unfit' from procreating. Terms such as idiot, imbecile, and morally defectives, all derived from the medical model of disability, and the influence of the eugenics movement, dominated the discrimination and social exclusion of the learning disability story for much of the twentieth century (Atkinson and Walmsley 2010; Williams 2013).

Moreover, de-institutionalisation began in the 1970s and it has been a key feature globally within learning disability policy. A significant feature of this, driven by a humane ideology to fight back against institutionalisation, has been the model of 'normalisation', whereby people with a learning disability were encouraged to distance themselves from others who have a stigmatised identity and, instead, mix with those considered to be socially valued (Wolfensberger

1983). Services that supported people with a learning disability began to adopt the 'five accomplishments' approach, addressing the complex issues of: community presence; relationships; choice; competence, and; respect to people who had historically experienced such marginalisation (Brown and Smith 1992), all within a normalisation framework.

Early in the twenty-first century, government policy shifted towards personalisation (Department of Health 2001; 2009). At the heart of these ideas is choice, control, and independence being exerted, over one's own life. The Disability Rights Commission defined this model of independent living as 'having the same choice, control, and freedom as any other citizen – at home, at work, and as members of the community' (Morris 2005:4). Fundamentally, then, this policy direction is about getting the right support to be included in everyday interactions. To achieve this, social care intended to shift from being crisis-driven and bureaucratic, to instead, acting to prevent crisis, personalise services, and empower citizens to shape their own lives (Williams 2013).

In contrast to these notions of autonomy, however, Ryan (2019) sketches out a bleak picture of contemporary life for disabled people in the twenty-first century. Characterised by financial insecurity, precarious and unsuitable living arrangements, and crisis responses to health and social inequality, she explores how the last decade has decimated much of the progress that had emerged before austerity policy measures took hold in the UK. Ryan (2019) draws upon interview material that captures some of the wide-ranging impacts of disabled precarity and explores the consequences of such measurements. Examples of 'David-and-Goliath' (p. 189) legal challenges against local authority service cuts are prevalent. One mother explained how she fought for a learning disability diagnosis for her child, Louis, with the expectation that educational support would be offered in response, to then find that there was no service provision available, even with such diagnosis. Concerned that with no educational provision and little hope of securing any qualifications, disadvantage would likely be a fixed feature of her child's life. Ryan (2019 p. 190) sums up some of the experiences presented here:

Louis's generation of disabled children are in many ways experiencing the sharpest end of what I would call the equality myth. In some ways, they are at a significant advantage compared with previous generations: where it was once culturally expected – and entirely legal – to segregate or exclude disabled people from education, jobs or transport, a disabled child growing up today does so in a Britain that largely tells them they are treated equally. But this increasingly feels like a cruel false promise, one that on paper dangles unprecedented opportunity and independence [...] but in reality overseas policies that are regressively pulling back their rights and life chances.

While Ryan draws upon a narrative approach to expose such inequalities, Hatton provides rich commentary and statistical analysis focused on people with a learning disability, particularly regarding inequality over the life course (including, but not exclusive: The Learning Disability Observatory 2015; Emerson et al. 2016; Glover et al. 2016; Flynn et al. 2017; Hatton et al. 2017; Emerson et al. 2018 James et al. 2018; Kaley et al. 2018). People in England die on average 15-20 years earlier if they have a learning disability, in comparison to the non-learning-disabled population. Further, people with a learning disability are more likely to develop unhealthy habits and addictions and are more likely to experience a whole range of diversities linked to poor health: poor housing, hardship, poverty, discrimination, social isolation, crime, restricted social and intimate relationships and employment (Hatton 2016a). Yet, a learning disability in itself is not a health condition. Rather, much of the difference in health between people with and without a learning disability can be accounted for by the greater adversities experienced by people with a learning disability (Hatton 2016a).

With such extreme inequality being experienced by the learning-disabled community more broadly, it is difficult to reconcile how, in the context of employment, people within this demographic would be welcomed into mainstream work, which was the solution offered by Lawrence in her response to Hart's suggestion of paying people with a learning disability a wage lower than

the national minimum wage (Stone 2019). Both sides of this argument push for employment inclusion, however, such a dichotomy simplifies an ever-complex landscape characterised by modes of exclusion. While the aspirations of Lawrence are similar to the position of the Disability Rights Commission (Morris 2005) who strives for choice, control, and the freedom experienced by any other citizen, including in the workplace, this brief section has captured how this situation is more complex and nuanced than the positive tone offered by policy and employment ambassadors.

The clash between the perspectives of Hart, the constituency candidate who suggested people with learning disabilities could earn less than the minimum wage, and de Cordova, the then Labour Shadow Disabilities Minister, highlights the conflicting tension on how best to support people with a learning disability into work. Caught within this friction, however, are the people with a learning disability themselves, who are an underrepresented voice in the debate on their bleak relationship with work. With little empirical sense of how this is experienced and dealt with by the individuals themselves, this study aims to explore the complexities associated with having a learning disability identity in everyday life, with a focus on accessing employment support. To do this, however, it is important to define both what a learning disability is, and what the current state of employment inclusion looks like, in England and Wales.

Terminology and definitions

According to the National Health Service, a learning disability (LD) ‘affects the way a person learns new things throughout their lifetime’. This can mean difficulty understanding new or complex information, learning new skills, or coping independently (NHS 2018). The cause of a learning disability can sometimes be unknown, or, it could be from a lack of oxygen getting to the brain during birth; inheriting certain genes from parents; illness, or injury in childhood (NHS 2018). Brain development is affected either before or during birth or in early childhood.¹ Around 30% of people with epilepsy have an LD and people with autism may have some kind of LD. According to the NHS (2018), everyone

¹ A learning disability can only occur in childhood (under 18). For post 18, the condition would be described as an acquired brain injury.

with Down's syndrome has some kind of learning disability, and so do many people with cerebral palsy.

Traditionally, notions of intellect underpinned an LD diagnosis, through intelligence quotient (IQ) norm-based tests. People with a severe LD would have had an IQ score of 50 or below, while a moderate LD would be scored between 50 and 69. These categorisations still linger within the health and social care sector (Williams 2013). While there are now no clear lines of IQ testing to divide the categorisation of LD level, the current terms are offered as a continuum between the grouping of mild, moderate, severe, and profound LD (BILD 2018). For people who have a moderate LD (the demographic of the participants in this study), people are likely to have the language skills to communicate some day to day needs and wishes and may be able to care for themselves, with support, in tasks. Yet, they are likely to need help with understanding complex ideas and will generally need help with practical tasks such as filling out forms and budgeting (BILD 2018).

A more nuanced understanding of LD is offered by the People First Movement. Subscribing to the social model of disability, the terminology discourse of learning disability is rejected, for it is perceived to be a label put on people to mark them out as not being able to understand the same things as others. As one self-advocate remarked, the term was:

‘given to us by other people – by those people who diagnosed us. We know we’ve got this problem, seeing, speaking, understanding – but it doesn’t mean we have to have this label on our forehead’
(cited in Williams 2013: 14).

Instead, the People First Movement prefers the term learning difficulty over disability, to reflect how learning and support needs fluctuate over time, situation, and context (Mansell 2010). Yet this term is contested. In the UK, ‘learning difficulty’ also includes people who have specific learning difficulties such as dyslexia, but do not have an impairment of intelligence (Department for Education and Department of Health 2015). The term LD, then, required

avoidance within this thesis to avoid confusion with additional learning needs alone.

Globally, the terms intellectual disability and mental retardation are both more commonly accepted, with intellectual disability, in particular, recognised internationally (Johnson and Walmsley 2010). My personal position here rejects the term mental retardation due to its negative connotations with the medical model of disability. For the purpose of this thesis, and similar to the stance offered by Johnson and Walmsley (2010), while uncomfortable with the label, I too, will adopt the term intellectual disability (ID). While labels are problematic and they can be a source of devaluing individuals, labels can also act as a mechanism to address the specific needs of a particular population (Johnson and Walmsley 2010).

The state of employment in England and Wales

Employment statistics in England for working aged people with an ID, who are in receipt of social care peaked in 2011/12 (7%) (Learning Disabilities Observatory 2015) and has steadily declined to 5.2% (Hatton 2017). However, there are huge disparities in the reporting of employment rates between local authorities. For instance, Bexley reports a 20.6% employment rate, while Lamberth is just 0.6%. Hartlepool cites a rate of 15.2%, while South Tyneside report employment rates of 1.2%. Reflecting on these disproportions, Hatton (2017) suggests that this could be for either of two reasons: either there are different practices of supporting people into employment at play, or, the reporting practices across councils are non-standard and inadequate.

Further, in 2015/16, local authorities reported that the employment status of over one-third (37.7%) of working-age adults with an ID that are in receipt of social care was 'unknown' (Hatton 2017). Hatton remarks that, the sheer volume of people receiving long term support from local authorities (LAs) who do not know whether they are in or actively looking for work, may well indicate the priorities when it comes to employment (Hatton 2016b).

In Wales, the Employability Plan (Welsh Government 2018a) broadly recognises and accepts that it is the responsibility of Government to prepare people for

work, while also developing a plan to remove the barriers that may stop individuals from doing so, not simply through a narrow concept of employment for financial security, but also to contribute to society. However, for people with an ID, there is little statistical evidence of the employment rates. In the recent key policy Improving Lives document (Welsh Government 2018b), there are disparities with employment priorities within different stakeholder groups. Stakeholders were asked to offer their five priorities for the future. People with a learning disability prioritised having a job as fourth (below having friends, having their own front door, and securing appropriate transport). Parents and carers also ranked employment fourth (below funding, housing, and transitions). Yet, sector professionals did not rank employment for people with a learning disability as a priority. Rather, funding, data definitions, commissioning, healthcare, and workforce were their key issues to address. Overall, the desired outcome of this policy is to 'increase planning and opportunities for people with a learning disability through strengthening of career pathways' (Welsh Government: 22), with a recommendation to explore paid supported work placements.

Looking to the future, Emerson et al. (2012) made population projections suggesting that, over the next 20 years, even if LAs only continue to offer support to those people with 'critical' or 'substantial' need, there is likely to be an increase of around 2% per year requiring support. By 2023, this is likely to be an increase of around 50% in the number of people who needed social services support from 2012 (Hatton 2015). Figure 1 illustrates these projections.

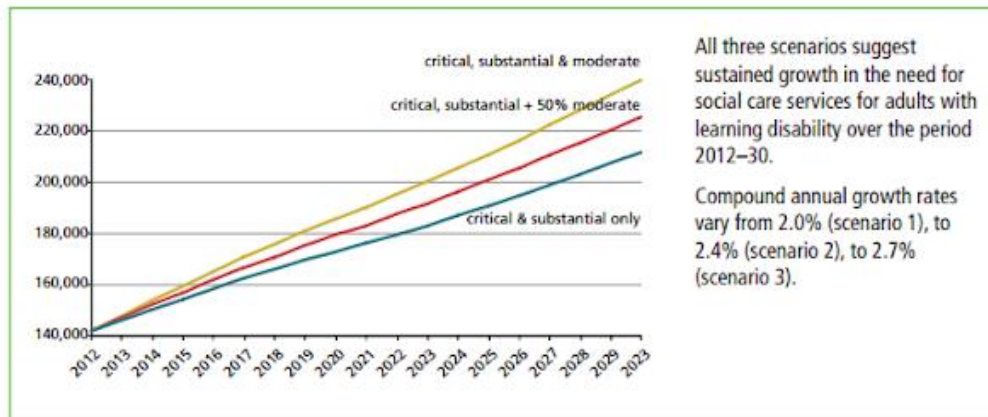


Figure 1. Estimated number of users of adult social care with a learning disability 2012-2030 (Hatton 2015).

The state of the employment landscape in both England and Wales for people with an ID who are in receipt of social care, is, I argue, rather bleak. I also suggest, by outlining the wider landscape of employment provision for learning-disabled individuals, how this is not only an under-researched area, but how there are contemporary clashes in how to proceed within policy – to increase the prevalence of people with an ID within the working population.

This study

My study unpacks the mundane, everyday experiences that occur at a job club specifically established to support people with an ID to engage with employment preparation, within its context of the historical ID backstory experiences. These interactions are largely drawn from ethnographic methods, as an active participant in the field. However, this study also has a political purpose, by contributing to research on social change, and, as such, my theoretical allegiance with ethnography is partial and fluid. This is particularly apparent in two ways.

First, vignettes drawn from raw data are plentiful throughout the empirical chapters. This advocacy/critical ethnographical point of departure differs from its conventional premise. Here, I have privileged the voice and experience of the participants, who have been silenced so often, to share their stories and experiences. As such, unless otherwise identified, data are presented as verbatim directly from individual participants. Consequently, it is often presented as grammatically incorrect. Secondly, my ethnographic study is complemented by

other qualitative research evidence. Both interviews and focus groups offer additional context to demonstrate that the experiences at the site of the ethnography – as a single job club – is not isolated. Rather, the experiences offered here are also prevalent across different geographical locations.

Combining the sensibilities of an ethnographic nature, together with perspectives from three other data collection sites, offered a distinct opportunity to analyse the social – that is, how people with an ID, that are in receipt of social care, experience employment activation policy. This research also allowed space to consider what work means to people who have an ID, and how this constructed meaning of work, plays out in the everyday. Finally, space is afforded to consider some alternatives to the current employment trajectory.

However, to do this, one theoretical framework, from a single discipline, could not adequately manage the complexity of the data. To try and achieve this would significantly restrict the analysis of the multifaceted reality of the everyday experiences of learning-disabled people. As such, to make sense of these experiences, my study is intentionally interdisciplinary, drawing upon ideas and concepts rooted in disciplines including critical disability studies, medical sociology, social policy, citizenship, and, employment literature. Drawing on a wide range of theoretical tools, including interactionist and conflict theory with their differing foundations, has offered a comprehensive account of a complex, nuanced, and context-dependent position. As this thesis progresses, what will become evident, is that people with a learning disability are not sharing in any general improvements within the labour market (rather, as these statistics suggest, the reverse is happening).

Thesis structure

Chapter two considers the background in which my research operates, namely, the broader context of ID and the history of exclusion and marginalisation. The tensions held within models of normalisation, as a route to re-include people in society, will be explored and contextualised through discussions centred on the contemporary landscape of ID policy. This chapter also engages with debates on the conceptualisation of disability more broadly, by considering the social and

medical models of disability, critical disability studies, medical sociology, and embodiment.

Chapter three offers a literature review based on the landscape of employment activation. Here, active labour market policies are connected to concepts of citizenship and expose how the 'welfare-to-work' trajectory is problematic for people who are excluded from both mainstream and targeted employment policy and support. These debates are contextualised more broadly, by affording attention to the move towards welfare conditionality and the transfer from Incapacity Benefit, to Employment Support Allowance (ESA). Moreover, this chapter considers how, academic literature on employment for people with an ID has little sociological engagement in the normative associations of work being good for us. Further, this chapter sketches out, through critical analysis, how academic literature has cited supported employment as the *best* route to paid work, for everyone with an ID, when instead, these models are underserving people with more complex barriers to engaging with employment. These two chapters, then, justify my empirical research, by exposing how the employment landscape for people with an ID is complex, nuanced and worthy of further exploration.

Chapter four sketches out my methodology. I lay out my justification for not utilising 'inclusive' research methods, ordinarily perceived as the 'gold standard' within the ID research field. For, while inclusive methods, such as co-researcher design, draw on a participatory paradigm that challenges the role of participants being subjects, I argue that such benefits are limited for this specific study. Rather, I sketch out how, to explore the everyday experiences of employment preparation, ethnographic research methods were instead, deployed. As such, this study has been able to yield a depth of data that I argue, was only possible through prolonged ethnographic methods.

Further, this chapter explores how access was negotiated to the ethnographic site, the job club. Managed by Green Meadow, the job club was in its infancy when my research began, having been set up using fundraised income.² In addition,

² Pseudonyms are used for all research sites and participants.

interviews and focus groups were deployed at three sites: The Roasted Bean, a small community café that offered work to people with an ID; Power, a Community Investment Company specialising in knowledge exchange, and, finally; broader contextual insights were offered from Bob, who worked with young adults with an ID who were aiming to secure employment. These additional data sites provide a broader context, one that exposes how the experiences offered at Green Meadow are not site-specific, but rather are prevalent more broadly within the ID community. Data analysis is also considered, and ethical considerations are attended to. Here, I have reflected on the insider/outsider dichotomy and, how vigilance was practiced in the field.

Chapter five presents the first of five empirical chapters. Here, experiences from the field are connected to employment activation policy. The participants that attended Green Meadow's job club were all in receipt of Employment Support Allowance and categorised to the Work-Related Activity Group. This means that they were not expected to engage with employment preparation and there was no attached work-related conditionality applied to their welfare support. Yet, when individuals here 'chose' to engage with such preparation, this was, at times, focused on seeking routes to increase levels of productivity. When the expectations of formal employment did not match up with ability, morally ambiguous practices, such as individuals working similar roles to their paid, non-disabled counterparts, were evident.

Chapter six draws on the first theoretical concept considered in my empirical work. In this chapter, data are analysed through Goffman's (1952) lens of 'cooling the mark', to expose how people who have been activated to seek employment are, instead, offered unpaid work as a substitute. In this context, paid work is presented as a 'con', self-perception is altered, and unpaid (or barely paid) work is offered as an alternative for the 'over-ambitious'. Moreover, this alternative solution is extended by Clark's (1960) interpretation of Goffman's framework, by exploring the concepts analytical power to analyse the tension between 'open-door' policies and its discrepancy with success. For, as my work shows, not everyone can succeed, and failure is often inevitable.

Chapter seven introduces a theoretical analysis framed by Berlant's 'cruel optimism' (2011). This chapter sketches out how, rather than a route to the 'good life', work can, instead, constitute a cruel fallacy that stops people flourishing. These considerations are more widely connected to neoliberal capitalism (Brown et al. 2011), whereby we are conditioned to believe that, if we work hard enough, we will achieve our dreams by reaching 'personal fulfilment and happiness' (Berlant 2011: 13). Yet, everyday reality paints a very different picture. This is captured through exploring the tension and interplay between individual agency and personal employment barriers, with structural and hierarchical labour market arrangements ensuring that only certain people 'belong'. Here, the work landscape exposes morally dubious work-like situations, where people are exposed to methods of exploitation, in the hope of one day being paid for their work.

Both chapters six and seven expose a contextual understanding of what constitutes work. Within this context, work is often constructed as something different from normative expectations, for example, not meeting the national minimum wage legislation thresholds. As such, chapter eight digs deep into exploring the employment motivations of, and the pressure applied to, individual job seekers to find work. Moreover, this chapter attends to some of the complex notions associated with different types of work. For instance, prolonged volunteering can act as a form of exploitation and is in tension with employment protection measures, such as the national minimum wage. Here, moral and ethical questions of work practices are connected to both third sector and profit-making companies.

The final empirical chapter is presented in chapter nine. While still empirical, it presents a broader space to consider the future trajectory of employment policy. As such, this chapter holds to account how employment policy landscapes will continue to perpetuate employment (in)exclusion. Moreover, alternative perspectives and approaches to employment activation are explored, which can offer people an opportunity to craft an identity away from mainstream models of employment activation. These models prioritise and cherish *contribution* over *productivity* and in this space, individuals can flourish and enjoy the positive

aspects that work can offer. However, this is not without tension. To enjoy such accommodations and alternative work arrangements, the issues inherently associated with the national minimum wage are again, continually, at play.

Chapter ten concludes the thesis by echoing the previous findings and their importance for consideration in employment policy and disability studies alike. As such, this chapter sums up how people with an ID themselves experience employment (in)exclusion and how, in this context, individuals are caught in a paradoxical position of needing to 'prove' dis(ability) for support and financial assistance, yet need to articulate ability to enter the job market. Moreover, in this final chapter, I also articulate my academic contributions of the project and offer suggestions on potential ways forward by identifying future areas of study that this thesis contributes towards.

Taken together, the empirical chapters presented here, share a story – a story often shaped by disappointment, rejection, and individualised failure, where people are blamed for the (unemployed) situation that they find themselves in. The stories sketched out, expose a very different experience of employment activation. With undertones of exploitation and questions of moral and ethical values brought to the fore, heated debates are the crux of this thesis, in considering how learning-disabled people are in/excluded within the conceptualisation of work and how this manifests in the lived realities of people with a learning disability in Britain today.

Chapter 2

Contours, contradictions, and the paradox of intellectual disability

‘To contemplate disability is to consider a politicised phenomenon framed by precarity, crisis and uncertainty’

(Jones 2018)

The overarching aim of this chapter is to highlight the background in which my research operates. This thesis cannot ignore the broader context of intellectual disability (ID) exclusion, marginalisation, and historical discourse. Nor can it ignore the contemporary position in which my research is located. Therefore, I will first provide an overview of the historical policy, practice, and *treatment* of people with an ID, which placed people within a devalued role in society. Next, three key approaches to disability studies will be explored. First, drawing on Goffman (1959; 1961; 1963) and Wolfensberger (1969; 1971; 1983) offers a theoretical lens to explore and contextualise the historical and contemporary position experienced by people with an ID and their relationship with occupying socially diminished roles. These discussions are then situated within a disability framework, whereby authors located in critical disability studies and medical sociology convey their varying perspectives on disability, while concepts associated with embodiment attempt to connect and reconcile some of these differences. This chapter, then, provides the contextual background to the subsequent chapter, which scopes out the specifics of employment activation for people with an ID.

The contours of intellectual disability

Discrimination and social exclusion have characterised the history of people with an ID for most of the twentieth century. The medical understanding of disability, together with the eugenics movement, played a crucial role in the construction of a negative societal stereotype of people with an ID (Atkinson and Walmsley 2010). Defined as ‘the science of improving the inherited stock, not

only by judicious matings, but by all other influences' (Galton [D] 1998: 263), the term eugenics is traced back to the ancient Greeks (eu- good, well; gen- genesis, creation) (Galton [D] 1998), where any children born defective would be 'hidden away' (p. 264). The eugenics movement believed feeble-mindedness was hereditary and 'mental defectives' had uncontrollable urges and degenerative characteristics that were a threat to society (Stefansdottir and Trastadttir 2015).

While the focus of eugenics in Eastern European countries was centred on the discourses of race (Porter 1999), countries including Denmark, Switzerland, Germany, Norway, Sweden, and North America all enacted compulsory mass sterilization of women with ID's during the 1920s, and up until the 1970s and 1980s (Galton [D] 1998). Moreover, in the United States, sterilization laws were introduced to prevent the 'insane, those suffering from epilepsy, and the feeble-minded' from reproducing (p. 266).

In Britain, the eugenics movement focused on social improvement by restricting the 'unfit' to procreate. The categorisation of who was 'unfit' was defined in terms of social status and deviant behaviour. This included people who had traits believed to be 'inborn errors of metabolism' such as 'mental retardation' (Porter 1991: 148). The movement was supported by key figures from across the political spectrum – for instance, William Beveridge [1879-1863], a progressive liberal economist and social reformer who was an authority on unemployment insurance, was a key advocate (Porter 1999). Author of the 'Social Insurance and Allied Services' (1942), Beveridge's report served as the basis for the post World War two welfare state (Macnicol 1989; Shearmur 2013). It is important to note, therefore, his personal world view and how the terminology and stance presented by Beveridge became the key driver in the institutionalisation of people with an ID over the last century. Other supporters included Winston Churchill [Prime Minister 1940-1945] and the economist John Maynard Keynes who served as the Vice President of the British Eugenics Society [1939-1946]. Keynes exerted an influence unrivalled in the history of economics, yet his theories of eugenics have been much neglected. These eugenic ideas deeply influenced some of his most enduring economic contributions and were threaded throughout his scholarship, whereby his eugenicist principles directly

influenced his beliefs towards unemployment and population control (Magness and Hernandes 2017).

With limited success in Britain, eugenicists concentrated their efforts to influence social policy and, in particular, the care of the mentally deficient. Here, their influence on the eugenics rhetoric within the classification and management of the feeble-minded was significant (MacNicol 1989). In 1913, the Mental Deficiency Act was passed by a political majority who agreed that the mentally deficient needed specialised care and that, because of their deficiency, they lay outside the parameters of being a responsible citizen (Macnicol 1989). Therefore, the control and welfare of people with an ID was undertaken by the state (Porter 1999) – the results of which are still evident today.³ Moreover, the legacy of the professional, medical community being legitimised, with their scientific data and concepts of ‘non-ideal status’ (Davis 1995: 29) redefined what ‘should be’ (p. 34) by ranking people in orders of curves and normal distributions, with a new kind of ideal being created.

Within the broader disability movement, the social model of disability emerged to challenge the medical model, particularly through the People First Movement and disabled-led organisations. A detailed discussion of the social model of disability will be presented in the latter part of this chapter. Yet for here, it is important to reference how, a lack of commonality between people with a physical disability and people with an ID, allowed space for normalisation to thrive.

Tensions with the social model of disability

Considered to be one of the founding fathers of disability studies (Mathews 2017), Wolfensberger [1934-2011] showed a particular interest in people with

³ ‘Transforming Care: A national response to the Winterbourne View Hospital’ (Department of Health 2012) called for people to be moved from institutional care and into community settings, rather than being held in inappropriate Assessment and Treatment Units (ATU’s) for prolonged periods. The report explicitly stated, ‘everyone inappropriately in hospital will move to community-based support as quickly as possible and no later than 1 June 2014’ (p.9). However, data obtained by Radio 4 (Adams 2018) revealed that, of the 3,400 people in ATU’s in 2012, the numbers were still broadly stable in 2018. Moreover, 665 people in England (no data available for Wales) were still in hospital after assessments had been completed, with the average time spent in one currently being 5 years (Flynn 2018), where over a third of ‘patients’ are placed over 50km from their family (Trojensen 2015).

an ID (see 1969; 1971; 1983 amongst others). His ideas have had a direct influence on the formulation of social policy in the Global North (Jones et al. 2016) and his presence continues to be found within contemporary disability studies (Mathews 2017). The central thread to Wolfensberger's scholarship was the importance of deviancy in his thinking. His definition of a 'deviant' was someone who 'is perceived as being significantly different from others in some aspect that is considered of relative importance, and this difference is negatively valued' (1972: 13).

Wolfensberger argued that the social construction of labelling was contentious because it does not imply that there is any conscious intention on the part of the individual to try and be different or deviant. Instead, the label of deviance is applied *onto* the individual by those around them, based upon their perceived difference. Furthermore, this perceived difference resulted in adverse consequences, such as isolation, persecution, and stigma (Wolfensberger 1983). Within this line of thought, Wolfensberger drew upon Goffman's theoretical contributions (1961; 1963). While work produced by Goffman will be drawn upon in detail in chapter six, it is an appropriate opportunity here to align the framework of critical thinking of Goffman and Wolfensberger, in their theorising of the regimes associated with life within total institutions and exposing disparities in power and a lack of common humanity (Mathers 2017). In particular, the limits to Goffman's work need to be acknowledged.

Goffman transformed the concept of stigma, defined as 'the situation of the individual who is disqualified from full social acceptance' (1963: 9) into a 'remarkable organising concept' (Hacking 2004: 18) to classify and understand an array of derogatory and discriminating social attitudes (Tyler 2018). Goffman claimed that as a perspective, stigma is 'generated in social contexts' (1963: 138) which is historically specific in its forms and has a key function in its use as a 'means of formal social control' (p 139). His insights strengthened the argument for the closure of long-stay institutions. Yet, Kusow (2004) critiques his position, suggesting that while concepts of stigma offered by Goffman provided a 'powerful analytical category for understanding how stigmatised individuals manage the everyday problems attached to their spoiled identities, his treatment

does not go far beyond the issues of identity management' (p 195). Moreover, Tyler (2018; 2020) exposes how research around stigma often side-lines both the production of stigma and its purpose whereby there is little space left to challenge or transform social norms. Mathews (2017) concurrently suggests that Goffman's examination of the status quo offered no dynamic theoretical framework.

In contrast, though, Mathews (2017) suggests that the theorisation offered by Wolfensberger, did have a dynamic effect, through the principles of 'normalisation'. As a conflict theorist (Thomas 2007), Wolfensberger (1983) argued that when people form collectives, it is at the expense of those who are automatically excluded from the social group, who are often perceived to be different or deviant. Applying this notion to people with an ID, he identified that, with the inherent characteristics associated with particular historic roles, people with an ID could never lead fulfilled lives, unless they were integrated within 'mainstream' society. His concept of normalisation promoted and encouraged people with an ID to mix with socially valued people and to distance themselves from Other people who have a stigmatised identity (Wolfensberger 1983).

Wolfensberger devised a typology in which he sought to historically position how disabled people, and in particular those with an ID, have been perceived and stigmatised by wider society (1983). To do this, he referred to what Morton (1948) termed as the 'self-fulfilling prophecy', whereby people with certain conditions adopt the behaviours or actions of others, further validating difference within the community (Wolfensberger 1983). These roles include the deviant being perceived as a subhuman organism (not fully human) and stripped of their human attributes, which systematically leads to the withdrawal of rights and privileges. Other roles include the deviant perceived as a menace (with an inherent badness); an object of pity (to be patronised, deserving of help, yet also a societal burden); an object of dread (exhibited to the public gaze); a diseased organism (in need of treatment, validating intervention); an object of ridicule (as a source of entertainment); a holy innocent and finally, as an internal child (younger than their chronological age, immature and blameless).

These perceived otherings emphasised difference, abnormalities, and limitations (Wolfensberger 1969; Race et al 2005; Mathews 2017). The loss of control and autonomy, abandonment, impoverished experiences, and exclusion can be the result of being cast into one (or more) of these deviant roles (Race et al 2005). Wolfensberger's perspective was not intended to offer a comprehensive history of labelling, rather, to understand the foundations regarding the perception and treatment of people who are viewed as different from those around them.⁴ As such, this lens continues to be drawn on within contemporary studies, to illuminate how people with an ID are still likely to experience systematic devaluation, low status, social rejection (Race 2005; Jones et al 2016; Mathews 2017) and are more likely to experience a premature death.⁵

The theoretical conceptualisation of normalisation offered by Wolfensberger, developed into the key principles of social role valorisation (SRV). When enacted, SRV promotes people with ID to have the opportunity to be as 'culturally normative' as possible by occupying more socially valued roles (having a job or being a tenant, for example). Wolfensberger argued that if people occupy more socially valued roles, people's perception of them will then be enhanced (Wolfensberger 1972). Non-segregated leisure and learning spaces were encouraged and were referred to as the 'good things in life' (Race et al. 2005: 512) whereby people with an ID would be recognised to be valuable, accessing the sites of everyday life. This principle, however, discouraged people with an ID from forming potential sources of support and friendship and collective action based on a commonality of experience (Boxall et al. 2009; Jones et al. 2016).

The concepts offered by Wolfensberger have been controversial, with some questioning what is meant by normal and why being normal should be seen as an attractive position to attain, since it reinforces difference as holding a negative

⁴ Mathews (2017) drew upon Wolfensberger's theoretical lens, to discuss two contemporary case studies from the United Kingdom. Westgate College for Deaf People and Winterborne View Hospital. Both sites revealed examples of neglect and abuse, where people were subjected to a culture both inherently demeaning and dehumanising, who were ridiculed and mistreated by people in positions of power.

⁵ 'Death by Indifference' (Mencap 2007) concluded that widespread ignorance and indifference throughout the healthcare services, is the real, underlying cause of some preventable deaths.

value in society (Boxhall et al. 2009; Jones et al. 2016). In this sense, normalisation demonstrates an ‘unquestioning acceptance of stigmatised identities’ (Chappell, 1997: 47) without the recognition that stigma is socially constructed and imposed by powerful groups *onto* a disempowered one (Tyler 2018). In the face of such critique, Jones et al. (2016) defend Wolfensberger by commenting that he was concerned with normalising people’s experiences, expectations, and aspirations, rather than forcing people into arbitrary stereotypes of being normal.

The tools offered by normalisation’s conceptual framework of social role valorisation (SRV), became a key driver in the support of adults with an ID, embedded throughout services from the 1990s and well into the twenty-first century (Race et al. 2005; Boxhall et al. 2009; Jones et al. 2016). These principles of supporting people to be *ordinary* led to the dream vision of a ‘moral blueprint’ for service design, being a cornerstone of normalisation (Jones et al. 2016: 43; Boxall et al. 2009) and SRV became the accepted strategy within policy to overcome discrimination (Thomas 2007). Moreover, the tensions surrounding the SRV model had the opportunity to flourish due to a lack of influence from the social model of disability.

The social model of disability strives for full economic, social, and political inclusion in society. In the UK, disability studies advocate the distinct standpoint of the social model of disability with its commitment to explicitly assist disabled people in their fight for full equality and inclusion (Thomas 2007). Refuting the causal link between impairment and disability, this perspective locates the *problem* with society, particularly in how society restricts people’s opportunities to participate ‘in mainstream economic and social activities’ (Oliver and Barnes 2010: 548). As consequence, disability is created by ‘hostile cultural, social and environmental barriers’ (p. 551). Through this lens, disability as a term reflects the way people with impairments can be isolated and excluded from full social participation (Oliver 1996), and emphasis is placed upon social exclusion over individual impairment (Shakespeare and Watson 2011). Here, whether impairment becomes disability is dependent on both the social and cultural context in which it occurs (Howson 2013). The standpoint of disability studies,

embodied within the social model, has been successful when used for political activism and is embraced by many disabled people (Owens 2015). For, as Davis (1995:9) notes, 'the problem is not the person with disabilities; the problem is the way that normalcy is constructed to create the *problem* of the disabled person'.

However, the progress made by the disability movement has not always been shared with people from the ID community. With their membership questioned and experiences neglected (Chappell 1997; 1998; Shuttleworth and Meekosha 2012) there has been little opportunity to establish commonalities (Boxall et al 2009). This absence then, accounts for the reduced representation of people with ID within the social model, which then allowed for the normalisation agenda to become the dominant challenger to the medical model of disability (Jones et al 2016). While attempts have since been made to reconcile these differences (Chappell et al. 2001; Race et al 2005) and models of disability have attempted to encompass the experiences of people with an ID, people with an ID have not fared well and continued to be neglected within its analysis. At best, the experiences of people with an ID within disability studies continue to remain marginal (Chappell 1998; Dowse 2009; Williams 2013).

Contradictions: theorising disability

Much like other social categories, the term disability is disputed, particularly regarding how it is produced and what it signifies (Coleman-Fountain and McLaughlin 2013). As a sociological subcategory, medical sociology has faced criticism for its focus on medicine and a medicalised interest in the (social) 'abnormal' represented by (biological) bodily impairment (Shuttleworth and Meekosha 2012: 351). This position is perceived to be subscribing to the lay meaning of disability – insofar as disabled people are not able 'to do things' and have 'limited activity', with a certified condition, preventing disabled people from carrying out activities considered 'normal' (p 351). Furthermore, Shuttleworth and Meekosha (2012) suggest that this approach invests in a taken-for-granted, normative sociology that assumes disability as a fact, therefore denying a role within the sociological arena in developing a more liberating and anti-oppressive stance on disability as a focus of its normative role. Titchkosky

(2000) presents a discussion on disability as a social problem, insofar that as a *body gone wrong*, it obtrudes the social world. This focus on impairment as abnormality sets the scene for the binary of what functions normally, and what does not. Fundamentally, then, as Thomas (2007) explores, the interests of the medical sociologist is not to contest or examine the meanings behind disability, it is to explore the consequences of disability, and its social dimensions at both a societal and individual level.

In contrast, critical disability studies (CDS) is defined by Thomas (2007) as a transdisciplinary space aiming to break discipline boundaries by deconstructing lay/professional distinctions and medicalised perspectives with, instead, socio-cultural conceptions of disablism. Goodley (see 2011; 2013; 2014; 2015; Goodley and Runswick-Cole 2015; 2016) theorises CDS in relation to ID, suggesting that 'CDS starts with disability but never ends with it' (Goodley 2013: 632). Rather, it is the space afforded to political, theoretical, and practical issues, a platform through which to 'think through, act, resist, relate, communicate, engage' (Goodley 2013: 641). Goodley's (2017) view of impairment is that it is produced by diagnosis, rather than intrinsically owned by the body. He argues that people with ID are best served by policies that are purposely designed to remove labels that refute citizenship rights to personal freedom. Drawing on Campbell (2009), he describes differences between disabled and non-disabled people as being socially produced, but moreover, this difference is politically constructed to maintain dominance, thus, allowing privileged (non-disabled) people to hold power, while simultaneously producing Others, that are perceived to be inferior or deviant (Goodley 2017).

The CDS approach is heavily influenced by other areas of difference, such as sexuality and gender (Butler 1993; McRuer 2006) and ethnicity (Campbell 2009; Berlant 2011). This interdisciplinary focus has offered the space for a 'merging of epistemological perspectives and ontological desires [that] has created a rich tapestry of concepts and frameworks' (Goodley et al. 2019: 974). A primary goal of CDS is to break down and explore how the impaired/non-impaired dualism can be more fluid, reflexive, and unstable to create a 'theoretically cautious approach' (Vehmas and Watson 2014: 640). Shildrick (2009) strengthens the

position of CDS by suggesting that it is ethically wrong to conceptualise group identity that has been formed on the binary distinction of difference, for, normative standards of acceptance become misplaced. Yet, as Vehmas and Watson (2014) critique, Shildrick (2009) does not provide how this could be enacted, using practical examples. Instead, Vehmas and Watson (2014) suggest that to acknowledge impairment as part of human diversity is not the same as 'seeing them as neutral or insignificant' (p. 641). This position is supported by Shakespeare and Watson (2011) who note that deconstruction cannot explain away the tangible effects of impairment, and, as Lister (1998) points out, within this discourse, there would be no disabled people left to fight for rights with a deconstructed kaleidoscope of shifted identities.

Vehmas and Watson (2014) adopt a critical realist perspective. Their argument rests on the lack of engagement with both ethical and political issues faced by disabled people within CDS. Moreover, they argue that CDS does not allow for the examination of how things 'ought' (p. 638) to be, due to a lack of theoretical framework. While CDS does challenge normativity (right and wrong; good and bad), there are no foundations or accounts for the implications of living with impairment. Moreover, Vehmas and Watson (2014) also take CDS to task for its lack of engagement with day-to-day mundane and pragmatic issues, and for not understanding the realities of disablism. They also allude to CDS in itself being normative, albeit with social rather than individual factors.

Goodley (2014) however, suggests that this is, indeed, the intention of CDS. For, impairment labels 'risk totalising the experience of life in terms of that impairment' (p. 168). By never settling the disability debate, and 'keeping dis/ability categorisation hanging' (p.168), this contradictory nature offers space to trouble and disrupt concepts of normalcy. This perspective is further strengthened by recent work (Goodley et al. 2019) where CDS scholars explore intersectionality and theoretical engagement across contemporary developments in disability studies.

While the CDS position is commendable and appears to subscribe to the tenets of empowerment and ability, it can be problematic. Redley and Weinberg (2007) explored the notions of 'interactional trouble' (p. 777) during their ethnographic

study of the 'Parliament for People with Learning Disabilities'. They explored the innovative advocacy group that contributed to the Valuing People white papers (Department of Health 2001; 2009). Their research suggests that there is a risk that the social reality of an ID can be obscured, to the point, that it could fail to explain why people with an ID are entitled to special assistance in the first place. Moreover, by focusing on the positive methods to aid inclusion, such as jargon-free literature, plain language, and pictorial references, Redley and Weinberg (2007) argue that intellectual impairments become little more than a technical issue. Here, there are political dangers with presuming the only source of interactional trouble with ID stems from the incapacities of people to recognise the competencies of people with an ID. This risk in assuming competence can, then, threaten entitlement to support (Redley and Weinberg 2007). Exposing these contours of both autonomy and dependence in interaction, particularly in situations that have a reflexive and nuanced approach, can both seek to empower citizens with an ID, yet recognise and understand their needs and vulnerability. In this context, the reality of impairment must be addressed, raising the question of whether the ID community is adequately served by policy and discourse that exclusively focuses on voice, ability, and independence (Redley and Weinberg 2007).

Yet, what CDS can offer here is to extend the notions associated with remedial programmes 'that claim to solve the problem of marginalised people' (Titchkosky 2003: 518). Goodley and Runswick-Cole (2015) describe labels as being contentious by inviting service support that act as a denigrate by limiting how people view those who are labelled. Titchkosky (2003) carved out, through the lens of exclusion, how bureaucratic remedial policy actually attempts to integrate people with disabilities as an 'exclude-able type' (p. 518). Titchkosky (2003) draws upon Butler (1993) to note that disabled people are only made to matter in an excluded or marginalised context and, therefore, this is what disability has come to mean. As such, policy responses such as work programmes, rely heavily upon disability as being framed in a way that generates narratives around disablism as a consequence that can be overcome through policy remedies. By its very nature, these kinds of policies legitimise the existence and control held by policymakers other than disabled people

themselves. Being included as an 'exclude-able type' reveals the paradox that perpetuates support and dependency by attempting to insinuate inclusion as 'implementing a consistent, coherent, and rationalised recipe of rules and practices' (Titchkosky 2003: 519), such as a vision or a policy paper. Moreover, professionals continue to make a living through disability that continually perpetuates, unquestioned, the aim of *normal* citizenship that devalues disability, ordinarily depicted as an expense (Titchkosky 2003).

The discussion thus far has explored how both medical sociology and CDS conceptualise disability, particularly in terms of classification. Medical sociology allows for impaired experiences to be understood, while CDS challenges impairment binaries. Yet, these perspectives co-exist, rather than actively engage (Thomas 2004). For, as Thomas (2007) notes, CDS would claim people with an ID as having an organic intellectual deficit, (albeit vastly variable) that situate them at one end of any given statistical bell curve measurement of intellectual capacity. Therefore, suggesting that an ID is simply constructed socially, would have no underlying reality and 'rejected as nonsensical' (p. 130). However, while medical sociology has been critiqued for being overly individualised and centered on abnormality, and CDS has been subjected to criticism for its lack of focus on the effect of impairment, the theoretical concepts attached to embodiment have attempted to offer an alternative perspective. Derived from CDS, embodiment can provide a conceptual framework to bridge some of these complexities between two epistemological positions. Synthesising Howson (2013) and Coleman-Fountain and McLaughlin (2013) can further this discussion.

Coleman-Fountain and McLaughlin (2013) focus on the interactions of disability and impairment through an interactionalist framework, by understanding how bodies are lived, perceived to be impaired and how particular interactional dynamics lead to particular social positionings. Adopting this embodied approach assumes that, central to self-identity and views of self, is bodily integrity. Practical work is done with and through the body in its interaction with others and with the physical environment (Howson 2013). As a notion, practical work can be captured within two concepts: agency and action. Derived from the

symbolic interaction framework associated with the Chicago school of thought, agency addresses the body's role in responding to and creating social worlds by attaching meaning to both the intended and unintended actions of others. Within this tradition, the self is not a discrete entity developed by rational thought, rather, it is an ongoing product of never-ending processes characterised by constant interaction between both the self and others and between different aspects of the self (Howson 2013).

At the forefront of this research are the body and its micro-interaction with society. To do this, I connect to the theoretical concepts of Goffman [1922-1982] throughout this thesis, echoing his position that an interactionist lens can unsettle the norms of social encounters. Goffman continues to 'carry considerable weight' in medical sociology (Thomas 2007: 23) by exploring the performance of social roles when stigmatised people interact with *normals*. As a key advocate of the corporeality of social interaction and order, Goffman established the fundamental importance of the body in society (Goffman 1959).

Throughout Goffman's theorising, he sought to expose how difference becomes a stigma when it is deemed as discrediting, and how differences in both appearance and capacity of some bodies can impact detrimentally with people's positioning in the world. Furthermore, derived from Goffman's work, one can appreciate the assumptions of 'normality' that shape responses to impaired bodies (Titchosky 2000). The meanings attached to difference are not inherent, but a production of what occurs while in the company of others. Norms of embodiment are constructed socially, privileging the able body over bodies of difference, thus producing others and marked master status (Goffman 1963). Excluding the appreciation and depth of understanding of impaired bodies reduces opportunities to further the understanding of how disabled people perform, to avoid stigmatisation and Othering (Coleman-Fountain and McLaughlin 2015). Within Goffman's perspective, self and identity are actively negotiating interactional work with others, grounded in 'felt identity'. With the body central to this process, there are times when the body is threatened by self-identity.

Moreover, this perspective was further developed by Giddens (1991) who argued that the ability to successfully navigate throughout public life, or to enact competence as a social actor, is dependent on following the rules of interaction order and in developing both routine and control over the body. Within this Goffmanian framework, our view of ourselves is often governed by a desire to present ourselves according to the expectations of the context in which we are situated (Howson 2013). Howson further commentates that, as a lived entity, the body is experienced and influenced by social processes and shaped by social context, with competent social interactions and personhood being dependent on becoming competent embodied beings (Howson 2013). Yet, where does this leave the individual who faces 'bodily betrayal' (p. 27) which has the potential to undermine the integrity of social encounters by damaging self and social identity? For Goffman, bodily control and knowledge of somatic norms were crucial to the presentation of self as competent (Goffman 1959).

Human embodiment is taken for granted within everyday life. Yet these aspects are subject to change, products of complex political and social processes and actions that are embedded within history and our social fabric (Howson 2013). Inseparable from culture and society (Bury 2000), the body is becoming increasingly a target of political control and discipline (Goodley 2014). Conceptualised by agencies of the state (welfare, law, medicine) exerting control over the movement of populations (schools, hospitals) and encouraging individuals to discipline (Howson 2013). Given the current political climate, economic uncertainty, and the dismantling of welfare rights (Barnes 2012), holding onto the body and retaining an awareness of difference of what the body is, and what it can do, matters (Coleman-Fountain and McLaughlin 2015).

Self, then, is the outcome of a complex social process, which continues to produce change. Understanding everyday life through a mesh of biological, psychological, social, and cultural relations are difficult to isolate and unravel (Howson 2013). Yet, to do so enables a richer appreciation of the meanings of difference and stigma, which are vital to be able to understand what kinds of impairment leads to different levels of prejudice. Further, it offers an understanding of how the relationship between interactionism and power, through narratives, can extend

this theory (Vehmas and Watson 2014). Moreover, exploring bodily differences can deepen understandings and challenge discrimination (Coleman-Fountain and McLaughlin 2013).

Conclusion

By drawing out the historical marginalisation often experienced by people with an ID, through grand narratives, eugenics, and the medical inductive approaches *onto* people, this chapter has offered a brief exploration of the landscape for people with an ID. Here, devoid of the social model of disability, Wolfensberger's typology of the historical roles depicting people with an ID as having a devalued role within society advanced the medical model and continued to Other people into arbitrary *normal* roles. These roles were then contextualised within contemporary disability discourse, whereby people with an ID are presented as an 'exclude-able type' (Titchkosky 2003: 518), in need of assistance to be re-included.

While CDS contests labels and binary categories, whereby one side of the dichotomy is considered more valuable than the other (Goodley 2014), medical sociology subscribes to tackling disability disadvantage, located with the individual. As Vehmas and Watson (2014) note, 'in order to create fair social responses to disadvantage, we have to have a common understanding about disadvantage, and a reasonable (non-arbitrary) way of comparing disadvantages and correcting them' (p. 643), by recognising the effects of impairment to increase participation and to target resources. This, for Ginsburg and Rapp (2013), is the 'paradox of recognition' (p. 187), where tension is held between the need for recognition of a medical diagnosis, and the struggles to de-medicalise individual identity. In response, the theoretical concepts of embodiment were considered, which account for the body, and its relationship with society.

This chapter, then, has provided the foundations to now move on to explore the landscape of employment activation. Valuing Employment Now (2009) focused on employment as an important outcome for people with an ID, and this emphasis is reinforced by the reduction in eligibility for financial support from the state, which has been systematically lined to strengthen the incentives to

work. Moreover, with narrowing testing on functional capacity and incentives encouraging people to take unpaid or low-paid work, the doctrine of 'welfare-to-work', through policy initiatives are almost entirely emphasised by 'supply-side' measures. These measures neglect structural barriers, blaming the individual for their lack of employment, without considering the broad *back-story* of ID.

Chapter 3

Work, disability and citizenship

Chapter two laid bare the backdrop in which my research operates, by considering the broader, contextual factors that affect people with an intellectual disability (ID) and its theoretical considerations. Chapter three, presented here, explores the relationship between work, disability and citizenship by drilling down on the specific detail of employment through active labour market policies (ALMP). Exploring how these policies exist in tension with concepts of citizenship, particularly over the last 30 years, then frames a discussion on employment programmes. This section highlights the exclusionary practices experienced by people who are considered furthest from the labour market. The latter sections are focused on employment policy directly aimed at people with an ID, followed by a discussion centred on the academic literature of employment activation for people who have an ID.

Overall, the aim of this chapter is to present how the landscape of employment activation operates for people who have an ID and are seeking employment. The focus here is the implications of employment policy directed towards people who are claiming Employment Support Allowance (ESA), rather than Job Seekers Allowance (JSA). JSA is the welfare assistance payment attached to people seeking employment that are not deemed to have an illness, impairment, or disability. In contrast, ESA is the main unemployment benefit available for people who are disabled or assessed as long-term sick.

Connecting active labour market policy and citizenship

Over the last thirty years, advanced welfare states have exponentially increased active strategies designed to 'activate' unemployed people. These labour market interventions have been advocated from all sides of the political spectrum and progressively tied welfare benefit entitlement with obligations to seek paid work (Sage 2015). Active Labour Market Policy (ALMP) targets unemployed benefit recipients onto employment programmes intended to increase the likelihood of labour market re/attachment. Together, this explicit linkage of benefits and

employment services aim to reduce the number of out-of-work claimants, promote employment, and reduce welfare support costs (Sage 2015).

ALMP is widely cited as the 'best' way to achieve citizenship and social inclusion throughout Western Europe and North America, with Governments establishing a range of policies designed to increase the supply of labour through ALMP programmes. While different countries within Europe emphasise diverse aspects of activation strategies, employment policies are presented as a route to increasing both productivity and competitiveness. This is played out by focusing on fair opportunities, improving human capital, and increasing both the quality and quantity of available workers (Taylor-Gooby et al. 2015). These policies include job creation, incentives, work programmes, and supported employment for marginalised groups (van Berkel et al. 2017). The UK adopts a supply-side fundamentalism approach, conceptualised through liberal employment measures that are characterised by low protection (both social and employment) and the pursuit of the *make work pay* mantra (Ingold and Stuart 2015; Taylor-Gooby et al. 2015).

Policies that require participants to engage in employment-related activities are not new in the UK. Yet, from 2008, what has shifted is the expectation that those who would have previously been entitled to Incapacity Benefit (IB) would have been excluded from such conditionality and/or subject to weaker forms of employment activation policies. This transfer from IB to Employment Support Allowance (ESA) strengthened the work-related conditions applied to out of work benefits on the grounds of disability (Wiggan 2015). Moreover, the method of increasing employability shifts the focus of secure employment away from government and, instead, towards the individual who must grab all opportunities available to them (Taylor-Gooby et al. 2015). Underpinning these policies is the premise that jobs are available if only the workless were prepared to take them (Ingold and Stuart 2015). Within the complex alterations to the welfare system, Frayne (2015) notes, 'paid employment is unambiguously promoted as the normal and superior state to which everyone should aspire' (p. 105).

Qualification for ESA is dependent on a Work Capacity Assessment (WCA). A WCA is a measurement tool designed to assess the employment prospects of sick and disabled people. Introduced as part of the Welfare Reform Act (2007), WCA's are based on a managerial model of assessment, whereby the assessment is based on a highly standardised, consistent design, strategically devised to prevent deviation and discretion. The focus of WCA is based on impartial treatment (Harrison 2011; Gjersøe 2016). The WCA criteria is focused narrowly on a physical and mental function assessment, designed to determine whether an individual is capable of doing *any* work. The overarching aim is to distinguish between those that cannot work and those that, with support and intervention, could be fit for some (and eventually full) employment (Gjersøe 2016).

There are 17 specific descriptive activities to be assessed in the WCA and if 15 or more points are scored, the eligibility for ESA (rather than JSA) is met. The ESA is then split into a two-tier system. A no-contact 'decision-maker' considers whether the claimant should be assigned to the Work-Related Activity Group (WRAG) or the Support Group (SG). In the WRAG, people are expected to engage with work activities and welfare benefits are conditional upon participation in activation schemes. There are presently no formal requirements for those within the SG to engage with work-related activity (Gjersøe 2016). ESA was originally broadly welcomed by disability organisations on the premise that proactive and tailored employment support policy, accompanied by inbuilt flexibility, would assist people with more complex needs to find work (Richardson and Benstead 2017).

However, before consultation, the 'Improving Lives: The Future of Work, Health and Disability' strategy (2017) outlined plans to consider imposing all sick and disabled people receiving out of work benefits to take part in mandatory employment activity by engaging in regular Job Centre contact or risk-benefit sanctions (DWP and Department of Health 2017). This work to cure approach was branded devastating, unethical, and cruel by disability activists (Richardson and Benstead 2017). Appearing to be a route to help people, critics deemed the proposals as a method to restrict choice and 'imposing an ideological goal of paid work on every disabled person, regardless of the appropriateness of this goal for

every individual' (Richardson and Benstead 2017: 5). The 'Improving Lives' strategy (2017) suggested that, if 1% of people claiming ESA moved into work during 2018/19, the exchequer would save £240 million. Yet, the strategy consultation received over 6,000 comments and 3,000 emails (p. 7), condemning the proposals and, based on feedback and official responses, the final report omitted the original plan for ESA SG to take part in mandatory employment engagement (DWP and Department of Health 2017).

Moreover, the strategy has come under intense criticism, with an extensive body of work contesting its approach to work assessment: the individual is held responsible for the life situation they experience, without due regard to disability and broader structural causes of unemployment and social exclusion (Levitas 2004; Dwyer and Wright 2014; Whitworth 2016; Curchin 2017). Moreover, rather than aiming to understand these wider social environment factors, individuals are being presented with a variety of incentives and disincentives to transform their own behaviour (Dwyer and Wright 2014; Curchin 2017).

As such, with a strengthened focus resting on impairments and work capacity, attention is diverted away from the broader considerations of skills, age, local labour market conditions (Hutton et al. 2012; Fevre et al. 2016), equal labour market participation (Wright 2012), and practical chances of someone successfully finding a job that they can do (Gjersøe 2016; Shakespeare et al. 2017). The ramifications of these policies see the boundaries between able-bodied and disabled people being redrawn (Gjersøe 2016), with the move towards a greater welfare conditionality challenging the principle that 'ill health constitutes an absolute barrier to engaging with work or work-related activity' (Garthwaite et al. 2014: 312). Here, the designed approach is to distinguish between those who are *really* disabled and those who are not (Garthwaite et al. 2014).

In a capitalist society, work is documented as the best form of welfare (Frayne 2015) and employment engagement is the dominant marker of the responsible citizen (Levitas 1998). For those who do not engage with employment, social exclusion is bound to both citizenship concepts and labour market (Levitas

2004).⁶ Fundamentally, citizenship is about inclusion and exclusion. That is, who is, and who is not, included in the citizenry. Within this discourse, attention is directed towards questions of membership, belonging, rights and responsibilities. Cumulatively, this amounts to the expectations directed towards those granted citizenship statuses, and in turn, what can be reciprocated (Patrick 2017) and political assertions often draw upon these liberal ideas of citizenship. Lister (2010) reflects that this position, focused on the relationship between the individual and the state, echo's the individualistic liberal thinking within the UK. This is particularly apparent when compared to Scandinavia, which enacts social citizenship through the relationship between citizens as a collective, within the social democratic traditions of political thinking (Lister 2010).

The classic liberal citizenship theorist, T.H Marshall (1950), emphasised the importance of providing social rights to citizens to ensure that they are able to enjoy, at minimum, 'a modicum of economic welfare and security' whereby every citizen shared a 'common equality of status' (Marshall 1950: 92). Faulks (1998) defined citizenship to broadly cover three domains. First, within the legal definition which is often an interchangeable connotation connected to nationality. The remaining two definitions are philosophical and socio-political. The philosophical ideas are concerned with the role of the state in providing for citizens' needs, and what the state can reasonably expect in return in terms of duties. The socio-political focuses our attention towards understanding the power and relationships existing within the context of that society and how changes to the political, cultural, and economic fabrics affect that society (Faulks 1998).

Bellamy (2008) suggests that to belong, citizens must contribute to the collective good, whilst prevailing to the norms and customs practiced within it, describing this as essential in achieving full and equal citizenship rights. Tonkiss and Bloom (2015) draw attention to the three interrelated attributes of citizenship. First, the legal aspect whereby citizenship is a status that grants rights, and in return,

⁶ For even when social exclusion was intrinsically linked to poverty, the presented solution during the 1980's was labour market participation (Levitas 2004).

the holder is expected to meet the obligations of the state. Secondly, political citizenship denotes active participation in the governance of the state, and finally citizenship which is connected with membership through identity within the citizenry (Tonkiss and Bloom 2015). Yet, how do these prevailing narratives align for people with an ID whose civil rights were stripped just over one hundred years ago, epitomised here, by William Beveridge, the 'father' of the welfare state ([1907]: cited in Tyler 2013: 191):

Those men who through general defects are unable to fill such a whole place in industry, are to be recognised as 'unemployable'. They must become the acknowledged dependents of the state [...] with complete and permanent loss of all citizen rights.

Marshall's (1950) 'equality of status' (p. 92) lingers within a disablist ideology where the legacy of the Poor Law (1834) saw individuals forfeit their rights as citizens in order to receive welfare assistance. Moreover, Barnes argues that with a hostile physical environment, disabled people are effectively denied the civil, political, and social rights that are central to the notion of citizenship (Barnes 1991). Chaney (2015) scrutinised exclusionary parliamentary practices from 1940-2012, highlighting how institutional structures and procedures did not begin to be principally concerned with the needs of disabled people until the Disability Discrimination Act was introduced in 1995. Oliver (1996) furthered this by arguing that the marginalisation of vulnerable groups by the state (structures, policies, and professional practices within the welfare system in particular) has exacerbated social exclusion, promoted dependency, and resulted in citizenship rights for disabled people remaining firmly anchored in rhetoric rather than reality.

This history of exclusion from the citizenry is still evident today, with policy and strategies specifically for people with an ID being directed towards fostering inclusion, explicitly acknowledging a framework of citizenship (Valuing People 2001; 2009). Yet, the intertwined relationship between waged work and citizenship is problematic for people who are distant from paid employment (Garthwaite 2014). For, as Dwyer (2010) notes, 'common-sense' (p. 133) accounts of citizenship fail to account for people who lack capacities to function

as *normal* citizens within these frameworks. Marshall (1950), then, failed to account for people with disability, with his emphasis on the rights and responsibilities of able-bodied males (Dwyer 2010). These threads demonstrate that it is hasty to suggest that the majority of disabled people are able to enjoy basic citizenship rights in any functional sense (Barnes and Mercer 2003).

In practice, the underlying, broader British narrative of citizenship is conceived through waged work (Patrick 2014; 2017). For those without work, particular groups of people with alternative societal contributions continue to be at-risk of citizenship exclusion (Singleton and Fry 2015). Moreover, the egalitarian ideas that once underpinned social citizenship are increasingly threatened with the decline of state protection (Patrick 2017). Successive governments have defended the increased conditionality to welfare reforms by focusing on social inclusion as a route to enabling individuals to become responsible (Levitas 1998), with the moral discourse of social exclusion used as a substitute for an 'underclass' (specifically youths, lone mothers and disabled people), being portrayed as morally distinct from society, hazardous and problematic, and as a consequence, targeted by policy (Frayne 2015).

Through his role as an advisor to the UK coalition government (2010-2015), the US scholar, Mead (1997), furthered this divide. Mead (1997) located an underclass of people that required government persuasion to advance their self-interest. He was influential in the call for well-intentioned states to enforce 'common obligations of citizenship' (Whitworth 2016; Curchin 2017) for the good of citizens who, despite their best efforts, either cannot or will not perform their citizenship obligations (Whitworth 2016). The paternalistic approach of Mead played out within a 'help and hassle' discourse, aimed at providing direction by ensuring support through the 'help' and compliance through the 'hassle' (Curchin 2017). Media criticism of the reforms was avoided, by popularising the policy binary between the 'deserving' and 'undeserving' (Prideaux et al. 2009; Roulstone 2011). Today, across mainstream UK political parties, there is an unproblematic acceptance of individualised active labour market engagement based on behavioural conditionality being used as a lever for personal change (Dwyer and Wright 2014). Yet, this rhetoric of claiming

welfare as a lifestyle choice is not supported by empirical evidence (Crisp et al. 2009; Shildrick et al. 2012; Garthwaite 2013).

The underlying ontology of neoliberalism is of rational subjects making decisions with agency. In contrast, the paternalism of Mead imagines subjects as lacking appropriate incentives, in need of steering, and either unable or unwilling to operate efficiently within the choice and responsibility framework (Whitworth 2016). These contradictions of unemployed individuals being both rational and feckless results in the desired subject being entrepreneurial in words, yet docile in deeds across analytical spaces of self-governance (Whitworth 2016). Furthermore, the conceptualisation of citizenship having a moral dimension in shaping 'good' behaviour invokes deeply normative assumptions on whether rights should be absolute or dependent (Faulks 1998).

Taken together, within today's context, citizenship operates increasingly as a form of social control, with welfare benefits stigma, conditionality, and compulsion working together to simultaneously create a governance regime (Patrick 2017). Punitive measures of activation, such as categorical uncertainty and financial penalties, aim to motivate unemployed individuals to intensify their job search. Consequently, this problematises, objectifies, and then pursues correcting the behaviour of certain groups of people (Patrick 2017). Here, the dutiful citizen is conditioned to accept this conditionality as a normalised experience (Curchin 2017). Fundamentally, the limits of these ALMP's are now being tested by some of the most vulnerable sections of British society (Deeming 2013).

Employment programmes

Hyped as a new model of delivery that would remove artificial structural barriers to employment, the Work Programme (WP) (DWP 2012) was created as a single route for a range of diverse groups. The WP's introduction by the coalition government enacted the ideological shift of the role of the public and private sectors, intending to transfer groups outside of the labour market into work, by incentivising private providers to move participants into paid employment (Ingold and Stuart 2015). The WP aimed to deliver a variety of innovative and

flexible services, with the government expecting most people to be assessed as capable of work-related activity (DWP 2012).

Based on a Payment by Results (PbR) system, new Employment Support Allowance (ESA) claimants have a figure of £6,500 attached to their entry into waged work. This fee is released to the employment programme that successfully helps the individual secure work. For the mandatory Work-Related Activity Group (WRAG) claimants (who are expected to be fit for work within 3-6 months), are worth £13,720 under the PbR model. For those who are assessed and categorised as within the Support Group (SG), where there is no attached conditionality to their ESA claim, their participation in the paid labour market is voluntary, and their figure is reduced to £3,285 (Carter and Whitworth 2014). This reduction to the fixed price for those within the SG is problematic and the rationality of such reductions must be explored.

The rationality of the PbR is that it will incentivise private providers to facilitate the entry of claimants deemed closest to the labour market into paid work. Yet, built within the performance model is the inherent practice of 'creaming' and 'parking' (Wiggan 2015). These terms refer to the skimming off of clients who are closest to the labour market, triggering a secure PbR ('creaming'), whilst under providing services for people with more complex needs by de-prioritising those deemed unlikely to generate an outcome payment ('parking') (Wiggan 2015; Rees et al. 2014). Carter and Whitworth (2014) class parking and creaming as an endemic concern within the marketised welfare-to-work system. Similar to Wiggan (2015) and Van Berkel (2010), Carter and Whitworth (2014) question whether the consequences of the outsourced PbR model that is inherent to the logic of marketised provision are indeed, intended as this deliberately removes resources from those unlikely to move into waged work.

Building upon Marx's body of work (2013 [1867]) and in line with Whitworth (2016), Wiggan (2015) suggests that concepts of the active and reserve army of labour (referring to those divided by formal waged labour and those outside of formal employment relations) is at play within these inherent creaming and parking tendencies. The active army (primary labour market) includes those with the highest level of job security and remuneration. The outlying 'contingent'

labour force (secondary labour market), characterised by lower wages and less employment security, is further stratified to include those close to the labour market (a floating segment/ JSA) that could be drawn upon and those who engage with non-waged work activity (the latent segment JSA/ ESA WRAG borderline) and people who are perceived as unlikely to engage with paid labour due to impairment (the stagnant segment/ ESA WRAG and SG).

Labour market legislation aimed at correcting market failures in the exclusion of disabled people from the workplace is, instead, working as it intended within free-market ideology. People who are excluded from the system of work are not excluded because of faults within it, rather, because the system *is* working exactly as it intended (Russell 2002). Further, meritocratic ideology deems personal shortcomings to be the reason when individuals fail. This individualism, where we can become anything we want if we endure, is often unrelated to the individual effort and motivation exerted, and instead, capitalist labour market structures are the absolute barrier (Russell 2002). Moreover, while the reserve army supplies labour to emerging growth, it also acts to discipline labour-power by enforcing conditionality. Here, targeted ALMP is acting as a vehicle for improvement, yet also an instrument to increase the reserve army of labour. By providing controlling self-surveillance measures to unemployment, through disciplining workers, individuals adapting their behaviour according to the social norms about how they should behave and modifying to fit with such expectations (Whitworth 2016; Manji 2017).

The individual positioning of participants in the queue for waged work and the assignment of a labour group (to WRAG or SG by 'independent' assessors) is structured through social divisions relating to personal characteristics including gender, educational qualifications, and disability (Wiggan 2015). Furthermore, historically, along with other marginalised groups, disabled people have been underrepresented in the core labour force and consequently, overrepresented within the secondary labour market as the reserve army. While the exclusion of disabled people from the workforce is steadily reducing (Fevre et al. 2016), the participation in waged work has not eliminated these inequalities within the labour market (Berthoud 2011; Fevre et al. 2016).

In response to these labour market inequalities, government has promoted a reshuffle of unemployment and economically inactive welfare recipients, intending to draw claimants into the 'floating' segment of the reserve army, able to compete for low-wage jobs. Most of these claimants are within the WRAG category (those assessed as temporarily incapable of waged work) and therefore positioned as requiring engagement with activities related to job preparation. Here, previous distinctions between inactive labour-power and unemployment are collapsing (Clasen and Clegg 2011), while simultaneously, a more refined sorting process of activation defines many participants as more employable (Grover and Piggott 2009). For someone in a weak labour position, with deficient labour market histories and an increased likelihood of other barriers (lack of skills, qualifications, experience, health, and social problems), there is a negative view by employers of people who are long term unemployed, resulting in the further distancing of the employment market (Ingold and Stuart 2015).

So far, literature has established that people with an ID are often explicitly excluded from the Work Programme unless they are deemed to be so near to the labour market that they are financially viable. This is unlikely for anyone that is in the SG and WRAG category – since 2011, only 5% of the WRAG group have moved into work through the Work Programme (Equality and Human Rights Commission 2017). Therefore, for anyone in this position and wishing to engage with paid work opportunities, alternative provision must be sourced, such as specific ID employment support.

Targeted employment literature and policy

People with an ID face a particularly challenging and complex position regarding employment. Low expectations, poor education, and the aversion from many employers to intellectual impairment have seen very few people enter paid work, yet, as we have seen, employment is framed as central to a *normal* life (Hall and McGarrol 2012). Until 2009, WORKSTEP had been the flagship disability employment programme for many years, administered by the Department for Work and Pensions (DWP). Alongside local authorities, third sector providers, and Remploy, WORKSTEP supported people predominantly within sheltered workshops (Melling et al. 2011). Work Choice replaced WORKSTEP as a new

specialist disability employment programme by contracting with ‘prime providers’ (p. 26) and was rolled out in conjunction with the publication of *Valuing Employment Now* (VEN) (Department of Health 2009), a dedicated employment strategy for people with an ID. While now disbanded (yet unreplaced), the VEN rhetoric lingers throughout ID discourse and *Valuing People* policy. The document acknowledged that people with an ID have not benefited from the progress in employment inclusion made by disabled people more generally, which have steadily risen over the last few decades. At its time of publication, 6% of working-aged adults with an ID in receipt of social care were in any form of paid employment, however, this figure has since declined to 5.2% (Hatton 2017).

In line with the broader strategy focused on cutting the disability employment gap (Fevre et al. 2016), the VEN set out to ‘radically’ (p. 2) increase the number of people with an ID in paid employment by 2025. The policy defined work as ‘real jobs in the open market that are paid the prevailing wage’ (p.13) and explicitly stated that it is possible for everyone to make an economic contribution. The policy cited that ‘getting a job should be a priority for all working-aged adults’ (p.22) and ‘everyone should be in real, paid, full-time jobs with people only working less if there is a genuine reason to do so’ (p.23). In tune with the *Valuing People* White Papers (2001; 2009), the document was set within the broader move towards inclusion, civil and legal rights, and choice. A key purpose of the VEN was to develop a ‘pathway into employment *and* equal citizenship’ (p.24), reinforcing the notion that citizenship can only be attained by waged work. Yet, Bates et al. (2017) reveal a ‘host of broken promises in promoting work opportunities’ (p. 172) from successive governments that have seen it being harder than ever for people with an ID to find work (Bates et al. 2017).

Supported employment (SE) is the main model of employment inclusion for people with an ID. As advocates of the SE model, the next section will draw significantly on the body of academic literature provided by Beyer and Kaehne (notably, Beyer et al. 2010; Kaehne and Beyer 2013; Beyer 2014; Beyer et al. 2016 amongst others) who both focus on the transition from education to

employment for people with ID and SE models in Europe. Their research has been instrumental in the evaluations of employment projects (Kaehne 2014; Beyer and Townsley 2017). Beyer's links to external organisations (Mencap, in press⁷) and partnerships with Cardiff University⁸ and Engage-to-Change, will be discussed in more detail in chapter five.

Emerging from the US in the 1980s as an alternative to vocational training and sheltered workshops, SE profiles individuals and 'markets' them to an employer as a mechanism for inclusion in the labour market (Beyer 2010). The SE model is 'evidence-based' (Department of Health 2010: 2) and encourages partnership between employers and providers. Here, as customers, potential jobseekers enter a process of job matching and in-work support, provided by job coaches who are trained in systematic instruction (TSI).⁹ Supported employment programmes are cited as successful models for work mobility (Bates et al. 2017) and, similarly to other non-ID models, the framework of specific employment support is one of rehabilitation whereby opportunities to overcome and adjust to coping with impairment are provided (Bates et al. 2017). Moreover, similarly to the VEN policy, with the right support, the fundamental principle of SE is that everyone can work (Department of Health 2010: 2-3).

Overall, SE methods usually convey a positive message, by offering an opportunity for people to engage in social interactions in a workplace, increase friendship circles, create a sense of belonging, and to embed people in the local community (Jahonda et al. 2008; Bates et al. 2017). However, figures suggest that SE, which is largely funded by government contracts, have impacted negatively on employment rates (Anderson Humber 2014). The concept is driven by ideologies that make positive assumptions about what work means to people with an ID (Banks et al. 2007) and frames inclusion in terms of achievement, independence, and productivity, embedded within the rhetoric and practices of neo-liberalism. Academic literature frames the benefits of work for people with an ID as having four characteristics that afford people an enhanced sense of

⁷ Research review commissioned by Mencap (in press).

⁸ The Welsh Centre for Learning Disabilities is rooted in the School of Medicine at Cardiff University.

⁹ TSI is a structured approach with emphasis on errorless learning.

control over their daily lives: autonomy; self-regulation; psychological empowerment, and; self-realisation (Wehmeyer et al. 1996). Johonda et al. (2008) explore the socio-emotional impact of supported employment, by researching the impact of work on the quality of life (QOL) through life satisfaction and wellbeing.¹⁰ Their method presents an overview of sixteen studies that explore the QOL from the USA, Australia, and the UK. Of these sixteen, eight include distinctions between levels of ID.

Jiranek and Kirby (1990) concentrated their research to focus on participants aged between 20 and 25, who had a mild to borderline ID. Their findings (n=73) suggest that participants who were in competitive employment (defined as, in non-segregated work that is supported by an employment programme) reported higher job satisfaction and networking opportunities when compared to people who were working within sheltered employment or unemployed. Similarly, Griffin et al. (1996), found individuals who are in competitive employment, had a higher QOL when compared to those who attended a sheltered workshop or were unemployed. The participants from this research were considered to have a mild ID (n=200). Similar patterns were established by Eggleton et al. (1999) (n=50), whereby there was a significant increase in the QOL between those employed in open employment and their counterparts who were either unemployed or working within a sheltered environment. These themes continue throughout the body of research interested in the intersection of ID and employment. Kilsby and Beyers (1996) focused on participants who had mild to moderate ID (n=16), finding that people in open employment had more interaction with the community than those who worked in a sheltered environment. Wehmeyer (1994) drew on data from a self-advocacy group (n=216), where the author suggests participants had mild to moderate ID. Their findings suggest participants had significantly more control over their own lives when compared to those working in sheltered workshops and unemployed.

¹⁰ QOL does not have a standard concept, rather indicators, that include life satisfaction; multidimensional factors (such as physical health, education, employment); cultural perspectives (values and goals) and well-being (Nussbaum 2006).

So far, the academic literature offered here has focused on participants who have a mild/moderate ID, and how non-segregated employment is evidenced as beneficial to the QOL for this demographic. However, when exploring literature that draws on data from participants who have a moderate or severe ID, the findings begin to shift. Kraemer et al. (2003) explored QOL using participants who were categorised as having a moderate or severe ID (n=188). Their research suggests that there is no difference in QOL between those who enter employment, and those who entered sheltered workplaces, remained at school, attended day centre, or were unemployed. Kregel et al. (1989) used a mixed, large scale, cross-sectional sample (n=1550) that had a mix of people classified as borderline, mild, moderate, and severe ID, as well as people with long-term mental illness and physical/sensory disabilities. Their study found that people with severe ID were more likely to be working in sheltered employment, and here, social integration with the non-disabled people was significantly lower. While Wehmeyer and Garner (2003) drew on data (n=301) from participants who had a range of level of ID (from mild to severe). Their study found that self-determination, autonomy, and IQ scores were all significant predictors of independent living. However, for employment, IQ was the only predictor of employment status.

These study examples indicate that the severity of ID can impact upon the benefits of employment, yet nevertheless, open employment is evidenced as the *best* way to attain work, for people with an ID, as a homogenous group. When instead, people with mild/moderate ID have a hegemonic status, privileging their employment success, and this fails to account for people who have higher support needs. For, as Johona et al. (2008) discuss, the overall findings of their systematic review produce consistent evidence of positive changes in the autonomy levels and QOL enjoyed by individuals who have an ID and access open employment. Even, if, this is in workplaces that are 'repetitive, boring, requiring little autonomous thought or action' (p. 14), because paid employment may offer an increase in choices in other areas of life domains.

The review presented here has evidenced an absence of discussion, concerning people who have moderate or severe ID and how their employment needs may

differ significantly. Moreover, the impact of the study offered by Johona et al. (2008) has had wider implications. Other key papers draw upon the findings offered by Johona et al. (2008) to claim that employment is a fundamental part of adult life that people with ID aspire towards (Trembath et al. 2010a); as a route to increasing QOL for people with ID (Lynsaght 2010) and, with people who have an ID being a source of 'untapped potential' (Lynsaght et al. 2012b: 409) in the workplace. Lynsaght et al. (2012a) compiled a similar review of employment-related research between 2000-2010, with a focus on inclusion.

Out of the 42 papers that Lynsaght et al. (2012a) considered, only five articles focused on inclusion, while the remaining 37 central concern was the work role achievements of pay and job role. The authors conclude that this lack of evidence, on inclusion, is problematic, particularly when social inclusion and socially valued roles of employment are often cited as evidenced within academic and policy literature. Six papers from the UK are discussed in their article. Banks et al. (2010) explored QOL, depression, and anxiety; Beyer et al. (2010) compared the QOL of those who were employed through supported employment, sheltered employment, or were unemployed; Beyer and Kaehne (2008) explored what works in employment support, while Hall (2004) scoped out employment within a sense of belonging framework, and being included as part of the local community. These papers will be explored considerably elsewhere within this thesis.

The remaining two papers are from O'Brian (2006) and Rose et al. (2005). O'Brian (2006) focuses on personal characteristics and psychosocial functioning for young people as they move into adult services. Interestingly, when discussing daytime occupation, he codes 'unemployment/no day care arranged' together (p. 197), reinforcing a confusion within the 'what is work' discourse (see chapter eight). O'Brian's analysis of a clinical cohort (n=149) found 61 participants to be in employment, with 41 of these (two-thirds) employed in open, non-sheltered occupation. However, *all* 61 participants who were employed had a mild/borderline ID.

Rose et al. (2005) drew on data from a supported employment agency where people seeking work are considered to have an ID, although no formal

assessment of this was made. Individual client files were reviewed, and the employment agency staff provided written descriptions of individual employment motivation, both at the beginning of the job search and again, at the end of their involvement. They found that 82% (n=164) of participants only received Job Seekers Allowance as their income source, suggesting that the majority of the participants were not in receipt of any form of social care, and therefore, either not diagnosed with an ID or borderline/ mild. Yet, 94% (n=175) self-reported communication problems (undefined or further explored) and issues with literacy and numeracy (70% and 65% retrospectively). At the end of their work placement, 49% (n=98) gained employment through the agency, 12% sought further training, while 39% returned to unemployment or continued to find an alternative employment programme. Overall, the study found that the assessment of motivation made by staff at the beginning of the employment programme was considered to be a significant predictor of an employment outcome. Yet, the study made little attempt to discuss staff investing more effort into helping clients that, they believed, were more able or more motivated ('creaming').

Again, focusing on motivation, Andrews and Rose (2010) researched with people with ID and the factors that affect their employment motivation. The participants were given a range of factors to draw upon (such as earning money; being independent; having status and acceptance, amongst others), reinforcing normative ideology of how people with ID should think and feel about employment. Moreover, while the authors cite factors that put people off getting a job (such as travel and negative attitudes), there is no mention of the low pay, hard manual, entry-level posts that people would generally be entering through work (Frayne 2015). Furthermore, a question asks what areas participants would like to work in, which is dominated by the stereotype of ID employment in services (e.g., catering, shop work, office duties). Research like this, and much of the other studies explored here, does little to avoid the rhetoric of waged work being the lever for becoming a 'good citizen' nor does it capture the complexities in the interactions between those who wish to work, yet are systematically excluded, fuelled by the supply-side to employment activation (explored in chapter five).

More widely, other studies captured in the overview provided by Lynsaght et al. (2012a) mostly take place in the USA, Canada, and Australia. Here, the general focus is also on QOL measurements and intrinsically individual characteristics. With the exception of the sense of belonging (Hall 2004), personal characteristics and competency dominate the review. In 2012, Lynsaght et al. also published a theoretical paper to provide a rationale for competitive employment inclusion. However, the authors cite that 40% of people with an ID are in paid employment. This again, then, suggests the focus is on individuals who have mild/borderline ID, and no distinction is made within the paper. Lynsaght et al. (2012) do, however, present some interesting suggestions on expanding the diversity of employment inclusion, and some of these ideas are built upon in chapter nine.

The Sustainable Hub of Innovative Employment for people with Complex Needs (SHIEC) (2016) aimed to support people with complex ID's and 'behaviour that challenges' into *genuine* paid employment. Across the UK, 49 people were supported by the project between 2010 and 2016, and by the time the project concluded, 7 individuals had entered paid employment. The evaluation report (Tame 2016) points to various barriers that were apparent during this project. These included difficulties with support providers not having a common definition for complex needs. As a demonstration project, SHIEC was set up to identify how individuals could be best supported into employment, yet, providers spent time and resources supporting individuals 'who did not fall into this particular category' (p. 11). Instead, there were examples of employment providers considering specific impairments such as a hearing impairment, rather than overall difficulties with learning new skills and communication. Moreover, it proved difficult to support individuals with more complex needs 'especially as many individuals without disabilities are struggling to find employment' (p. 11). The evaluation report identified particular difficulties with the time commitments required to support people adequately and explores the anxiety support staff felt with the challenges of supporting individuals who would be disappointed if they did not secure any work.

Ineson (2015) is one of the few projects with employment for someone with a severe ID as its focus. Following a case study approach, Ineson (2015) captures

the journey of one person's attempt to secure a paid job. This research started from the position that wide-scale employment exclusion for people with an ID from the labour market, leads to occupational injustice and perpetuates stigma. Drawing on the Valuing Employment Now (VEN) (2009) policy, the author discusses how it could be argued that people with milder ID are comparatively easier to place in work, using the supported employment model. Thematic analysis identified five areas for discussion: employment outcomes; raising aspirations; supported employment providers; remaining person-centred, and; extending occupational therapy skills.

Over a period of six months, the participant was not successful in securing paid work. Instead, work experience and volunteering were both regularly suggested as alternatives (see chapter eight). While the participant developed her own aspirations to achieve employment and actively made decisions, the author notes that 'acknowledging a person with higher support needs in an empowered position of employment, rather than care-recipient, requires a cultural shift' (Ineson, 2015: 63). Of the three specialised employment support providers contacted, none had the experience of supporting someone with a severe ID into employment, and here, negative terms such as 'low level' and 'poor skills' (p.63) were used to describe the participants' ability. Moreover, none of the three could identify suitable roles for her, or how she could potentially access any. Instead, it was suggested to Ineson, that she 'cold call' (p. 63) supermarkets for potential vacancies and to consider more 'realistic' options of volunteering in charity shops.

Overall, while there is the obvious limitation of only one participant in this study, Ineson (2015) highlights how the aspirational language of policies such as VEN and Valuing People (2001; 2009) is very different from the reality of putting policy into practice. Ineson's paper (2015), was one of the first to consider cultural and sociological aspects of employment, and normative judgments of the construction of an ID. In comparison, other studies focused on function, capacity, and psychological determinants of employment prospects. The direction from Ineson perhaps indicates the path of policy and its consequences for a

demographical proportion of the VEN, and how people with moderate/severe ID's are beginning to *think employment as possible*.

More recently, Bates et al. (2017) take a critical disability studies stance of ID employment inclusion, drawing upon cultural attitudes that continue to 'emphasise the innate incapacity' (p. 164) of people with an ID. The authors (which include Goodley and Runswick-Cole) draw upon data gathered from their 2015 Big Society research project.¹¹ Here, with five people considered to have an ID, they explore how people with ID experience 'differential precariousness' (p. 167). In one instance, this was a positive experience, with a participant setting up his own business. However, for the remaining four, such positive experiences were not shared, with uncertainty, reduced support, and funding issues defining their experiences. Moreover, an example was drawn here from a participant that struggled to find work after her internship finished, with multiple job coaches. As such, she actively stopped seeking paid work and, instead, concentrated on volunteering opportunities.

The examples presented here by Bates et al. (2017), are nuanced and complex. They begin to carve out some of the interconnected factors that family, home life, funding, support, and day activities all impact upon work choices. Advocated as a space to 'craft identities' (Bates et al. 2017: 172), work is considered, within this framework, to offer a 'counter-distinction to the passive subject positions afforded by the psychiatric and psychological literature' (p. 172) and the authors consider the difference between an active, 'I work' and passive, 'I go to day centre' (p. 172). However, the work/day centre dichotomy is, generally, more complicated than this. As we have seen in chapter two, sheltered worksites and day centres have been dismantled over the last decade, in favour of non-segregated opportunities. Consequently, people with higher support needs, are being underserved, further isolated, and distanced from both the labour market and opportunities to work in any form. As Goodley and Runswick-Cole (2015: 5) note:

¹¹ As part of the Coalition Government, previous Prime Minister, David Cameron, set out the aims of Big Society, about how society *should* be. Underpinning the principles of Big Society, was that the state should be smaller, and decision making should be led by the general public, by devolving power to civil groups.

While understandably many disabled activists have fought for access to a meaningful and well-paid job, this has not transpired for many people with learning disabilities who require more interdependent forms of support or for whom work is not a practice they will engage with. The closure of segregated and sheltered housing schemes and workshops – while in line with the commendable ambitions of inclusive employment activists – has left many disabled people with learning disabilities with few to no opportunities to labour.

Here, Goodley and Runswick-Cole (2015) acknowledge the inequality of opportunity is the result of both measures of austerity and a continued policy focus on non-segregated employment opportunities. Overall, by exploring only the studies that indicate the severity of ID, those classified as having a borderline/mild ID are, indeed, more likely to have a higher QOL in open employment. Yet, this fortune is not shared by those who have a moderate to severe ID, who were more likely to have been employed within sheltered workshop sites, or who are attending day centres, unoccupied or unemployed. This position adds to the precarious situation experienced by people with more complex ID who are also simultaneously experiencing a reduction in community inclusion provision. This is particularly poignant when, as Lynsaght et al. (2017) found, there is a strong sense of belonging felt by people who work in a segregated work setting, often because people in these working environments often have an opportunity to develop friendships, socialise, and ‘complete activities that increase self-competence’ (p. 927).

Conclusion

This chapter has explored how citizenship and waged work have become interwoven over the last 30 years. The discourses projected within concepts of citizenship and waged work were contextualised through the ‘welfare-to-work’ activation policy trajectory. With a shift in the expectations of the capacity to work, people are transferring from welfare assistance that considered employment to be an absolute barrier, to a position whereby individuals are now expected to engage with work preparation activities. Yet, here, privatised employment programmes are implicitly and explicitly excluding those furthest

from the labour market, through parking and creaming tendencies. In response, ID employment policy reaffirms employment as both attainable and expected from all citizens, through supported employment models. These models, cited as the *best* way to achieve paid work, are under scrutinised and this literature review has revealed that the success and fortune of the supported employment model is not shared by people with more complex employment support needs. Put simply, this model is not necessarily serving this demographic appropriately.

Moreover, the alternatives of yesteryear (sheltered employment and traditional day centre work models) have been significantly reduced through austerity measures and pressure from inclusive activists. This further advanced supported employment, leaving little space for those considered to have a moderate, or more severe, ID to have meaningful opportunities, community presence, or social inclusion (Bates et al. 2017). ID specific employment literature generally frames the benefits of work using psychological and assessment modes, which, like the supported employment advocates, tend to focus on people with a borderline/mild ID. Here, there is little sociological engagement, and, with a few exceptions (Hall 2004; Ineson 2015; Bates et al. 2017) an absence of questioning the normative assumptions associated with notions of work. There is also, importantly, a lack of engagement with the nuanced and complex perspectives provided by the people with an ID themselves. Together then, this literature review highlights and justifies areas for further exploration. In chapter four, I present my methodological positioning for this research study, where I intend to thread the narrative accounts of people with an ID, who are in receipt of social care, throughout my empirical investigation, exploring both the impact and consequences of employment activation.

Chapter 4

Methodology

This thesis so far has explored the backdrop of ID research, considering both the historical context of ID discourse and the contemporary exclusion and marginalised position people with an ID can encounter. Space was afforded to explore how the landscape of employment activation operates for people considered furthest from the labour market – holding the individual to account for their unemployment. Moreover, literature has demonstrated that models associated with supported employment may well serve those closest to the labour market – yet this is at the expense of those considered to have higher support needs and more complex ID. This groundwork has informed the research process.

In this chapter, I situate my study by discussing how and why methodological decisions have been made. It provides detail on securing and navigating access to the research sites, how research data was collected, the processes of fieldwork, and how I analysed the data. I also offer an in-depth discussion on the limitations of my study through ethical reflection. Thinking critically about the responsibilities held as a researcher towards participants opens up critical engagement with ethical tensions that are a part of doing research in an everyday sense (Guillimin and Gillam 2004). Sketching out these inherent dilemmas associated with prolonged engagement in the field offers a nuanced and complex account of a study that aims to represent the voice of people that have been silenced, by making them visible (Pillow 2003).

Positioning the research

In this section, I need to make explicit my biographical and philosophical position, to locate myself within the text. I recognise and take responsibility for my situatedness within the research, reflecting upon the effect that my position may have had on the questions I have asked, the data that I collected, and how it has been interpreted (Berger 2015). As Sword (1999) notes, ‘no research is free of the biases, assumptions, and personality of the researcher and we cannot

separate self from those activities in which we are intimately involved' (p. 277). Blumer (1954) invites us to critically reflect upon our position within social research. I would interpret his account of 'policy' theory (p. 3) as aligning with my study. This analysis is of a 'social situation, or social structure, or social action as a basis for policy or action' (p. 3). Blumer points to the inability to formulate objective traits (such as benchmarking) through micro empirical data. Rather, research accomplishment is achieved by 'yielding a meaningful picture... which enables one to grasp the reference in terms of one's own experience... how we come to see meaning and sense in our concepts' (p. 9).

This *yield* includes detailed descriptions of behaviour and group dynamics through ethnographic study. While objective methods of social science 'may well describe social phenomena, it fails to provide an understanding' (Plummer 1983: 6), whereas qualitative methodology reminds us of the 'lives that exist behind the label' (Goodley 1996: 334). This is particularly important for research with people who have an ID, given the historical ramifications of ID study (Northway 2014), (as detailed in chapter two). Moreover, subscribing to a narrative approach reinforces the subjective understandings of the insider, prompting readers to challenge 'their own (often generalised) understandings of the teller' (Goodley 1996: 335). In short, as Goodley theorises, by taking the words of an informant with an ID, we can question assumptions made on *behalf* of people – 'why do people have to tell me what I have to do and what I haven't to do?' (Goodley 1996: 335). By threading narrative accounts through the empirical data chapters, I aim to contribute towards deconstructing the homogenous position people with an ID are often dominated by. For, by exploring past experience and prospects for work, space is afforded to allow for 'these people' (p. 337) to be represented as individuals (Goodley 1996).

Moreover, this project also draws on research sites away from the ethnography, to contextualise the data and analysis process. The ethnographic site was located in rural England and it was important to offer counter perspectives, from other regions, to enable claims to be made that occur not in isolation. This counterbalance offers what Thompson (1988) considers as essential, since 'too much emphasis on the individual aspect of accounts may fail to present the cut

and thrust of contemporary political narrative and the unseen pressures of economic and structural change' (p. 258). Without this additional data, as a researcher, I may well have, as Goodley (1996) notes, failed to adequately represent the broader implications of the individual's world by turning a 'blind eye' (p. 343) to the social order, without accounts from outside of the dominant research site. Before I started initiating the data collection process, I had toyed with the ideas associated with inclusive research, as an ethically appropriate methodology to explore the field. I now need to explicitly articulate why I did not pursue this research route.

The perplexities (and boundaries) of inclusive research

As part of the wider movement towards emancipatory research in disability studies (Oliver 1992), a growing body of ID research practice advocates the role people with an ID can play within research as a process. Organised coalitions between researchers and people with an ID (such as People First) challenge the role of participants being 'subjects' and 'informants' only, by drawing on the participatory paradigm of co-produced research. Walmsley and Johnson's (2003) seminal text first included the term 'inclusive research' to ignite a change in the relationship between research and people within this demographic. They depict inclusive research to involve people who 'may otherwise be seen as subjects for the research' (2003: 10) as instrumental in the research process, generation, and analysis. The authors pathed the way for future possibilities, 'beyond rhetoric to new realities' (p. 189) of research inclusion.

Nind (Nind and Vinha 2014; Nind 2016; 2017, for example) is a leading scholar on conceptualising inclusive research with people who have an ID, particularly within inclusive education practices. Drawing on processes associated with Freire (1970), Nind offers the guiding principle conceived as the liberation of people that have been oppressed, by using reflection and action and encouraging participants to be active providers of research knowledge (Nind 2017). Moreover, inclusive research holds the *gold* standard of research methods within ID studies (Nind and Vinha 2014; Williams 2011; Walmsley and Johnson 2003). For, as Nind argues, 'more attention will be paid to the knowledge generated by inclusive research and the authors will have stronger, better articulated grounds

for arguing its credentials' (Nind, 2016: 196). By disrupting the assumption that the researcher is the 'expert', inclusive pedagogies embrace the 'nothing about us, without us' (Charlton 1998: 3) commitment to the philosophy and history of the Disability Rights Movement.

Yet, for my research, however much I would like to have worked with these guiding principles of inclusivity, I subscribe to an account offered by French (1993) whereby the limitations of inclusive research would outweigh the benefits for this specific study. First, my data site was a naturally occurring setting for employment preparation. Trying to attain inclusive, participatory research principles within this setting, risked either becoming overly complicated or 'tokenistic' (Woelders et al. 2015: 531), particularly as the research site was not affiliated with a self-advocate movement, nor had job seekers been privileged to attain the resources available to such sites, such as research methods training, networks and access to advocacy services (Walmsley et al. 2018). These significant tensions between the goals of inclusive research and the demands of academia are often at odds.

Moreover, inclusive research tends to use focus groups as the method of choice (Llewellyn 2009; Nind and Vinha 2014) on areas around collaborative, innovative, or alternative knowledge sharing. McClimens (2004) explores collaborative learning; Welsby and Horsfall (2011) researched arts-based methods to express everyday practices of exclusion/inclusion; Fudge-Schormans (2014) disrupts relationships of power through photographic imagery; Povee et al. (2008) promote 'photovoice'; Aldridge (2007) advocates participatory photographic research methods; Mathers (2008) explores toolkits to assist communication; Garbutt et al. (2010) researches accessible material, while Walmsley (2003); Gallacher and Gallagher (2008); Williams (2011) and Nind (2018) all explore a variety of participatory methods.

Inclusive research that is not centrally concerned with methodology as a process, explores attitudes towards people with an ID (McEvoy and Keenan 2013); oral histories (Atkinson and Walmsley 2010); life histories (Stefánsdóttira and Traustadóttir 2015); tensions between choice and disempowerment (Llewellyn 2009); accommodation (Barr et al. 2003) and best value in services (Cambridge

and McCarthy 2001), while Kellet (2010) challenged perspectives on status within society. Here, knowledge based on lived experiences is connected with the social community (Nind 2017; Walmsley et al. 2018) to improve commodification, materialism, or societal positions.

However, before this methodological surge, Walmsley (1994) offered a cautionary position, arguing that the vision of the social model of disability created an imagined group of people with an ID, who get together and identify a research project. They design the research intentions, implement data collection, and formulate analysis. In essence, then, her critique offers the perspective that the social model of disability implies that with the removal of barriers, people with an ID can *take back control* (Oliver 1997). Yet, this perspective rests on disability being analysed as a function of social and cultural barriers. This position neglects impairment within the social model of disability and pays little attention to the cognitive abilities and intellectual capabilities of individuals with an ID. Instead, it is normatively seeking a 'manic desire' (Woelders et al. 2015: 530) to erase difference. Moreover, French (1993) calls out the neglect of impairment within the social model, suggesting 'some of the most profound problems experienced by people with certain impairments are difficult, if not, impossible, to solve by social manipulation' (p. 17).

The boundaries of inclusive research are also not fixed upon research topics. As Simpican and Leader (2015) discuss, inclusion always generates exclusion. Even within a marginalised research area, membership to research groups for people with ID are generally afforded and privileged to people with mild ID, who are actively seeking to support both societal change and recognition, at the exclusion of research involving people who are not within this dominant domain (Simpican and Leader 2015). For, as Clegg and Bigby (2017) note, the representation of someone with an ID often relies on an image of a person mild in temperament, living in a welcoming world within policy and public discourse. As Lyle and Simpican (2015) note, research generally relies on people with a higher IQ and lower support needs, and much like the focus of this thesis as a whole, I connect my research with people who are not necessarily within this demographic or targeted by inclusion within policy and practice.

Moreover, inclusive research is problematic insofar as its idealised principles for actively striving for ‘empowerment and normalisation’ (Woelders et al. 2015: 528) as important values. Normalisation principles are a source of apprehension. While the principle is associated with leading a ‘normal’ life by taking on socially valued roles (Wolfensberger 1983) (discussed in detail in chapter two), where people with physical disabilities strived for involvement in the research process, Woelders et al. (2015) remind us, this was not the case for people with ID. *We* have placed this upon people with ID as a normative concept that *they* must *want*. Adopting an inclusive paradigm would assume job seekers would want to be involved in the time-consuming process associated with research methods. Yet, participants at job club did not attend sessions with the view of becoming researchers; they were seeking a job.

Technical difficulties are also a dilemma with inclusive research, particularly with doctoral studies. Co-authored or co-owned knowledge production creates tension with ethical anonymising procedures (McClimens 2004), particularly where the research location is not an open site of knowledge exchange. As Stalker (1998) addresses, the formalities, demands, and constraints of a single-authored PhD study that has been funded does not lend well to inclusive paradigms, to the point that the study can be incompatible with a co-produced framework. Recently, Armstrong et al. (2019) have explored good practice within co-produced research, developing a self-evaluation tool kit for self-advocacy projects. Yet they also reflect honestly upon the challenges the research project presented, particularly around the costs and investment of time. Fundamentally then, the need for people with an ID to act as collaborators in the research process creates ontological and epistemological concerns. As Humphries (1998: 1-2) notes:

There is a risk in academic debate that preoccupation with the philosophical aspects of any discipline can obscure the lived realities which constitute the substance of the theoretical arguments.

Further, within ID inclusive studies, there is a view that people who have an ID hold:

Unmitigated access to the experience of disability denied to the 'non-disabled' individual whereby constructed knowledge from this position offers a privileged ontology, allowing the construction of 'perspectival epistemology' (McClimens 2004: 72).

McClimens (2004) claims here that inclusive studies of this nature assume the expert by experience holds 'unmitigated access' (p. 72) as representative of people with an ID as a whole. Overall, inclusive research, then, would not have been the most appropriate method to deploy at a research site focused on employment preparation. Instead, an ethnographic study, considered more broadly to be the most ethical form of research (Atkinson 2015) was selected to explore the impact of paid work together with the complex, persistent, and prevalent barriers to employment inclusion.

Notes on ethnography

'Putting into writing, what it is like to be somebody else.'

Van Maanen (2006: 16).

At its core, Hammersley (2018) defines features associated with the research method of ethnography as general principles based on assumptions. These assumptions include direct observation by a researcher, as this is more likely to produce accurate data of what people do, how they do it, and why. This observation is likely to be in a naturally occurring setting, where accounts of participants are collected. The method is likely to feature the lives of the participants, which the researcher is unlikely to have been aware of without participant observation, hence, research is more likely to be valid and interpreted correctly as it is context-sensitive. The elusive nature of Hammersley's (2018) description here, is symptomatic of the nature of ethnography.

Atkinson (2015) draws on Blumer's (1954) 'sensitizing' ideas (p. 7) as a general principle of 'directions along which to look' (Atkinson 2015: 9) to understand ethnographic work. Owing much to the theoretical tradition of interactionism, the interpretive view of sociology puts emphasis on understanding participant actions based on their experiences of the world and how their actions both arise

and reflect back on this experience (Burgess 1984). This 'closeness to the action in situ' (Dicks 2014: 663) is a shared commitment across ethnographic epistemologies, as an 'intersubjective' (p. 664) space shared with participants (Dicks 2014). Blumer (1969) notes that this study on action must be conducted from the actor's position, in order to understand how the actor perceives their situation. Moreover, this presentation of self (Goffman 1959) through the behaviour of individuals is influenced by the presence of other people (other job seekers, facilitators, visitors, and myself), whether this is actual, implied, or imagined (Mannay 2013).

Ethnographic research with people who have an ID has had limited use within the social sciences. Bates et al. (2017) used ethnographic case studies as part of their wider research project focused on the 'Big Society? Disabled People with Learning Disabilities and Civil Society'. Their prolonged engagement (eighteen months) with five participants enabled the complexities of work engagement to be explored through 'rich qualitative snapshots of employment experiences' (p. 166) in times of austerity. Ginsburg and Rapp (2013) used ethnography to explore innovative transition programmes for young people with an ID in America, aimed at de-medicalising the experience of disability. More broadly, Cooney et al. (2006) explored stigma and self-perception, while Redley and Weinberg (2007) researched the limits of liberal citizenship. Still sparse, ethnographic methods have been deployed to explore group homes and residential settings (Antaki et al. 2009; Bigby et al. 2012), and surveillance technologies (Niemeijer et al. 2015). Niemeijer et al. (2015) explored the tension between the increase in freedom of movement offered through the medium of tracking systems and video surveillance for people living in long-term residential settings and how this can impact privacy, autonomy, and intrusion.

Ethnographic space is afforded more opportunity within health research for people with an ID. Kaley et al. (2018) explore the use of video in ethnographic research around health and well-being interventions; Tuffrey-Wijine et al. (2010) research the understanding of cancer diagnosis and prognosis; McCabe and Holmes (2013) explore sexual health through a critical ethnography, while

Bernert and Ogletree (2013) drew on ethnographic methods to explore how women with talk about their perceptions of sex.

My research aligns with critical ethnographic methods, associated with Denzin and Lincoln (2003). Described as 'ethnography with a political purpose' (Koro-Ljungberg and Greckhamer 2005: 296), critical ethnography seeks to contribute to change, with the author positioned as a 'mediator between two separate worlds' (p. 294) that is 'always affected by moral and political processes as well as the researcher's themselves' (p. 296). Moreover, this position is reaffirmed by the ability of the researcher to connect with questions concerned with broad social movements. Thomas (1993: 4) describes that critical ethnographers 'often speak on behalf of their subjects in an attempt to empower them and/or to contribute to social change'.

Critical ethnography has, more recently, been claimed as a form of advocacy ethnography. Coined by Smyth and McInerney (2013) in their methodological commentary paper, the authors call for advocacy ethnography to connect ethnographic points of departure offered by critical ethnography and activist research, with the hope of moving beyond the conventional and, instead, towards ethnography as a route to influencing social policy. Advocacy research stems from a range of 'liberating' methodologies such as feminist research and reflexive approaches, which 'incorporates empirical investigations of social problems by people who are deeply concerned about those problems' (Gilbert 1997: 101), placing social justice and calls to action at both the front and centre of the research project (Gilbert 1997). Using this lens, I contest claims made by Haight et al. (2014) that 'ethnography does not offer us a road to better practice and policy' (p. 128). This position would subscribe to the idea that ethnography is a secular enterprise, 'concerned with understanding people's behaviour for its own sake, rather than in order to serve some practical goal' (Hammersley 2018: 7). Rather, the framework for advocacy ethnography is to take an active stand in representing the experiences of oppressed groups, without compromising the integrity of the research when it is 'based on rigorous, robust, authentic and documented ethnographic accounts' (Smyth and McInerney 2013: 2).

Fundamentally, advocacy ethnography offers the theoretical positioning of *what is it* and *why do it* by directly pulling on an openly ideological (Lather 1986) framework to research that actively denies social research as neutral; we all carry theories that are worked or re/shaped by the field and existing knowledge. Smyth and McInerney (2013) suggest that if research were to be ‘hermetically sealed’ (p. 3), it would be ‘severely diminished and impoverished’ (p. 3). In essence, then, adopting the position that we stand for those who are not represented, working ‘*with* and *for*’ (p. 4) those who are silenced, unfairly ignored, or marginalised, brings policy pressure to interrupt exclusion. This position promotes the social policy pathway of exploring patterns of inequality and policy, with ‘consideration of how human action relates to social structures’ (Wright 2012: 311). In this paradigm, my reflexivity is situated as a commitment that my research is compassionate and not exploitative, with the aim of helping address the negative effects of Others (Pillow 2003).

Getting in

For some time, I had been following various social care sector organisations on social media and subscribing to email newsletters. A few months before I embarked upon my PhD, I saw a social media post celebrating Green Meadow’s success in securing charitable funding for a three-year employment preparation programme.¹² This project immediately sparked my interest as a potential research site, for four reasons: I was familiar with the organisation; the project would not dependent on local authority funding, and therefore, was not subjected to their outcome criteria; many of the people supported by Green Meadow would not be able to satisfy the entry requirements of supported employment programmes, and; I was confident I could negotiate access to the research site. Initial contact was made with Jennifer, the Chief Executive Officer (CEO) at Green Meadow.¹³

While I did not know Jennifer well, we had been in the same meetings at various points over the previous decade. Before beginning my Higher Education journey,

¹² Green Meadow and all other named research sites and locations are pseudonyms.

¹³ Jennifer and all other names of individuals throughout this thesis, are pseudonyms. Some participants choose their own pseudonym.

I had previously been employed as a Community Outreach Manager for a similar organisation to Green Meadow (discussed in more detail in the ethics subsection). This route to access was invaluable, providing initial reassurance to her that I had experience in the field, and as a mechanism to encourage trust-building. For, as Hammersley and Atkinson (2007) note, access to a research site is often granted not on the research topic, rather, the kind of person that will be carrying out the research.

After emailing Jennifer a brief overview of my research intentions, I was invited to Green Meadow for an initial visit. Multiple emails were subsequently exchanged, supported by a further three visits. Jennifer was very studious in her approach. I satisfied her concerns about participant consent and the Mental Capacity Act, risk assessments regarding the impact of potential research to participants (both of which I shall return to in the ethics subsection), and how I could operationalise my research intentions. Jennifer and I agreed that I would be ascribed to the position of a volunteer at the job club. This offered a two-way beneficial arrangement; I would be able to adopt a participant observational approach, being active in the field, rather than a passive bystander and, in return, Green Meadow would secure a regular volunteer for around a year. As a conceptual tool, this position of participant-observation had many benefits. The ability to be active in the field is described as the yardstick for qualitative research (Burgess 1984) by enabling a greater informational yield (Blumer 1954) than many other methods. For, participant observation offers the most complete information about social events and their occurrence (Becker and Geer 1957).

As a volunteer, I went through an induction process with Green Meadow. This involved completing an online training programme, multiple meetings with the volunteer coordinator to sign off the policy and procedures of the organisation, and completing the Disclosure and Barring Service (DBS) process. In return, I was able to provide my volunteering hours to the volunteer coordinator every month as a 'payback' (Silverman 2005) so that these hours could be collated and contribute to the overall volunteering reports. These reports could then be used positively for future funding bids. Towards the end of the formal volunteer

induction process, Jennifer introduced me to Sally, the job club manager. Sally instantly raised concerns with Jennifer on who would 'supervise' me on a weekly basis. While I reassured Sally that I would work under her direction and carry out any duties she felt appropriate, Jennifer then revealed to Sally my previous professional experience, and the benefits this could offer both to the job club and Green Meadow. This, with my offer of being a (free) 'extra pair of hands' at Sally's disposal, became appealing – I now had my gate-keeper. Being a volunteer at the job club had many benefits; Sally was reassured that I was there 'officially' and I was very pleased to have the freedom to ask questions to job seekers as part of my volunteering role. Moreover, I would be able to build a rapport with the job seekers and gain access to information that may not have been available had interaction been limited or controlled.

Fieldwork

'We follow the phenomena'

Atkinson (2015: 35).

Ethnographic fieldwork is, as Atkinson (2015: 3) eloquently summarises:

Immensely satisfying personally and intellectually. It provides uniquely privileged opportunities to enter into and to share the everyday lives of other people. It provides us with the challenge of transforming that social world into texts and other forms of representation that analyse and reconstruct those distinctive lives and actions... the conduct of ethnographic fieldwork is the most rewarding and most faithful way of understanding the social world.

I started volunteering at the job club as soon as my DBS check was through.¹⁴ This was sometime before my ethical approval had been confirmed, yet Green Meadow was keen for me to begin and I did not want to risk their momentum and commitment. For the first two months, I volunteered without collecting any data. This time allowed for a relationship to become established, prior to data

¹⁴ A DBS (Disclosure and Barring Service) checks the criminal background of an employee.

collection commencing, which has been emphasised as important within the ID research field (Stalker 1998). Job club was in its infancy when I first attended and located in an inaccessible space above the café where the group met each week. While it did have internet access, not everyone who wanted to become a job seeker with Green Meadow could access the room – it was an awkward messy space with a steep staircase and no lift. Sally arranged to move the club down to the local church hall and, while the location was now accessible, internet access was not available, and this regularly limited the weekly activities. To overcome this, Sally, Lucy (job coach), or myself would regularly accompany job seekers down the street to the local library, to access half an hour of internet each time.

The church hall was spacious yet dated. There was a small kitchen area, which was often used to role-play 'café experience' (an important space, explored in depth in chapter nine). We frequently had unexpected visitors; the vicar would pop in to complete various tasks, and the local church community would come in as part of their routine, often slightly perplexed to see us there. From early November until Christmas week, the space was shared with a table-top sale organised by the church, who were selling Christmas paraphernalia. Members of the public would regularly come in, and, when seeing us there, would often turn around embarrassed that they had interrupted the group. We would take turns in reassuring the shoppers that they were in the right place and the sale was on. Moreover, shoppers would gaze over at us, trying to understand what was going on in their church hall, and sometimes we would engage in conversation, explaining the group. The response was generally of wonder and confusion. Well-meaning exchanges of 'well, they need to do something don't they' and 'it's nice to see them out and about' were commonplace.

As time passed, I felt I became a 'regular' volunteer. I facilitated workshops, helped job seekers devise their CVs using specific ID supporting visual and audio software, and helped people to fill out online application forms. Sometimes, I would not collect any data as I was tasked to work with people who were not within my research remit (i.e. either did not have an ID or were undiagnosed). Yet, where possible, Sally matched me to work with people who would be able to contribute. At times, Sally asked if I had any areas I would like to cover, for she

was concerned that I was not 'getting enough' data. In response, I suggested a 'what motivates you to want to work' workshop as this was something that had not been engaged with in detail and was a gap within my data collection.

Each week we (facilitators and job seekers) would meet at a local café for around half an hour. Here, facilitators spoke freely (sometimes together, sometimes alone, depending on who was facilitating the session). This time provided an unequivocal opportunity to ask questions and listen to weekly updates. After tea and a chat at the café meeting point, job seekers walked collectively to the church hall. A risk assessment was in place stating that job seekers must walk in single file due to a busy road. As the work manager, Sally facilitated the job club and was trained in systematic instruction (discussed in chapter three). Moreover, she had an extensive work history of supporting disadvantaged people into paid employment. Yet, this role was her first facilitating employment within the intellectual disability community. Lucy was a job coach, also trained in systematic instruction. She attended the job club depending on her coaching commitments and planned activities, for, she was only employed by the job club for eight hours per week, with the rest of her working hours being provided as a support worker elsewhere within the organisation.

At the beginning of each job club session, there would be an opportunity for job seekers to speak about how their week had been. Initially, this was viewed by Sally as an opportunity for job seekers to share their experiences of job seeking activities over the previous week. Sally would attempt to keep this space as a work-focused opportunity to share progress, however, it soon altered in focus to be an additional space for a general catch up, even after spending half an hour chatting at the café. Job seekers would use their time to share details of their holidays, weddings, pets, and socials. The catch-up time was usually facilitated by using a wooden spoon, where, whoever was holding the wooden spoon could talk, as a route to stop job seekers from interrupting each other. This ritual, Goffman (1983) would suggest, attunes to interactional order, specifically about turn-taking. As an interactional device, the wooden spoon enables social encounters to be possible, while limiting the disruptions associated with groups

of people who have an ID (Dowse 2009a). The wooden spoon then, acted as an artifact to enforce interactional order.

After the collective catch-up, job seekers either worked one-to-one with Sally, Lucy or me, or worked in small, facilitated groups. Individual job seeker's each had their own work file which stored their CV's (promoted as an *opportunity to sell yourself*), personal profiles (identified strengths, weaknesses, and work preferences), an employment information guide (how best to support the individual in the workplace- a guide for a potential employer), and worksheets that are completed each session. Most sessions included a themed workshop. These themes were identified from three monthly objectives set out by the group and dependent on identified employment needs from the profiles. These themes included workshops on dressing for work, banter, feedback at work, conduct, following instructions, health and safety, and time management. Some of these workshops were specifically driven towards increasing productivity (a subheading in chapter five). Workshops would be delivered predominantly using quizzes, picture cards, and role play. For example, Sally explained to the group one week:

I've got a little game with lots of pictures of different work places and I thought maybe we could go through it and have a little quiz or something – working out what people are wearing and why they are wearing it and if it is right.

Completing worksheet tasks were often a source of anxiety and discontent for the job seekers due to literacy abilities, and in response, Sally and I established a pattern. She would ask the questions and I would write the answers on plain paper for the job seekers to copy onto their worksheets. An example of this can be seen in figure 2. Worksheets were always accompanied by pictures and symbols to support understanding:

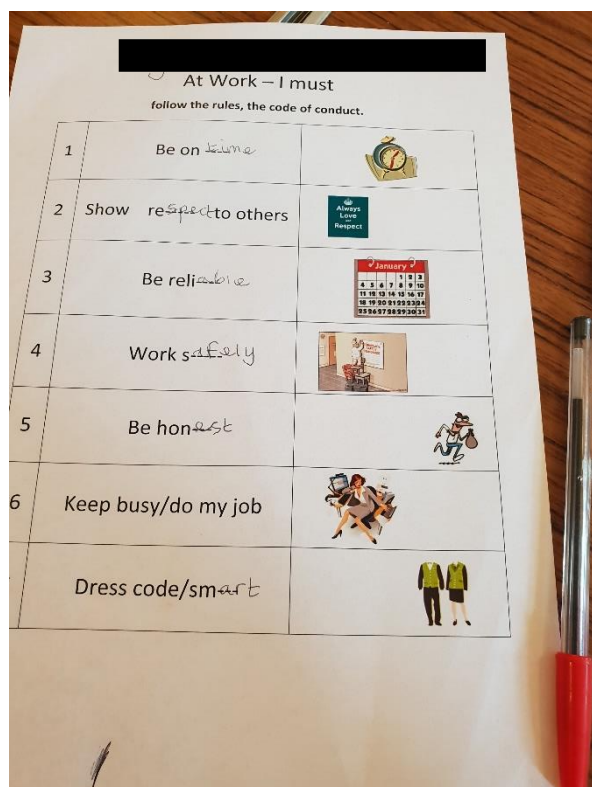


Figure 2: an example worksheet

Even with clues, it was necessary for me to write out the full answer for the job seekers to copy over to their own sheet. This worksheet (figure 2) had some of the letters already in the answers and the right amount of gap for the correct answer; “when you have a job you must be on t_m_” “we must all work safe_y”. Once a sheet or an activity had taken place, it would be recorded in their individual work file. Job seekers all had complex and varied intellectual capacities and capabilities. For context, this is a brief overview of each job seeker, involved in the data collection:

Job Seeker	Brief overview
Sophie	Sophie lived independently in the community, through an independent living scheme. She received half an hour of support twice a day. This support helped Sophie with her medication, food preparation, household tasks, and budgeting.
Karen	Similar to Sophie, Karen lived independently in the community, through an independent living scheme. She received half an hour of support twice a day. This support was

	to help Karen with her medication, food preparation, household tasks, and budgeting.
Millie	Millie also lived independently in the community, through an independent living scheme. She received half an hour of support twice a day. Millie only attended job club for the first few months as she secured a (paid) fortnightly paper round. She would, however, often meet with us for a drink at the café before job club and attended functions and social events.
Naomi	Naomi lived within a registered residential care home. She required one-to-one support to access the community, including having a one-to-one supporter at the job club.
Verity	Verity lived within a registered residential care service. She required one-to-one support to access the community, however, she was assessed as 'safe' to be dropped off at the community café as long as Sally, Lucy, or myself were already at the café. She was then collected by her supporter at the end of the session.
Tara	Tara lived within a registered residential care service. She was risk assessed as being able to access the community independently and can use public transport by herself.
Huw	Huw lived in the same residential care home as Verity. He required one-to-one support whenever he accessed the community. Huw had behaviours that would be considered to be challenging. He was often verbally inappropriate towards females and would use inappropriate language.
Jackie	Jackie was not diagnosed as having an intellectual disability. She lived locally with her husband.
Robin	Robin did not have an intellectual disability. He had issues with his mental health. He lived locally within a sheltered housing scheme.
John	John lived in a registered residential care service. He required one-to-one support to access the community. John had a one-

	to-one support worker with him at the job club. John joined the job club towards the latter stages of data collection.
Rebecca	Rebecca lived in a registered residential care service. She required one-to-one support to access the community. Similar to Verity, Rebecca would be dropped off and collected from the job club. Rebecca joined the job club towards the end of my data collection.
Barry	Barry did not have an intellectual disability. He was referred to the job club by the local job centre for assistance with his additional learning needs. Barry did not attend secondary education and struggled profoundly with his literacy and numeracy skills.
Esme Ian Lara Jill	Esme, Ian, Laura, and Jill all lived within a registered group home, attending job club periodically. They were, however, all very involved in the 'pop up café' work experience project that is detailed in chapter nine.

The additional context presented here lays bare the diversity of need for the people attending job club. Presenting this information is at odds with an inclusive research paradigm (Nind 2017; Johnson and Walmsley 2010) yet my research project is very much aligned to understanding impairment to highlight different experiences (Thomas 2004). Moreover, it is essential to note here that while many of the job seekers had one-to-one support workers in attendance with them, I made an active decision not to draw on the voice of support workers (unless to illuminate a point within the analysis for context). This decision was based on the argument that 'dominant constructions of mental incompetence and lack of agency have kept the voices of people with an ID 'in the shadows' of research' (Hall 2004: 300). Such research projects are designed in ways that prohibit 'talk' by people with ID, and instead, only the representative voices of carers or supporters are heard (Coles 2001). By including data from support workers, I risked losing the 'voice' of the job seekers that this very study is advocating for. This justification is also used for my decision to privilege the

words of the participants over my fieldnotes. Therefore, unless I have explicitly referred to drawing upon my fieldnotes, the analysis presented within the empirical chapters, are vignettes directly recorded from the job club.

Collecting data

I spent approximately 15 months collecting data at Green Meadow. Over 200 hours of observations were collected from the job club at this specific research site, and two evaluations of a pilot work programme. These observations were supplemented with a documentary-style analysis (photographs of worksheets) collected from job seekers. Other times, CVs, application forms, and mind maps from the job club were captured visually. During this time, I had weekly access to Sally and frequent contact with Lucy, where I could ask questions freely.

Each job club meeting was voice recorded using a mobile device. Sometimes, if individual workshops were occurring, I would leave the device on the centre table and move away to work with my smaller group/ individuals. This meant that I could capture data that I was not physically present for. While Hazel (2016) suggests voice recording data sites have the possibility of contaminating the evidence and setting ecology, I decided from a practical position to yield data and openly record each session. For, I would not have been able to adequately take notes while being an active participant in the field and facilitating workshops.

After each session, I would return to my car and make initial notes in my fieldwork notebook. Generally, these were the observations of 'things' that would not be captured by the recorder, for instance, eye contact and dynamics and events from the café meet-up. I would then spend an hour driving home, where I would relive the events and pick up on particular situations. I used my recording device to 'talk to myself' and work through emerging ideas, which I listened back to, ideally (and usually) that same day. These notes and emerging ideas were then added to my fieldwork notebook, where, fieldnotes heightened and focused my interpretive and analytical processes to provide a deeper understanding of the events and scenes that unfolded (Emerson et al. 2011). As Emerson et al. (2011) comment, fieldnotes are 'a major vehicle for beginning to capture local knowledge and indigenous understandings' (p. 129).

Moreover, I would transcribe the raw data usually within a day or two of each session. Here, while listening back to the data, I made additional fieldwork notes. I did consider employing someone to transcribe the data due to time constraints, however, some of the job seekers (particularly Verity and Karen) have difficulty with words and it was very important for me not to have their representation and contribution to the data collection diminished or erased in any way. It was only by familiarity, time, and contextual understanding that confidence could be gained to transcribe these rich narrative accounts. While time-consuming, transcribing the data myself also allowed for a continued familiarity with the data and to collect and analyse simultaneously (Charmaz 2001).

Green Meadow intended to provide 3-monthly cohorts of employment preparation support. I intended to stay for a year, and, if according to plan, this would have allowed access to four different cohorts of job seekers. However, this did not happen. Occasionally new people joined the group, yet most were there for the full year. The extended period of contact with job seekers provided a much more detailed, nuanced, and richness to the data, particularly as the data emerged from a naturally occurring data site, where every session at the job club was focused on employment and employment preparation. There was no hanging around waiting for data to arrive, as associated with much of ethnography. The trade-off to having such rich, narrative material, was that the sample size was much smaller than I had anticipated.

Fossey et al. (2002) address this impasse by suggesting it is not the fixed number of participants that should be of concern, rather, whether the depth of information collected is sufficient to enable the description of the studied phenomenon. The adequacy of the sample size is therefore determined by the appropriateness of the data, instead of the number of participants that take part (O'Reilly and Parker 2012). Towards Christmas 2018, Sally began trying to move people on (and out) of the club and I took this as my cue to exit the field – I had not been collecting any 'new' data for a little while, and conversations were becoming overly repeated. In essence then, this depth of data allowed for a range of experiences to be collected, yet with regular repetition, it was time to withdraw (O'Reilly and Parker 2012).

Still, in addition to the ethnography, I met with various other stakeholders to explore some of the experiences felt by the participants and to supplement the data with a broader understanding, from a range of settings. I met with twelve key stakeholders - this included third sector organisations, academics, and local authority employment representatives, from various localities. One of my PhD supervisors put me in contact with the head of a third sector organisation, who in turn, suggested I meet with Bob, a local employment support manager. Bob became a key site for contextual understanding and complementary data collection. Moreover, he was able to provide a Welsh perspective to my data and I was able to draw on his wealth of experience to offer a broader context, particularly in regards to specific examples around funding requirements, decision making, and project evaluations.

Bob worked with people who were diagnosed with an ID and were in receipt of social care (albeit with a focus on younger people, under 25). His organisation was the only one I came across that did this routinely. For, while there may have been an occasional example from the other potential stakeholders, work here was overwhelmingly occurring with people who were classed as 'disadvantaged' (explored in detail within chapter five). Other potential stakeholders may have appeared to be supporting employment for this group, yet after an initial meeting, it became clear this was not the case. The examples offered here, of the initial expectation of finding people within my research demographic, yet these people being absent from employment inclusion, will be further picked up for discussion within the ethical section of this chapter.

In addition to speaking to the *professional* stakeholders, it was also important to continue my approach of seeking to understand and interpret the experiences offered by job seekers themselves. Here, two further sites became key for complementary data collection, with both of these sites located in different parts of Wales. Similar to accessing Bob, my PhD supervisor offered to negotiate access to The Roasted Bean, a small, community café that offers work to people with an ID, who are in receipt of social care. During an initial visit, I explained my research and I was subsequently invited back to take a table in the café for a day. Five staff members shared their experiences of work, from both at The Roasted

Coffee Bean, and past encounters (discussed in more detail later in this chapter). In addition, three parent-carers asked to share their experiences, as too, did two of the café founders. The Roasted Bean is a self-reliant group, defined here, as between five and ten people who share a common purpose, built on shared interests and skill development. The group received a small loan for set up costs and equipment, help with a website, and had access to a mentoring programme during its first year. The experiences of people working and/or supporting The Roasted Bean are drawn upon particularly in chapter nine, through the exploration of an alternative approach to employment activation.

The final substantive data collection site was offered by Power. In my role as a trustee for a local People First organisation, a fellow trustee asked if they could pass my details on to a third party, that may be mutually beneficial. I agreed, and Power, a Community Investment Company specialising in knowledge exchange, training, and consultancy, made contact with me. Initially, I met with one of the founder members, and we agreed that there was significant overlap between our areas of interest. I was asked to attend and contribute to a 'knowledge sharing' session based on employment services and scoping out provision, with my contribution aligned to underpinning knowledge of both supported employment literature, service development, and design. I contributed to the knowledge sharing session and the reciprocation of knowledge exchanged, broadened my local awareness and different policy contexts.

What I had not anticipated, however, was the kind offer made by the knowledge exchange attendees: to return after a short break and allow me to collect data. In this room, I had key informants to hand, both from Power and other representatives. The founding members of Power – Richard, Margaret, Gerry, Roger, and Steve – are worker/directors, making company decisions equally and they trade as a cooperative. Richard and Steve, both have an ID, being experts by experience – they had both been through various employment programmes. Gerry, Margaret, and Roger, do not have an ID, rather, they have all worked with people who have an ID over many years, in various settings. Mia and Grace both had long-standing relationships with Power established, supporting the social

enterprise in its infancy. Mia was from a social firm's organisation, while Grace was from a cooperative exchange programme.

It was unlikely that I would be able to gather such a group together again for some time, and while underprepared for the unexpected opportunity, I could not refuse this offer and therefore, I devised an ad hoc focus group. A focus group would not have been my method of choice, for dominant voices may overshadow other participants (Aldridge 2014). Yet, on this occasion, there was a yield of data on offer to me. I spent the first 10 minutes talking about my data site and the emerging themes. By drawing on keywords (pretend work; fake work; therapeutic work and; unpaid work) to explain my study, participants had the tacit knowledge to understand what my research was exploring. In this context, conversation flowed between participants, and when the conversation naturally concluded, I presented new ideas and themes. In total, the focus group spoke together, sharing stories and ideas, for over three hours.

The group dynamics here offered a shared space built on respect, validation, and a safe environment. It enabled all participants to contribute to the discussion and contributors were able to collectivise their contribution (Llewellyn 2009). Yet this approach had significant ethical dimensions and I shall return to this in the ethical subsection. Once I had gathered additional data from Bob, The Roasted Bean, and Power, the contextual ground from a Welsh context completed my data collection process. I was then able to analyse and interpret these findings, embedding them within the on-going analysis-interpretation associated with the analysis process offered through ethnography.

Analysis

Early on in the data collection phase at Green Meadow, once I had transcribed the collected raw data, I began to use computer software to aid the process of coding and analysis. Yet, I felt distant from its 'rawness' and struggled to recognise the data once it had been separated, categorised, and fragmented (Atkinson 2015). Rather than continuing to render data down to fragmentation, using reductionism, I altered tact. For, with a small scale, in-depth study, I could instead, focus on the authenticity and complexity of lived experience by conveying the perspectives of job seekers (Lawrence-Lightfoot 2005). This

occurrence was simultaneous with my preference for an advocacy ethnography approach in the research journey. Pragmatically, early on, once the data was transcribed, it was printed out and colour coded by hand into emerging themes. The process was consuming, and many hours were spent on this section of the analysis, particularly when raw data could be coded to multiple themes.

After a while, I was able to 'sift systematically' (Emerson et al. 2011: 171) through my fieldwork notes and transcribed data. Here, I could identify threads that could be 'woven together' (p. 171) to offer a story about the social world that I had observed. To achieve this, I coded data analytically related to topics, categories, and phenomena (Emerson et al. 2011). This process was fluid, however, and the simultaneous data collection and analysis that Charmaz (2001) point towards within the data collection section, resonates. I had initially connected my theoretical insights fluidly towards Dean's (2003) life first approach to employment, based on the initial data analysis, as themes emerged. As the ethnography developed, Dean's work did not provide an adequate theoretical explanation, for it did not explain why people who were not formally required to actively seek work, were choosing to do so. Further, in the early stages, the analysis also lent to Mouffe's (1991; 1993; 2000; 2013) radical democratic approach. Again, there was an inadequate theoretical connection offered by this framework. For, my emerging analysis was exploring grey spaces sometimes based on undertones and nuance that could not fit such a direct concept to challenge structures of power.

Next, I explored the connections with Goffman's theoretical offerings, and still, the concepts offered by Goffman alone left unanswered questions and did not fully satisfy when connected with themes. I continued to connect the themes with alternative theories, from different perspectives and it is here that, by connecting Goffman (1952) with Berlant (2011), and her conceptual framework of *cruel optimism* that I felt I could adequately explain what was occurring at job club theoretically. This process then, offered what Atkinson (2015) describes as a 'pari passu' (p. 9) process, whereby the 'collection of data is informed by the emergence of potentially rewarding analytical concepts and in turn, fieldwork

helps us to extend, develop and refine those concepts' (p. 9-10). Fieldwork and analysis are, therefore, not mutually exclusive.

By avoiding snippets and fragmentation methodically, I could document real-life conditions (Foley 2002) and allow local and situated culture by deconstructing the cultural location through historical connections, language, and influences (Derrida 1981). Utilising rich narratives, life history, naturalist inquiry, commentary, and storytelling (Emerson 2011; Atkinson 2015), invites 'understandings which are moving, ever-changing and flexible – just like the stories we hear every day' (Goodley 1996: 337). Complementing this with the additional data collection offered by Bob, The Roasted Bean, and Power, provided context for a broader account, by drawing on the participants' constructed experiences and memories. These contain narratives of 'hard luck stories, stories of success and failure, and stories of troubles overcome' (Atkinson 20015: 95), to extend the plausibility of accounts offered from the ethnography (Atkinson 2015).

Ethical considerations and space for reflection

While I present a specific subsection to attend to ethical considerations, I have threaded my ethical values and subsequent decisions throughout this chapter, for example, how attention to the boundaries of anonymising data collection and providing pseudonyms are at odds with inclusive research. Ethical approval for this study was submitted early on in year one of my PhD programme. This decision was based on the availability of Green Meadow as a research site and the opportunity to gain access early on in their funding period. My application was subsequently approved, on the proviso that any person accessing the job club would not be impinged in any way, from either choosing to take part, or wishing to decline, participating in my research. All job seekers at the job club agreed to take part.

Just before I began the data collection phase, Jennifer (CEO) made contact to ask what she termed as a 'hypothetical' question. She asked what would happen if, as the host organisation, Green Meadow were to refute my research findings and contest its publication. Instead of providing an instant answer, I said I would seek advice from my supervisors. My supervisors and I discussed this dilemma. We

decided that I would have the freedom to use my own research without risk, as, to revoke the data would be to retrospectively silence the job seeker participants. The only way to remove data would be for individual job seekers to revoke consent. Jennifer appeared satisfied by this response and it was only months later that I understood why she had suddenly asked this after all of our initial contact. It was at this point that she became aware of an impending take over by a national organisation, and I am indebted to her for 'future-proofing' my data, even if I did not fully appreciate her efforts at the time.

Fortunately, the new organisation did not contest my position at Green Meadow or my data collection. Yet, this too has an ethical dilemma. When the new organisation took over, the volunteer coordinator was made redundant. For me, this meant that no one at Green Meadow's head office knew that I was volunteering (and collecting data) at the job club. Neither Sally nor Lucy referred to my presence and I stayed 'off the radar'.¹⁵ However, I think this was by chance, and the outcome could easily have altered had a representative from the new organisation dropped in one week. On reflection, I do not think it would have been possible to secure access to the research site under the new organisation, for I would not have had the connections or established networks.

Returning to the early stages of the project, once granted, I sent my approved ethics documentation along with draft information and consent sheets for participants to Jennifer at Green Meadow. Information sheets and consent forms were devised using an 'easy read' format which avoided long words or unnecessary jargon, used the appropriate font size, and was accompanied by photo references (appendices 3, 4, and 5). This in itself holds debate, for, it assumes that individuals will then promptly be able to understand the details of the text as a homogenous group, which in itself, falls short of the premise to reject a 'one-size-fits-all explanation of the world' (McCleimens 2004: 84).

Moreover, there is an inherent assumption here, that participants have the relevant details before they agree to be part of a study and informed consent is gained when the participant signs the consent form to agree to take part, along

¹⁵ Sally and Lucy were, at the time, preoccupied with their own employment concerns.

with their right to withdraw at any time. Yet, informed consent is an on-going process (Allmark et al. 2009; Josselson 2007). In response to these concerns, I reminded participants regularly as to why I was there. Each time there was a new job seeker, a visitor, or a different support worker attending the session, I explained my research and that I was recording the session - captured through the audio recording device and subsequently transcribed. I also made the active decision to make a point of exaggerating my turning on of the voice recorder in front of participants each week and openly leaving the audio recording device in the middle of the table.

These processes and considerations offer what Guillemin and Gillam (2004) refer to as a checklist of ethics to thereby grant 'institutional credibility' (p. 269) for the researcher to conduct their research. Yet, somewhat absent from these formal ethical procedures and clear-cut, justifiable decision-making rationale, is capturing the dilemmas associated with ethics in practice. Guillemin and Gillam (2004) scope out the significant differences between procedural ethics (seeking approval from the ethics committee) and ethics in practice, or, to adopt their terminology, 'ethically important moments' that are concerned with the 'everyday practice of doing research' (p. 262). Guillemin and Gillam (2004) draw upon reflexivity being used as a resource to adapt to ethical notions that are unanticipated. Examples of these everyday dilemmas are threaded throughout the remainder of this subsection.

First to consider is my perceived role as a volunteer. In this role, I adopted the behaviour of a volunteer. I accepted small gifts (a box of chocolates for Christmas, a 'thank you' pot plant when I withdrew from the field), yet I tried to maintain a professional 'working' relationship with the job seekers. However, similar to other research with people with ID (Stalker 1998), these boundaries became fluid and friendliness crept in. Naomi (job seeker) in particular, became over-familiar and very tactile. She would often seek me out during activities and take my hand, sometimes holding it for the whole 2-hour session, letting go only to allow me to complete a task (such as writing) before 'grabbing' my hand back. While this may have been interpreted as inappropriate, I did not ask Naomi to

stop using touch as a form of communication and sensory connectiveness (Jensen 2015).

Further, job seekers, particularly when we were in the café before the session started, often chatted about how their week had been and I joined in, with general offerings of what I had been up to. This friendliness transferred to the job club session. When we took turns around the table to spend a few minutes each talking, I took the same approach as Sally and shared surface-level insights into my life, such as disclosing if been to the beach at the weekend, or that I had been to visit family somewhere. These disclosures built trust and familiarity with conversation as a two-way process (Stalker 1998). Naomi, Sophie, Jackie, and Verity would all ask after my children, appearing to enjoy listening to what they had been up to and Verity would invariably ask me what I was cooking for tea that night, and share stories of what she was planning on having for her meal. While small, these seemingly everyday dilemmas offer an insight into whether my role as the researcher, demonstrates ethical competence (Guillemin and Gillam 2004). More significantly, ethics in practice can be explored for this research project, by paying attention to the insider/outsider continuum.

The insider/outsider dichotomy

As Coffey (1999) discusses, conventional approaches to ethnography point towards a duality; the observed and the observer. As the observer, the ethnographer adopts a position of 'ignorant outsider' (p.22) and fights familiarity (Delamont and Atkinson 1995) as a way to de-familiarise the accustomed studying of familiar settings. To address this conundrum in my research, I avoided my previous employment, and, instead, I drew upon my networks to gain privileged access (Drake 2010) to a different organisation. While it is fair to say, the representations, observations, and position at Green Meadow were familiar, and I had connections with some of the job club participants through mutual acquaintances, as an alternative field, I was not familiar with the job club attendees or job coaches directly. This was a purposeful decision to avoid the perplexities of challenges to the insider (Leigh 2014). Yet, I had enough 'insiderness' (Leigh 2014: 429) to secure access, build trust, and have privileged access to a site that would not have necessarily been secured to

a researcher without enough insight into the issues people with an ID can face, or the challenges and complexities of navigating everyday life for people who are often reliant on services.

Hammersley and Atkinson (2007) refer to this insider/outsider dilemma as a research continuum. On this continuum, I held prior knowledge of being experienced in the field of supporting adults with an ID. Yet, I also had a fairly unique experience of securing charitable funding, developing a work programme similar to Green Meadow, and evaluating the key performance indicators to the funders. These similarities appealed to Green Meadow, albeit with a different working model and framework application being offered at the site. For, Jennifer (CEO) and I negotiated that I would assist Sally with a programme evaluation, yet this decision had implications. Sally could have easily decided to perceive me as a threat somehow, with me silently judging her decision-making, rationale, or her becoming overly aware of my professional 'clout'. Fortunately, Sally was not phased, and instead, she proclaimed that she, *'wasn't great at the reporting stuff'* that was required of her. As time went on, Sally did not ask me to help with the evaluation and I did not explicitly offer. Instead, to reinforce that I record all of the sessions, I wrote up a simple evaluation of a work experience programme that Sally implemented (explored in chapter nine), and I emailed it to her without copying anyone else into the email, for her own use.

Furthermore, these positions of the duality of the insider/outsider often became fluid and context-dependent (Coffey 1999). During this project's infancy, while I was going through the DBS process at Green Meadow, initial contact with potential stakeholders and/or alternative field sites posed a significant challenge. For, while trying to grapple with the context of how local policy is enacted, I was routinely presented with 'success stories' to the extent that I internally agonised over whether my research was warranted. Had I not had previous experience in the field, both professionally and at Green Meadow, and seen first-hand the depth of exclusion that is experienced by some people, I fear I would have altered the direction of my research. I vividly remember an initial meeting at one potential site where I met with two employment support officers. Here, it appeared there was no problem with employment support models – they

presented me with outcomes, statistics, and promotional material supporting their claims. I could not marry up how my experience was so different from the information being offered. Schutz (1964) suggests that when a researcher is inadequately immersed in a world they fail to understand, theories flounder. Here then, had I not had 'insiderness' (Leigh 2014: 429) and privileged access (Drake 2010) to Green Meadow already established, I fear I would have moved away from my initial research questions and considered other research areas.

Moreover, the insider/outsider dichotomy also became distorted during certain periods of disruption. Green Meadow was taken over by a national organisation eight months into my field research. This was a situation I was familiar with, as the same had happened some years back at the third sector organisation where I had previously been employed as a manager. With the experience of dealing with issues around employment contracts, risk of redundancy notices, and the "Transfer of Undertakings (Protection of Employment) Regulations" (colloquially known as TUPE), the position I held as 'researcher' shifted. Support workers accompanying job seekers to the job club, and the facilitators alike sought me out. They revealed highly confidential company knowledge, and offloaded their concerns, seeking advice.

In a position of trust, this insider knowledge was troublesome, and I made substantial fieldnotes for reflection, particularly capturing the specifics on how this takeover could impact the job seekers. This was focused on funding and the job descriptions of the facilitators – for, the new organisation did not have 'employment preparation' within its strategic aims and objectives, which further supports the position that employment support is much more dependent on funding provision, policy direction, and strategic priorities, rather than it is on the premise that an individual wishes to seek work (Dowse 2009b). This internal dilemma (Sabar and Yehoshua 2017) on what was and was not appropriate to publish, led me to decide not to include this area within my data analysis. The most pertinent example of ethics in practice, however, can be captured through the interview encounters experienced at Green Meadow.

Interviewing troubles

Interview encounters are privileged within qualitative methods and within participant observation studies; there is indeed, an assumption that researchers will conduct interviews (Pinsky 2015). When Tara (job seeker) secured paid work, I asked her if we could chat the following week about her new position. Tara appeared keen to speak to me and share her experiences. I devised a semi-structured interview scheme, divided into three distinct areas of interest (previous jobs; the context of her new job; feelings about work) along with prompts for my use:

- Can you tell me about the kind of jobs you've had in the past? (Where, when, how long for, what kind of work? Paid? Who with? How did you get the job? Enjoy? Reason for stopping?)
- How did you hear about your new paid job? (Did you fill out an application form? CV? Interview? What will you be doing? Will you have support? Do you know who you are working with?)
- Paid work (Does the idea of paid work feel different from other jobs? How do you feel about it? Why is a paid job important to you? What will your hours be? Will they increase over time? Will you still work at the hotel?)

Arriving at the café for our weekly pre-job club meeting, Sally approached me. Tara's care manager had been in contact with her, concerned that Tara was anxious about the interview. I had never referred to the interview using the term 'interview'.¹⁶ Sally and I spoke to Tara, reassuring her there was nothing to worry about. I suggested we did not go ahead with the 'chat'. Tara was, however, convinced she wanted to. The *interview* lasted less than nine minutes. Tara was agitated and stressed throughout, and I ended it as soon as reasonably possible. My fieldnotes here, capture my reflections:

¹⁶ My experience in the field of supporting adults with ID had meant I had inherently avoided the association with the term and all of the negative connotations and means attached to the word. For, within adult services, the term is associated with power dynamics and hierarchies of assessments, care reviews, financial instability, and general 'problems' to be addressed.

I've learned nothing new from Tara during this process... Instead, I have caused her upset and stress...Interviews are most definitely not a good research tool to utilise at job club...rather than speaking freely [as freely as Tara usually does within the job club], she was cautious and guarded...the associated risks with interviews are bound by authority and power...her guardedness bound by '*how* should I answer; *what* is at risk; *what* could I lose'...Did Tara think her new job was at risk if she shared her worries and feelings?

I had absorbed the literature on researching with people who have an ID. I had 13 years' experience in the field. I had followed the guiding principles of not planning for a lengthy interview process and meeting the participant several times before the interview and I had considered using visual symbols (Hollomotz 2018). At no point, did I think Tara was at fault, the guilt I felt that I had caused her upset was all mine. For, as Lieblich (2008) notes, even when it was never the intention, interviews can be psychologically harmful. Yet, my experiences of interviewing 'troubles' are not isolated.

Roulstone (2014) suggests, while researchers often cast difficulties in interviewing as failures on the part of the interviewer, an unsuccessful interview is methodologically rich. Power et al. (2016) used interviewing as their research method to explore the role of peer support and advocacy in the landscape of personalisation. Their study acknowledged that their interview practice fell short, with interviews typically taking only 15 minutes each. Instead, they suggest, less 'discourse intensive' (p. 187) methods would have been more appropriate than relying on scripts to capture events from everyday lives. Moreover, in hindsight, Booth and Booth (1996) suggest open-ended questions be avoided, as these questions often fail to extract any information at all. They note that to yield data from people with an ID through interviewing, abstract and time-bound questions are often difficult for people to comprehend. In response, I did not conduct any more formal interviews at the job club, and instead, people shared their stories through naturally occurring phenomena. It was important then, to continue the research adopting only ethnographic methods and thus avoid 'fast research' (Booth and Booth 1996: 67). Instead, I returned to the traditions associated with narrative researchers, recognising that it can take a

long time to ensure stories are not lost (Booth and Booth 1996) and appreciate that interviews are 'not the whole story' (Atkinson 2015:13).

This concern with interviewing extended to other stakeholders that I had considered contacting. My initial research proposal (and ethical approval) had included the option to interview local employers (or potential employers) of job seekers from the job club, to seek their perspective. Yet, once in the field, ethically, this was not appropriate. I could not draw attention to individual difficulties, which could potentially further highlight employment barriers (such as productivity levels, or cognitive understanding).

Moreover, as chapter eight will explore, some of the job seekers were engaging with morally ambiguous, long-term work experience, sometimes for many years. Highlighting to an employer that these practices were both illegal and morally questionable, or simply engaging employers with topics of unpaid work, could have had potentially disastrous consequences for individual job seekers that found their work roles to be acceptable. Yet, I did conduct interviews at The Roasted Bean, and I now need to situate the decision-making process and justify my approach, particularly after the *interviewing troubles* experienced at Green Meadow.

Practicing vigilance

The café workers at The Roasted Bean were all invited to come and share their experiences with me. I did not ask to speak to specific workers, even if I knew their story would complement my data. The actual interview was what Pinsky (2015) perceives to be – one aspect of an ongoing interactional process. With extended interaction, I chatted with workers, customers, and carers alike, to create more naturalistic approaches to what is, an 'unnatural occurrence of polite interrogation' (Guillemin and Gillam 2004: 271). Moreover, I did not have formal pre-set questions, considered to be a static research design based on neutrality (Pinsky 2015). In practice, I spent time *hanging around* and being present. In turn, workers and parent-carers came and sat at the table through choice. Here, while potential participants were aware that I was particularly interested in hearing about work, and what work means to people, some shared

only non-research related information.¹⁷ While for other participants, I was free to ask what they had been up to that day, what tasks formed their work, and then, where it *felt* appropriate, I posed further questions about what participants had done before starting at The Roasted Bean and what they would like to do in the future.

My position towards interviewing at The Roasted Bean and further shared more broadly with the focus group at Power, risked data contamination (Plummer 1983), whereby the approach may be considered as to leading participants towards particular answers or expectations. Yet, once mutual acquaintance and familiarity have been established, it is impossible to erase or detangle from the relationships that have already occurred (Pinsky 2015). To settle this concern, I argue that my methodological decisions are robust. First, at The Roasted Bean, questions were surface level, such as, 'what is your job' 'do you like it' 'what did you do before'. The direction of these questions is grounded in tales of lived experience and individual stories to be shared (Goodley 1996).

The more nuanced and multifaceted methodological concerns are evident within the focus group at Power. For, my access to the field here was based on the participant's willingness to share their stories implicitly linked to the knowledge sharing session that had already occurred, and therefore, our world views were more likely to be intrinsically aligned (Berger 2015). Berger (2015) explores some of these methodological complexities, where an insider's familiarity carries risks of 'blurring boundaries' (p. 224) where, as a researcher, my own values and beliefs hold inherent bias. Moreover, at Power, I had to offer up my emerging themes from Green Meadow, as focus group themes, in exchange for data. Yet, by doing so, I was able to understand the nuanced reactions and experiences of participants (Berger 2015) and contextualise these experiences more broadly, within a social policy framework. Here then, I was able to draw on my own understanding from the ethnographic study, and offer an intimate familiarity, to evoke a deeper understanding of the phenomena (Pillow 2003). Yet, it was imperative that I let the participants tell their stories to ensure I did not 'block

¹⁷ One person spent quite some time telling me all about their favorite football team, and I listened enthusiastically.

hearing other voices' (Berger 2015: 224). This tacit knowledge provides both a contextual and thought-provoking addition to chapter nine in particular.

Moreover, the encounters at both The Roasted Bean and Power, were after my ethnography had ended and directly based upon my research findings. Here, I claim that my interpretation of the data is driven by the narratives offered by the job seekers, and not by 'bringing my agenda' (Berger 2015: 225). For, while I knew that there were multifaceted and complex processes at play within the employment activation policy for this demographic of people, I had not known before entering the ethnographic field, what I would discover. Rather, I knew the 'directions along which to look' (Atkinson 2015:9) and then the narratives shaped the data analysis.

To legitimise the representations offered in my study (Pillow 2003), validate the claims shared within my empirical work more widely, and align to the framework of participatory research methods (Cahill 2007) I have presented key ideas drawn from my project, with people who have an ID and that are in receipt of social care. The Learning Disability Wales conference (2019) focused upon an overarching theme of 'Right Here'. This theme broadly explored the 'importance of people with a learning disability of all ages being seen, heard, included, and valued in all walks of life. Like at school, college, work, home, community, arts, leisure, and positions of authority and expertise' (LDW 2019: np). My request to deliver workshops at the event was approved, after completing an application process that highlighted the research findings. Here, the research was made accessible to people with an ID through facilitated workshops. This responsibility to share my research findings and dissemination acts as a mechanism to validity and is a route to advocate for groups with little representation (Cahill 2007).

In essence then, while I cannot claim my research to be 'inclusive' or participatory in the sense of subscribing to the defining features of inclusive research, such as 'the research problem is owned by disabled people' (Nind 2017: 279), key distinguishing features have been established within the research process and I embraced an advocacy approach (McKenzie et al. 2015). For, while participants are not necessarily in control of either the research, or

the research process, nor are they necessarily clear about how the research outcomes will be used, or how it may affect social change, the results will have some kind of political action, even if this is not within the community where the research has taken place (Gilbert 1997).

Conclusion

Chapter four has positioned this research project. I have located myself within the text by exploring, and taking responsibility for, my situatedness within the research process. To do this, I have explored and justified why inclusive research methodologies were not suitable for this project, and instead, a position of participant observation through an ethnographic study was the most appropriate method. I have argued that I have been able to capture data that would not have been possible from any other method, apart from an ethnographic study. For instance, inclusive research, interviews or focus groups alone would not have allowed the space to examine ideas such as the construction of a non-universal understanding of work (chapter eight) or the theoretical concepts of Goffman and Berlant, played out on a continuum (chapters six and seven) would not have been brought to fruition. I have also explored how my study is aligned towards notions associated with forms of critical/ advocacy ethnography, insofar as it intends to be affected by moral and political processes (Koro-Ljungberg and Greckhamer 2005).

Moreover, this chapter has detailed how access was granted to Green Meadow and negotiated at The Roasted Bean, Power, and with Bob. The complex and nuanced reflexive decisions that were associated with this process have also been explored. This includes justifying my position of being a volunteer at the job club, and my reflexivity in the field at The Roasted Bean and Power. Here, I have laid bare the inherent ethical risks and dilemmas that this kind of research entails, such as the blurred boundaries of prolonged fieldwork and the duality of the insider/outsider researcher. While this chapter has also attended to the procedural processes associated with formal ethical clearance, a key aim has been to highlight the ethics in practice that are concerned with the 'everyday practice of doing research' (Guillemin and Gillam 2004: p. 262). As Atkinson (2015) points out, we 'wax lyrical about how to gain access to a given setting,

how to establish social relationships with our hosts, how to behave in ethically approved ways and so on' (p. 11) yet the latter half of this chapter has sketched out what happened in the field, as 'ethically important moments' (Guillemin and Gillam 2004: 262). This reflexivity then, has offered to bridge between ethics as a procedure and ethics in practice (Guillemin and Gillam 2004). This chapter has also detailed how data was collected and, in turn, analysed. My overarching aim here has not been to represent *another* – rather, my aim is to share the stories of people by making them visible (Pillow 2003).

Chapter five, presented next, is the first of my five empirical chapters. It explores the (un)intended consequences of employment activation policy, experienced by the job seekers at the job club. In particular, chapter five offers space to consider the landscape of employment activation for people that are not specifically targeted by active labour market policies.

Chapter Five

Navigating the tightrope

‘Once you’ve put someone on a benefit that says you are too ill to work, you’ll always be up against it’.

Bob, stakeholder participant

The following five chapters outline some of the key findings from my study. While the subsequent four chapters focus on the experience of ‘job seeking’, this chapter attends to the landscape of employment activation in both England and Wales, for the participants involved in this study. This chapter, then, analyses how people navigate employment activation when they are not targeted by active market labour policies. Moreover, this chapter captures how ID specific employment strategies are both implicitly and explicitly excluding people from accessing employment support programmes. As a consequence, people within this demographic are, instead, accessing employment preparation support from organisations that do not have access to the networks and links afforded to larger, established organisations. Further, this chapter lays the foundations for the subsequent chapters by sketching out the implications of employment activation. In addition to the experiences of the job seekers at Green Meadow, Power and Bob complement these perspectives by providing a wider context of employment activation.

In the second half of this chapter, I am critical of the employment provision provided by two key organisations. To be clear, I am not in any way blaming their admissions criteria as the only *problem* to truly inclusive employment support. They have their own strategic priorities, funding pressures and outcome requirements to adhere to. It would be overly simplistic to lay the blame at their door. While my aim is to illuminate the employment barriers of admission criteria, more importantly, it is the consequences of the decisions to act like

mainstream employment activation services that is the intention of my scrutiny.¹⁸

Inherent tensions within classification

In contrast to the conditionality attached to the Work-Related Activity Group (WRAG) of Employment Support Allowance (ESA) claimants, all of the job seekers at job club who are in receipt of social care, are categorised as being within the Support Group (SG) of ESA. The SG is streamed for people who are classified as having a severe illness or disability and therefore, no such conditionality is currently being applied (Gjersøe 2016). However, this status and categorisation hold tension since the government estimated that 90% of ESA claimants would fall into the WRAG category due to tight eligibility and regulation of the SG (Baumberg et al. 2015). An example here can be drawn from the experiences of Karen, a job seeker at Green Meadow. Karen is being monitored by the DWP via her local Job Centre – she is not attending the job club out of choice, rather, by scrutiny. Karen’s employment status is called into question bi-annually because Job Centre workers are unable to comprehend how she can maintain her voluntary role at a garden centre, while simultaneously being assessed as unfit for work through her Work Capacity Assessment (WCA).

This tension is further compounded by Karen’s General Practitioner (GP) who has advised on her records, *‘patient not able to read, slow at tasks, not to be placed under pressure to speed up - she is likely to fall and increased risk of seizure’*. Yet, her GP has ticked the, *‘you may be fit for work with advice, amended duties and/or workplace adaptations’* section. The aim of the DWP here, evidenced throughout Karen’s case, is a potential transfer to the Work-Related Activity Group (WRAG) category. The WRAG category is for those deemed to be short to medium term unemployable, with intervention and work preparation aimed at transferring people towards Job Seekers Allowance (JSA). However, this transfer is not without controversy - with an appeal rate of around 40% of individuals contesting their classification (Baumberg et al. 2015).

¹⁸ To clarify here, the organisations that have been named in this chapter have not been used as sites for data collection. All data gathered in regards to these organisations is freely available.

Absent from discussion here, within this fit/not-fit for work binary, is the contextual information regarding Karen's role at the garden centre. Karen does not have the same work schedule as her paid counterparts, and nor would she be able to fulfil the range of tasks within the job descriptions of similar roles. For instance, Karen is clear that she would not be able to work directly with customers, rather, she has carved out her role to focus on maintaining the plant stock. Yet, for Karen, this lack of clarity, on whether she will continue to receive her welfare support without the risk of enforced conditionality, causes confusion and anxiety for both her and her grandmother, who acts as her advocate. Karen's grandmother is under the impression from the most recent letter that Karen has received from her GP, that she does not need to be actively seeking employment. In conversation with the group, Karen says, '*my nan thinks I'm not capable, my balance ain't that good*'. However, Sally reads the letter and replies:

That is not what the doctor is saying - actually, the opposite. It says that you are fit for work... I'll put it in my diary to call your nan... we need to be clear about what is happening here... to me, that indicates that they are expecting you to get a job. This gets very complicated. It's very interesting Karen, as to why you are getting this, and I can think of other people who, yeah, erm. Well, nothing to worry about Karen. At the end, it's just a piece of paper but we need to make sure that we all understand the same thing.

Some weeks later, Karen discloses she has been back to the Job Centre. Her Nan has informed representatives there that she cannot get a job because of her balance. This conversation then takes place:

Sally: So, they are going to leave it at that are they? They aren't going to expect you to be getting a paid job at the moment?

Karen: [unsure] Nan asked why I keep coming in too many times which it has been so far.

Sally: Well, I hate to say it, but I think they will. Unfortunately, balance isn't a reason to not be getting a job. Because, I think the answer would be, "well get a sit-down job then," I'm afraid! That's the world we live in. I mean, we're just at the moment trying to help a lady who is blind,

completely blind. I know it is hard, she's your age, but at least you've been, and you've sorted it out for the moment.

Yet, while the push by the DWP aimed at re-categorising Karen to the WRAG group is concerning, there is a lack of consideration regarding her ID and her stress-induced epileptic seizures. With the focus on her balance, I reflect in my fieldnotes:

If Karen's balance was ok, would she be expected to be 'signing on' as an active job seeker within the WRAG category? Has her ID disappeared and been replaced with a balance issue that can potentially be improved? Is it easier to rehabilitate her balance and completely ignore her ID?

Karen's experience is not isolated. With the prior distinctions between the *deserving* and *undeserving* blurred (Garthwaite et al. 2014; Roulstone 2011), the failure to understand the complexity of disability has resulted in some disabled people being conveniently reclassified to fit Treasury cost-saving imperatives, leaving a mismatch between people reclassified as fit for work and sufficient employment options (Roulstone 2011). This narrowing of eligibility and criteria has resulted in this re-categorisation by the state (Bowker and Star 2000) on those deemed capable of either paid work or engagement with work preparation activities (Wiggan 2015). Yet, for someone such as Karen, they can occupy a particularly precarious position when it comes to accessing the labour market when it is compounded by this binary approach to the employment of those who can, and those who cannot, work.

For Karen, the *tightrope* of employment activation is evident within her experiences. Under the scrutiny of the DWP, there is a consequence for her involvement at the job club. Within workshop activities, productivity becomes regularly framed as a route to gain paid work. Time management, timekeeping, and completing tasks when expected are all often covered within her worksheets. For Karen, motivation (or lack of it) to seek paid work is inherently associated with increasing productivity to enable her to join the labour market. Consequently, efforts with her are focused on developing strategies to *quicken her up* at her unpaid job at the garden centre.

Productivity and employment chances

Over the course of six weeks, Karen and I worked on her productivity at the garden centre, with the intention of 'quickenning her up' to join the labour market, even though her GP has clearly noted that she should not be placed under this kind of pressure. All of the tasks Karen completes at the garden centre were listed with a photo added for a visual prompt. We worked together to put these tasks in a 'productive' order, so she could work more methodically. Karen was often quite confused at our activities: she did not appear to realise there was an issue with her work and she enjoyed having the ability to complete her tasks in an order that suited her, even if that meant she was slower than a paid employee.

Karen was, however, able to grasp that in order to get a paid job, she needed to work more quickly, *'could get better at it... now I've got a checklist'* she suggested. Towards the end of the six weeks, Sally spoke to Karen's boss at the garden centre. Sally and Karen's boss planned for Karen to use her new task sheet to work out how long it should take her to complete her tasks in each specific area to, *'speed her up a little bit'*. Sally explained to Karen, [the task sheet] *'might help to speed you up a little bit, so you get more satisfaction from what you are doing, and he [the garden centre boss] gets more work done! Yeah! So, everybody is happy!'*

This *happiness* described by Sally contributes to what Soffer et al. (2011) consider to be a fundamental issue with productivity. For, the Welfare Reform Act (2007) focuses so heavily on productivity, to the extent that 'productivity has become shorthand for defining entitlement, worthiness, citizenship, and inclusion... which maintains power structures and promotes the marginalisation of oppressed groups' (p.269). In this sense, the struggle to access waged work is conflated by societal expectations on productivity (Soffer et al. 2011). At the job club, these notions of productivity are intrinsically linked to personal ability. For example, when Karen says she wants to *'get better'* at work, Sally replies to both Karen and the rest of the job club:

So, are you saying that if you get better at work, there'd be more chance of you getting money? Getting paid? [Karen nods]. That's a very good point. So, people are only going to pay you if you can work the same as

an able-bodied person... and you made an excellent point there as that's actually one of the key reasons that people with learning disabilities don't get paid. Because they are not as productive.

This comparison, offered by Sally to the job seekers, is a stark reminder that the Disability Discrimination Act (DDA) (1995) infers that disabled people should be able to compete with their able-bodied counterparts (Piggott and Grover 2010). Yet, while the DDA was designed to end illegal practices of employer discrimination against disabled people, evidence demonstrates that many employers are still not willing to hire such people, particularly if they have an ID (Department of Health 2009; DWP & Department of Health 2017).

The tension between employment policy and pressure from external sources, such as the Job Centre, is only applied and directed towards Karen. This is in contrast to Sophie, Naomi, Huw, Verity, Jenny, Tara, Mark, and Jess, who all want to gain employment at the job club or have been encouraged to do so by Green Meadow, support workers, or family members. For these job seekers, the path to employment through activation is unclear, nuanced, and complex. The question to consider here is why people that are furthest from the labour market (i.e., those in the SG of ESA who are in receipt of social care) are not able to access employment preparation support from specialist providers. And why, in response to this exclusion from employment support, Green Meadow secured fundraised income for the project in the first place. My research highlights two key explicit exclusions for job seekers with complex employment support needs: ability and age. Both of these applied restrictions are inherently bound to each other throughout policies, strategies, and initiatives, and these will now be explored, drawing on the context of both England and Wales.

Justified employment activation?

In England, the Valuing Employment Now (VEN) (2009) initiative was abandoned in 2011 and has not been replaced (Blamires 2015). During its time, there were small pilot schemes (for example, the 'Getting a Life' project¹⁹ and the

¹⁹ Focused on whole system change by improving transitions (Getting a Life 2011).

Youth Supported Employment Project²⁰). These initiatives were funded by re-directing allocations previously allocated to Remploy factories. The closure of Remploy factories as a collective employment site reinforced individualised, employment support (Blamires 2015) and signalled the shift in approach away from segregated workshops, and instead, towards open employment (Bates et al. 2017).²¹ Now, with the absence of ID focused strategies, there has been a shift towards mainstream disability policy (DWP and Department of Health 2017). For people who fall within the support group (SG) of ESA, there are two options. First, a return to mainstream employment support through the Work Programme, with its inherent and endemic creaming and parking tendencies outlined in chapter three. Secondly, small, discrete, localised employment programmes that do not have the networks and partnerships negotiated and privileged to the national organisations. Green Meadow would be described as a small and discrete, localised employment programme.

In Wales, there is an increased focus on the aspiration of young people. This is supported by Welsh Government's exerted effort to increase employment pathways, reinforced by policy (Social Services and Well-being Act 2014; Wellbeing of Future Generations Act 2015; Children's Commissioner for Wales 2018) to reduce social isolation, and ensure people with an ID are able to attain their 'place' (2018: 5) as full and active citizens. This policy focus came to fruition based on research that demonstrated post-19 transition pathways were dominated by further education routes, with funding streams geared towards college and day services (Kaehne and Beyer 2013). Bob provides additional context on his organisations rationale for working exclusively with younger people:

I think it's an ideal age group to work with. I think we can change a generation by working with this age group and focusing on that... there is no doubt that from the [project]... it is the key group... I think recently, a lot of younger people have higher aspirations through school or college... that's the key part. I wasn't a strong believer in 14-25, [it's]

²⁰ Focused on aligning non-disabled and ID teenagers together to seek paid work (Good Practice Wales 2008).

²¹ Half of its 54 factories were closed, the remaining, sold (BBC 2012).

awkward to exclude people. But I do feel, that when you have limited capacity to help, you can change a generation... It's quite important that we catch them before they leave college. Because once they leave college, their parents are working, what are we going to do? Right, ring the social worker. The social worker will come with activity-based stuff. It won't be meaningful in work terms. They're [social workers] generally over worked and occupying someone in a voluntary setting, training centre slash day centre is easy.

Here, Bob has justified why, even though it is '*awkward to exclude people*', his organisation does exclude people over the age of 25. Broader still, Roger from Power discusses the tension and justification on age barriers:

There are so many people that we meet that are past the age of 24, that have a learning disability but haven't had the opportunities to develop the skills needed in a work setting. The basic stuff around timekeeping; how to dress for work; socialising; when work is about work and not chatting. All of those things. People have skipped the bit where they learn them, and then have to come back. When I was at [organisation], we were working with people from [college]. And they were of a generation understanding some of those skills. The older people, in their 20s, 30s, and 40s had never been in that work situation. We worked with people on the work development programme, to talk about the importance of having a shower before you go to work, really, everyday basic stuff. The fact that when you are in work at 9, you stay there till lunchtime, then you go for lunch and then you come back after lunch. You can't just... the basic skills.

Bob and Roger have both sketched out the consequence for individuals who are not targeted at a young age, and the job seekers at Green Meadow fit with this description, being previously in a voluntary setting – with day centre-like activities. These explanations explore why engaging with younger people is essential, yet, they expose the vulnerability experienced by people who are over 25 and wish to seek work. Moreover, specific ID policy in Wales further exposes an under focus on employment preparation for people who are over 25. The 'Learning Disability – Improving Lives Programme' (Welsh Government 2018), focuses on a holistic, life-course approach to ID. Here, employment

opportunities, administered through traineeships, are identified as a key recommendation for adolescence (age 14-25). However, by the time young people enter early adulthood, this focus has been weakened to 'opportunities for daytime activities/work' and is further reduced to 'meaningful occupation/activity' by midlife (identified as 30 years plus).

Crucially, stakeholders and professionals (ranging from commissioners, service providers, support staff, health board workers, and policy leads) do not share the enthusiasm for employment to be a priority for people with an ID at any stage of the life course. While 'having a job' (p. 16) is listed within the top four priorities for both people with an ID themselves and their families (along with friendship, transport, housing, and healthcare for example), professionals, who make commissioning recommendations, prioritised funding, data, and definitions, commissioning, healthcare, and workforce as their top priorities, highlighting the continued tension between vision and reality.

While Learning Disability England does not advocate a particular employment support model, Learning Disability Wales is in partnership with Engage-to-Change, who work exclusively with people under 25. Engage-to-Change is the overarching employment project, funded by the Big Lottery Fund. Over a 5-year period, the project aims to work with over 1000 young people and 800 employers, offering job coaching and specialist employment support. This includes provision offered by Project Search, an internship programme in partnership with Welsh Government, with sites including Cardiff University and Welsh University Health Boards (Engage-to-Change 2019).

Project Search emerged from the United States in the mid-1990s. The movement began with a medical Clinical Director in Cincinnati launching the project to train people with 'developmental disabilities to fill some of the high-turnover, entry-level positions...which involved complex and systematic tasks such as stocking supply cabinets' (Project Search 2018: np). In the UK more broadly, Project Search is in partnership with (amongst others), 16 NHS trusts; local authorities; Heathrow airport; GlaxoSmithKline; distribution centres; universities; shopping centres; hotel chains, and; banks (Project Search 2018). Successful outcomes for participants of Project Search are defined as: employment in an integrated

setting; year-round work of 20 hours per week or more, and; paid at a minimum wage or higher (Kaehne 2014). An evaluation review (Kaehne 2014) highlighted that 75% of graduates had a learning disability (n=228) with 36% of participants going on to secure work, which was overwhelmingly in hospital environments (p. 24).

National organisations, such as Project Search, have been set up specifically as a broker to employment. It is therefore logical to also explore the counter side of employment support – support offered by national learning disability support providers. In 2018, Mencap spent £5,223,000 supporting 2,600 people with employment-related activity (2.65% of their income), with 284 people supported into paid employment (7.3%) (Mencap 2018), by working in partnership with businesses such as Marks and Spencer and Sainsbury's (p. 46).²² However, in 2017, Mencap announced employment support would become a separate priority, with the launch of their 'Three Ships' model: supported internships; traineeships, and apprenticeships. These programmes are for young people, aged 14-25. For Mencap, this strategic shift towards 'non-care' models (similar to Project Search) is in response to financial pressures:

Mencap has a long-standing history of supporting people with a learning disability into work through a supported employment approach. This is mainly funded through local authorities. However, there is no statutory requirement for local authorities to support people with a learning disability into work, and as budget cuts have deepened, there have been fewer opportunities for us to capitalise on (Mencap 2018: 45).

Moreover, rather than strategically capitalising on the acknowledgment by the government that more needs to be done to support people with employment options who have an ID that are in receipt of ESA and known to social services (such as Green Meadow job seekers), Mencap focuses on an alternative challenge: concentrating on how people are currently being identified as having a learning disability to ensure 'everyone with a learning disability who needs support to access employment will get it' (p. 45). Not only are Mencap now

²² This is similar to trends within previous years (for example, 2224 people supported with employment related activity, with 300 (6.7%) people supported into paid employment in 2017.

predominantly working with only younger people, they have also strategically moved towards capitalising on working with people who are undiagnosed as having a learning disability, and, by default, not in receipt of ESA or social care provision. This theme of shifting from the intended supported employment (SE) target group is apparent more broadly, through an implicit discourse that will now be explored.

In 2010, Beyer et al. compared SE across Europe, finding that, when compared to other models of vocational rehabilitation, SE has been successful in relation to wage levels, increased self-esteem, meaningful activity, and cost-benefit. Moreover, it can offer an 'effective solution for community-based employment for people with disabilities' (p. 131). However, they identified a key issue with SE: a shift from SE's original focus on people with an ID towards other groups of people deemed to be at risk of marginalisation, with the use of job coaches being deployed to help those considered marginalised, rather than people with an ID into employment. Consequently, as Beyer et al. note, this shift has been at the expense of people with an ID, who are at risk of '*again*' (p. 131) being left without help. Beyer et al.'s analysis found that in the UK, 35% of SE users (the largest group) do have an ID. This is similar to the findings offered by Tame (2016) in the Sustainable Hub of Innovative Employment for people with Complex Needs evaluation, where providers invested the most time and resources to support individuals who did not fall into the category of having complex needs.

Prioritising support towards people who are 'disadvantaged', reinforces the idea that everyone can maintain work of 16 hours and above. At the job club, Sophie is the only job seeker to express a desire to secure at least 16 hours of work per week (chapter six will discuss Sophie's situation in detail). All other job seekers said they could not manage to work 16 hours, and, instead, between 4-8 hours of work per week would be desirable. This is a similar path shared at Bob's organisation:

The barriers of 16 hours for large percentages of all groups, especially people with [condition], 16 is a very long-term aim. [People] fatigue quite quickly, when I put people into work, its 3 or four hours maximum in one shift. After that, you start to see quite a noticeable difference in

performance. There're always exceptions, I've put people in for 16 hours or more, but it's not common.

Yet, without the ability to work 16 hours per week, comes additional implications. In the UK, working 16 hours per week is the pivotal entry to no longer being *just* a recipient of welfare benefits. At 16 hours per week, people are entitled to 'in-work' financial assistance and are 'fully included' (NDTi 2014: 63) as contributing members of society (VEN 2009; NDTi 2014). This framing of inclusion in terms of achievement, independence, and productivity is embedded in neo-liberalism and, as previously explained here, is highly problematic (Dowse 2009b). Instead, for job seekers at Green Meadow, individuals are required to work under the 'Permit to Work' scheme, legitimately able to earn a supplementary wage, yet not transformed into the tax-paying members of society envisaged by the VEN. Consequently, people here still lack the privileged membership of 'full' citizenship, offered to taxpayers through economic contribution (Baldock et al. 2012) since having people work less than 16 hours per week is of 'no benefit to the taxpayer' (NDTi 2014: 63).

Exploring the Permit to Work scheme highlights vulnerability at a site such as Green Meadow. Under this scheme, job seekers claiming SG ESA are able to work as long as their earnings do not exceed £125.50 per week. Sophie continually worried about her benefits being affected by work, *'because if I get a job I want to know if I will still get my benefits or not. Some people have said I won't... I'm on benefits at the minute and I don't know if it will interfere with my benefits'*. Karen is similarly concerned, *'you can only earn so much before it affects your benefits'*. This 'benefits trap' (Garthwaite 2014) is a de-motivator to seeking paid work and is very much felt by those accessing job club. Moreover, this position is echoed more widely by other people with an ID (Health and Wellbeing Scrutiny Committee 2010; Wilkins et al. 2012; Beyer and Townsley 2017).

However, the concerns expressed by Sophie and Karen are dismissed by Sally. When Sophie asks for advice about how her benefits could be affected by attaining paid work, Sally replies, *'well they don't know what they are talking about'* and the conversation is closed. Worryingly, during the time that I was attending the sessions, job seekers shared their apprehension and fears around

the perceived 'benefits trap' multiple times – yet, I only once heard Sally refer loosely to the Permit to Work scheme. This occurred when Jackie, a job seeker without an ID diagnosis, was about to start a work trial at a hotel.²³ Jackie received Universal Credit (UC). She asked Sally what she can earn and how it will affect her claim. Sally informed her:

I think you should do no more than 10 hours per week... coz then you're only going to be earning about £80 or £90 a week and I don't think you'll reach the threshold. I think if you went further than that, then it could put you in danger of losing money. But that was certainly the case, well it was up to 16 hours actually, a certain amount of earnings with ESA but I don't know what it is with Universal Credit. It's not clear. I have tried to dig around a bit.

While Sally's information regarding UC is factually incorrect, her interpretation of the 16-hour threshold for ESA claimants is also concerning. For, Green Meadow's job club initiative was in its infancy and the organisation was not a 'registered supported agency' with the DWP. Bob contextualises this:

So, if you are on ESA in SG, you're entitled to work. So [for example] John Smith, on ESA SG, can do permitted work. If he does it without a supportive agency like [organisation], he can do permitted work, rules are, under 16 hours, under £125.50 per week, but he can only do that for 1 year. If you're in SG you can do supported permitted group, only if a supportive agency like us, or [organisation], or whoever, sign the form as well, agreeing that we would monitor the opportunity and then they can do it ongoing. So, the vast majority of people who we support will do it under-supported Permitted Work. Unless they do 16 hours or more. Which means that we are signing up to support them ongoing.

The description and example offered here by Bob has not been discussed at the job club and Green Meadow did not have 'registered supported agency' status, nor did it have the resources or capacity to provide such a commitment. Bob explains that his organisation does not get any funding for this ongoing commitment to support the workers, who require an organisation to provide this

²³ This will be significantly explored in chapter six.

service. Rather, they absorb the additional cost commitment because, as Bob explains:

We are doing it because we know that it's the best route for them into work. It's a strange one because for them to do SPW [supported permitted work], which allows them to do it ongoing, they have to have someone to put down that's supporting them. Now I guess, in an ideal world, we wouldn't want to do it. We've signed up for a long-term commitment. That said, we could just fold the project tomorrow and just notify them that that's it, we're gone, you'll need to find someone else. And that's then for them to find another organisation to do it. Again, who's going to sign up to do that ongoing. This is a lightly policed sort of agreement through DWP. We don't get many calls at all from the DWP to say, 'what's happening with Joe Smith'. Ok, it is lightly policed because they generally know the people who are in this group would need that best.

The workers supported through Bob's organisation are relatively secure in the knowledge that Bob will continue to perform these functions as long as he is working for the organisation to maintain the role. Yet, he identifies future concerns for both existing claimants and new claimants that are rolled on to UC. While he had not worked with any UC claimants yet, he was anxious:

I dread to think what will happen because I probably will have a lot of people give up work – they are not going to be as well off. They will still be better off [in work] but they are not going to be as well off. I have just seen someone. He has £125 per week ESA, he works 10 hours a week, £8 per hour, another £80, not taxed, DLA [Disabled Living Allowance]. Quite a lot of money coming in, you know. But under UC, DLA would be kept to one side, he would need to be inputting into the computer that he's worked 8 hours, and then it would recalculate then the new payment due but it would, I may be wrong here, but I think you only get 65% of the earnings worth, whereas now, it's 100%. Again, people with [specific ID] are going to need support to input it into the system. There will be people giving up work thinking, it's too much. Apart from that, the person I've just met now, he's 30 years old. His mother is 70 – she's not classed as a carer, but it's her natural job to care. I mean, she's 70, there isn't

computers and technology in the house, is she going to input it? It's not going to happen.

This insight, offered by Bob, demonstrates that the benefits system is set to become more complicated as UC continues to be rolled out. Moreover, it demonstrates that the wrong information has been offered to Jackie at the job club. Without the correct financial advice and support, the work landscape is set to become more complex, time-consuming, and precarious. For Jackie, the transfer to UC has, as the policy intended, pushed her towards seeking paid work. She and her husband had been on tax credits and Jackie explained:

They don't give you the benefit of the doubt like they used too... We're struggling really, financially, we are struggling... You're worse off on this UC... The tax credit overpaid, and they take it all back off the UC. We're not getting anything at the moment because they are taking the debt back... All our UC money's gone until they sort it...Don't believe the publicity about UC, coz it's a death to some people. A death.

Power is also concerned for the future of their workers, who will be affected by the UC rollout. Richard explains to the group that he currently gets his income 'from Power...tax credits and...PIP [Personal Independence Payment]'. Margaret replies, *'so, the PIP won't change, but one day you will get taken off the working tax credit and put on the universal credit and that's the point at which your income will go down. So, even for in-work, the amount will go down'*. Power interact with the structures of the welfare system regularly. In practice, to ensure the workers who are also in receipt of benefits can keep on top of their finances, this has meant that Power pays their workers a weekly fixed wage, even when there is no work available, making it more straightforward for employees to navigate the system. However, the implications of this cooperative decision are that all workers, whether they have an ID, an enhanced skill set, or complete only administrative tasks, are all only paid the living wage, as the enterprise cannot then afford to pay higher rates.²⁴

For the job seekers at Green Meadow, the implications of UC for people who are currently in receipt of social care is highly concerning. Yet, what is also being

²⁴ This is discussed in more detail in chapter nine.

exposed here, is that people who are furthest from the labour market (i.e., those in the SG of ESA, who have an ID and are in receipt of social care) are not being supported by agencies who hold knowledge on how the benefits system works. Nor does Green Meadow have the established contacts or networks at the disposal of larger employment-focused organisations, such as the links already established by sites such as Project Search and Mencap. Instead, Green Meadow is operating to support those furthest from the labour market, into paid work locally.

Conclusion

This chapter has sketched out how employment activation policy operates to exclude people who have an ID, are in receipt of social care, and are over 25. This context is set with the backdrop whereby additional scrutiny is applied to people who do not neatly fit into clear classifications of requiring support group or work-related activity group intervention measures to employment activation. Moreover, how measures to increase productivity are introduced to 'fix' some of these discrepancies has been explored. This chapter has also briefly considered how this position is set to become more complex with the introduction of Universal Credit.

Overall, chapter five demonstrates that this interaction to employment activation is set in a time of increased governmental conditionality that can be problematic for people who wish to explore work, yet can be far from 'job ready', particularly in a society that prioritises productivity over forms of social inclusion. While England and Wales have adopted different policy approaches (e.g., in England, absorbing ID specific employment policy within mainstream strategies, while Wales continuing with specific policy), the consequence of both directions has seen the increased focus on younger, more 'able' people being supported through apprenticeships, internships, and work experience within the supported employment (SE) framework.

This position is echoed more widely by traditional 'care' providers, who are also now focused upon supporting people who are younger and more able. As a consequence, small and discrete organisations such as Green Meadow, are responding to the call for employment preparation support, for people who are

excluded from accessing established sites of employment preparation. Yet, Deeming (2013) suggests that 'paid work will not be appropriate in every circumstance and not all adults will benefit from being activated' (p. 558). Whilst Hunter (2019:3) considers paid work as 'neither necessary nor desirable for everyone in society'. This holds tension for people when they are actively encouraged to explore work preparation since neoliberal thinking and rhetoric mobilises employment expectation as possible, yet, the consequences sketch out more morally ambiguous practices.

In chapter six, I explain, through the lens of Goffman's (1952) 'cooling the mark', how the interactions at job club align to this perspective, whereby, with minimal opportunity to engage with paid work, people move from expecting to secure formal paid employment, to instead, being 'cooled out' to accept unpaid, prolonged work experience and volunteering as an alternative.

Chapter six

“Just be realistic”: the cooling out of job club members

Chapter five sketched out how people with an ID, who are in receipt of social care, experience and navigate the tightrope of employment activation. In this context, the activation occurs for people who have not been mandated to seek employment (such as the requirement for JSA claimants) but rather, the individual has chosen to do so. Chapter six explores the processes that are evident at the job club through the lens of Goffman's (1952) 'cooling the mark'. Known for his observational work on the social arrangements of institutions (1961), self (1958) and stigma (1963), Goffman's earlier work, has received limited attention. He used an analogy of the 'mark' being a victim (or potential victim) of fraudulent activity, with a 'cooler' used to pacify the 'mark' and convince them not to involve the police. In this context, the mark is the 'sucker' (p. 1) taken in, while the con is the person making direct contact with the mark, winning their confidence and offering a new opportunity. The cooler, then, cools the mark into accepting their loss by maintaining the feeling that they will be able to instead, invest differently, thus avoiding a loss of status.

For example, The New Yorker, a contemporary US media outlet, published an article that drew upon these concepts, to explain how a 'crooked-psychic' was able to obtain over \$700,000 from fraudulent activity by offering to build a golden bridge for evil spirits to cross over into the other realm. However, the psychic had not *cooled* the *mark* sufficiently: ultimately, the case was reported to the authorities, the psychic was exposed to not be *everything she purported to be*, and she was later charged with taking money under false pretences (Menand 2015). As Goffman notes: 'In essence, then, the cooler has the job of handling persons who have been caught out on a limb – persons whose expectations and self-conceptions have been built up and then shattered' (p. 2). More broadly, Goffman applied the same principle to other general problems with the self in society, such as the end of personal relationships, missed job promotion, and

drug abuse, amongst other analogies. In each case, a person is 'involuntarily deprived' of their position or involvement and, in return, offered 'something that is considered a lesser thing to be' (p. 4). The cooler's primary function is to 'cool him [or her] out' of something that is, ultimately, 'proof of an incapacity' (p. 4).

Goffman's theory has had limited (and mainly dated) academic use, with some recent exceptions, including how mothers interpret their child's diagnosis of Down's syndrome (Thomas 2014), and how teaching assistants perceive their work in the inclusion of pupils with special educational needs (Lehane 2016). Earlier work framed by Goffman's 'cooling out' metaphor includes employment in relation to career progression (Becker and Strauss 1956), open-door admission policies in the US education system (Clark 1960), and managing the disappointment of job termination (Miller and Robinson 1994).

This chapter will draw upon Clark's (1960) interpretation of cooling the mark, extending its analytical framework. Clark (1960) drew upon the functions of cooling the mark to explore the expected failure of students within the US higher education system during the 1960s. With its ideologically placed open-door admissions policy within publicly supported institutions, Clark explored the predictable, inbuilt disappointment for some students. Attending college was framed as a route for 'guaranteeing equal educational opportunities to all of its citizens' (Clark 1960: 570), yet this position could not be maintained and failure was accounted for:

The conflict between open-door admission and performance of high quality often means a wide discrepancy between the hopes of entering students and the means of their realisation. Students who pursue ends for which a college education is required but have little academic ability gain admission into colleges only to encounter standards of performance they cannot meet. As a result, while some students of low promise are successful, for large numbers, failure is inevitable and structured.
(Clark 1960: 571).

This account of inevitable failure offered by Clark (1960) can be found in other settings where functions of a substitute achievement are offered as an alternative to the intended expectations. Following the path of Goffman's observational tools associated more broadly with the cooling the mark analogy, so too can they be applied to contemporary, specialised employment programmes in the UK. I discuss several strategies of 'cooling out' the job club members below: creating an alternative achievement; getting tough, and; the role of the proxy.

Strategies of cooling the mark

Create an alternative achievement

The practice of cooling the mark, as interpreted by Clark (1960), draws on *latent terminal students* continuing on an educational path, when in reality, their education had been terminated and replaced by a 'reorienting process' (p. 572). This process encourages underperforming students to accept a 'lower status in both the college and society in general' (Clark 1960: 572), with various tactics employed to edge low-ability students towards terminating their programme. These tactics include steering students to realise their own shortcomings by 'laying out the facts of life' (p. 572) and assisting students to evaluate their ability and capacity. Moreover, Clark's (1960) interpretation offers an *alternative achievement*, with substitute paths, as 'one does not fail, but rectifies a mistake' (p. 575).

At job club, the process followed a similar path; paid work is an often-impossible aspiration. Sally (work manager) knows that the promise of paid work is often a con, and instead, encouraged job seekers to redefine their expectations to accept *more* volunteering and work experience. Sally emphasised the additional benefits of volunteering over paid employment, even though the job club had specifically been set up to support people in their quest for paid work, by offering it as a pleasant, feel-good alternative. First to consider is Sophie (job seeker). Sophie asks whether there is any paid work available locally. Sally informed her that there is not, yet there is a local voluntary project that may well be of interest:

Sally: Would you be interested?

Sophie: Yes please.

Sally: Really, ok Sophie, that would be fantastic. It's not a paid job, it's voluntary, so it's not paid work.

Sophie: Could I get a paid job as well?

Sally: Well, you could try, but if you wanted, it might be nice to think about it as it'll be a bit different.

Here, Sally presented the opportunity of volunteering as a route to engaging with different experiences. This direction of conversation continued over several weeks:

Sally: There's a couple of voluntary jobs coming up... I'm hoping that in the summer you might want to do some work there.

Sophie: What about getting paid still?

Sally: Well, that's true isn't it... we need to think about how we are going to move you on to work don't we really. [Name] was just telling me earlier about a place in [city] where they do... like a training place... they take people on, but they don't pay you there... I'm not making any promises... [but] it sounds very suitable.

Sophie: Because I've worked on a till before anyway... I worked in the [café] but I want to really find a paid job.

Sally: I think, whatever it is, you need to move on... don't you? You spent 3 years, sitting there folding the napkins... just going to [city] is good, going somewhere different, meeting some new people.

Sally offered the voluntary opportunity as a chance to try something different and meet new people, as a work-like alternative, whilst simultaneously shifting the boundaries of Sophie's self-perception. Sally was '*not making any promises*' that this work placement may come to fruition. Moreover, Sally then pointed out '*even getting a job as a volunteer and you're not getting paid is quite a challenge actually*'. This statement followed the similar contours of the impossibility of paid work. In this context, it is hard enough to find unpaid work, let alone paid. Goffman (1952) discusses this process of how the 'con' alters the self-conception of the 'mark' through supporting someone to surrender their claim, and instead, commit themselves to an altered self, which a new role offers them to have. Naomi and Verity (job seekers who both have one-to-one support workers with them when they access the community and live in residential care homes) both

accept the lower status on offer and the cooling process was somewhat easily instilled. Naomi was offered accumulated evidence specifically through the scrutiny of any potential workplace, presented to her by Sally:

We have to think about the type of place we work at, as in, the type of noise, and whether you can cope with that... we need to go through some more work with you and you might need to think about the sort of place you feel comfortable at and maybe a type of place that is noisy is not a good place for you. Maybe somewhere quieter. Maybe in the kitchen? Maybe it might be better for you behind the scenes rather than in the front where it can be very noisy... the key is... the right environment.

Here, Naomi accepted her loss, disentangled her involvement with paid work, and began to focus on volunteering opportunities. Similarly, Verity too wanted to attain café work. Verity and Sally spent some time one week visiting all of the local cafés to see if they would be a suitable workplace. Unfortunately for Verity, each was either too dark, too small, too noisy or had too many stairs, and therefore, unsuitable – even though no vacancy was available at either establishment. For both Naomi and Verity, these situations act as a buffer to further weaken their position as marks. Sally, offers a ‘new framework in which to see himself [or herself] and judge himself [or herself]’ (Goffman 1952:6). Further, as Clark (1960) notes more broadly, the problem of a democratic society is the inconsistency between the encouragement to succeed and the realities of limited opportunity. Here, then, Sally presented a ‘de-courting’ (Goffman 1952: 6) situation that is continually at play whereby the construction job seekers have made of themselves is separated from paid work, which cannot be sustained.

Yet, for Sophie, this ‘hurdle’ (Clark 1960: 573) in contemplating her work options, required Sally to become more tactical in her approach, as she ‘is not quite prepared to accept [her] loss... and to say and do nothing about [her] venture’ (Goffman 1952: 1). Instead, she resisted the cooling out process, as ‘status if won by individual effort and rewards are secured by those who try’ (Clark 1960: 569). This agency evoked by Sophie, led to weekly tension at the job club, as she continued to repeatedly seek out paid work independently. Sophie spent her time wandering the local village asking businesses if there were

vacancies (*'is there any work going?'*), sometimes returning with an application form. These vacancies included positions of a carer, multiple shop roles, pub work, and cleaning. Sally worked hard to pacify Sophie's intention to apply for any of these positions. The local chip shop was not an *ideal* working environment due to evening work. Neither was the role of cleaner at a local public house, because, as Sally commented:

Cleaners are well paid so there are high expectations... and when you do cleaning jobs, you've got to think about the kinds of places you are cleaning... somewhere like [public house], do you think it's quite a dirty place?... dirty shoes, spilling beer.

Moreover, in addition to creating such barriers, the desire for a non-existent *ideal* job also saw Sophie's lack of technology skills, personal abilities, and age brought to bear, when she informed Sally that she would like to take her curriculum vitae (CV) around local supermarkets:

They won't accept CVs. You need to apply online... It's quite hard to do it online actually... they are quite demanding jobs, supermarkets... very physical. Much more physical than other shops. I'm not trying to put you off, just be realistic... they'll want you to do a whole range of things... well, it's good you are looking... you turn up, you've got good skills, however, you're a bit of a dreamer aren't you. You want to do jobs that aren't suited to you and you need to think about that, you're not 20 anymore!... I've had these conversations with you before haven't I. As you get older, you have to find places that suit you really. We wouldn't be doing our job if we let you carry on trying to get jobs that are not suited. It's not that I am trying to tell you what to do, we are just trying to help you... Sophie, you keep harking back to your youth... you need to be a bit more honest about where you are and what jobs you can do... Now, this is something I am going to put very tactfully. I think, when you are looking for a job, because Sophie, you very quickly say, "I want to work 16 hours" ... but actually, as we go through life, we change, some of these jobs are quite hard...[It is easy to say you want paid work]...it's not as easy to do and as I say, as you get older, it gets even harder, it's not, it's not about disability necessarily, it's about us all getting older, yeah?

Sophie then, was presented with the notion that the barrier to employment now is not only her ID. Other barriers are working against her as factors cumulating to the body of evidence that she cannot attain paid work. Still, she was convinced that paid work was the answer, asking if she could get a leaflet distribution round, like a fellow job seeker. Again, this was instantly curbed, *'you have to be pretty fit, quite a lot of streets to walk'*. Sophie replied, *'yes, yes, please... I don't mind walking... I like my walking I do'*. Sally concluded, *'ok, well, erm, well, who is interested in some café projects over the summer then?'* instantly appeasing Sophie, who clung to this café idea and left the leaflet round (for that moment). Moreover, Sally had to continually work to highlight the non-financial rewards of volunteering and present it as an opportunity for Sophie to still become a 'something or someone' (Goffman 1952: 4):

It's not as simple as just earning money. Money is important, of course it is, but if that's the only reason.... but wherever you make an effort to do something, its work isn't it... satisfaction, you've achieved something... because that's what work is... a sense of achievement... you keep your mind occupied.

This reframing distorts the understanding Sophie had of work equating to financial reward. For, it is now that Sophie reveals the external pressure she felt to attain it. Sophie would not accept that she had to take a 'chin up and make the best of it' (Goffman 1952: 10) approach to accepting solely volunteer work, because her support worker had told her she needs a job. Sophie explains, *'[name] said why don't you get yourself a job'*. Sophie then, directly attributed her commitment to finding work, to the pressure she felt from others, *'he said I should be working'*. Moreover, she also revealed that she finds it hard to manage financially each week *'my money is going down all of the time, I need to get a job...I used to get my £10 and I don't get that anymore'*. For three years, Sophie worked at a café where she would fold napkins and perform other light duties for two days per week. She was paid £10 per month for her work. It is the loss of this job, that falls out of the bounds of work experience or volunteering, that is the route of frustration, and it is this type of work that she would like to re-engage with. Unregulated roles such as these, are historically considered to be of a therapeutic nature (Reaume 2004), yet my research explores how these positions are still

prevalent within the learning-disabled community and, moreover, that some people with an ID have a different construct of what work is (discussed in depth in chapter eight). Yet, rather than explore how these therapeutic type roles are not the same as open employment, Sally instead confirmed the support workers opinion to be correct:

He is right Sophie, but it really is hard to get a job. It's hard for everyone and I'll tell ya, as you get older it gets harder... if you were a little fitter, coz if money really is an issue for you, that little news round [delivering leaflets] would be an option for you, you know. It's only £10 every two weeks... you have to get yourself a little fitter though Sophie.

Sophie had an ongoing medical problem with her leg that was unlikely to improve for some time. This focus on health, however, acted as a mechanism to maintain Sophie's interest in finding work. For, she now had hope – once her leg got better. This function is an important aspect of the employment programme cycle, which differs from both Goffman's (1952) and Clark's (1960) static interpretation. Instead, in this context, cooling the mark must fluctuate to ensure Sophie, and her peers, remained just interested enough to continue being present at the job club so that the project remained viable and could document the need for employment preparation in the local community. Yet, Sophie was becoming increasingly frustrated at the lack of work available to her, and in turn, Sally was irritated at Sophie's agency. Therefore, Sally deployed another function of cooling the mark – getting tough.

Get tough

Sally grew to foster a 'talking tough' (Clark: 573) approach, directed at Sophie, by explaining *impersonally*, 'the facts of life for the over-ambitious student', which was performed within the group discussions rather than within individual sessions, for, 'talking tough to the whole group is part of the process' (p. 573). When a local shopkeeper advised Sophie to take her CV in for consideration, Sally replied, '*but everybody would say that. He's being polite. I'm sorry but they do*'. Yet, again, Sophie is undeterred, '*he said to bring it in after Wednesday, my CV*'. Sophie is in 'objective denial' (Clark 1960: 575). Here, 'the latent student may ignore the counsellor's advice to see what happens... on receiving low grades [or in this

case, rejection and disappointment], he [or she] is thrown back into the counselling orbit' (Clark 1960: 575). When Sophie tried to point out how much she would like to attain paid work, Sally replied, in front of the whole group:

Yeah, to be fair, you've always said that Sophie but it is harder and you've got to, one of the things I'm always trying to get across to people is if people pay you, they have much higher expectations and that's a little bit why I'm telling you about the rules and everything so that you know, if a boss is going to pay you, he is going to want you to work in a certain way.

Still undeterred, Sophie replied to the whole group, *'I focus on what I'm doing – when I was at [café] I focused on my job'*. Sally interjected, *'that was a long time ago Sophie. As you go through life you change'*. The following week, Sophie had returned to see a local pub manager about a cleaning vacancy. She left her CV with the manager, returning there a few days later. Sophie explained, *'I said, have you got my CV and he said yeah, but I've decided you are not qualified to work in the [pub]...he said I'm not qualified... he really is quite rude he is. I was thinking about working up there I was'*. Sally went further than before with her response this time:

He's entitled to say it. Perhaps he hasn't said it the right way... he could have been politer, I grant you that, he didn't need to say it so rudely, but it's his decision. Maybe he has got people's CV with much more experience... think carefully. Not every job suits you. It's very easy to say I want a paid job and I want to do cleaning... Sophie, go to [city] but remember, you are 47 years old. You're not 27 anymore, be honest, say what you're good and not so good at.

Sally suggests, after this, that Sophie should seriously consider a move to a different job club, in a city 10 miles from the village and she is now actively encouraged to do so. Cumulatively, this leads to the functional performance of *agents of consolation* within the cooling out framework offered by Clark (1960). Sally performed the never-ending task of enacting patience with 'the over ambitious' (Clark 1960: 575). As the 'cooler', she offered a status that somewhat differed from the one that has failed, but it is presented in such a way that it

allowed space and hope for Sophie to at least become 'something or somebody' (Goffman 1952: 7).

This position is further reinforced by both individual and group sessions at the job club where participants work on different employment inclusion activities, such as work profiles and self-appraising worksheets. These profiles and worksheets were used by participants to identify their skills and weaknesses, with an aim to increase employability by engaging with various workshops provided at the job club. Yet, in reality, these activities were tools to ensure participants were 'repeatedly confronted by the accumulating evidence' (Clark 1960: 573) of realistic expectations. Here, the procedure is intended to 'heighten self-awareness of capacity in relation to choice' with councillors urged to 'be alert to the problem of unrealistic vocational goals' and to 'help students to accept their limitations and strive for success in other worthwhile objectives that are within their grasp' (Clark 1960: 574). Figure 3 highlights the personalised limitations of job exclusion, compiled during a group activity:

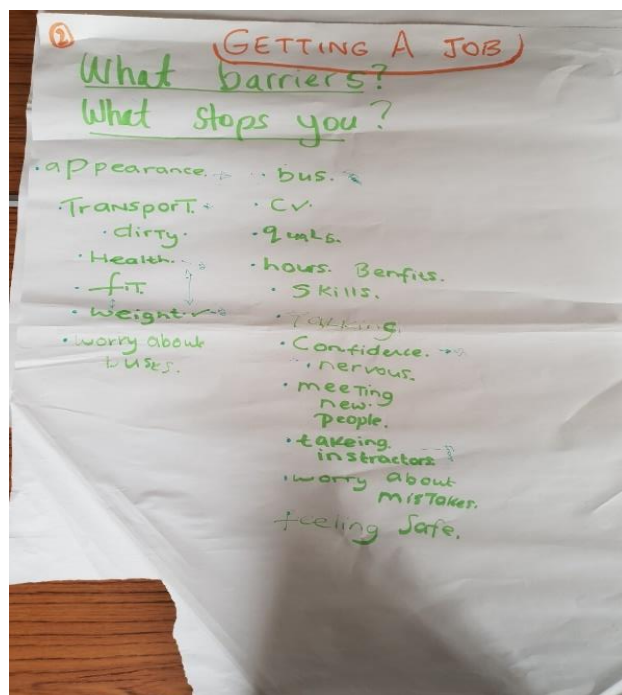


Figure 3. Group activity work based on personal barriers to employment

Figure 3 outlines the barriers that job seekers felt stopped them from getting a job: appearance; transport; dirty; health; weight; worrying about buses; CVs; qualifications; hours; benefits; skills; confidence; meeting new people; taking

instructions; worrying about mistakes, and; staying safe. Taken together, these intricately personal and external barriers act as a body of self-cumulative evidence, that job seekers were simply too far from paid work. For, these barriers had been individualised and collated as a problem with agency, rather than the structure of the job market. Moreover, Sally then drew upon other job seekers to enact the support of her performance of this function. Making sure that Sophie was listening, Sally said the following to another job seeker, drawing on their comparison to Sophie:

It gives me confidence [name], that you've stuck with it. One of the problems I have is that people often say 'oh I want a job' but they've got no commitment... one of the things you are going to struggle with Sophie, is commitment. You need to show commitment. You see what [name] is doing, is showing somebody that she is committed. Because it's not easy to work there but she is committed.

Yet, this comparison of Sophie was pitched against someone who does not have an ID. What has also emerged from this focus on *getting tough*, was the important function of using other job seekers to support Sally's claims and lower the self-perception of the individual – that is, the use of a proxy.

The role of a proxy: a source of aspirational envy

While distant from the labour market, neither Robin nor Jackie had a diagnosed ID. Robin had schizophrenia, while Jackie had never been assessed for a borderline ID. Tara did have an ID, and she was in receipt of social care provision, living within a registered residential group home. However, her paid work was not gained through open competitive employment. Rather, a local employer purposely sought out an employee with an ID for their own altruistic motivations. As such, Tara worked for two hours per week at a factory, where she was paid the national minimum wage. Tara was only present during the first few sessions of job club while waiting for her factory induction, yet she became an established and essential feature with the role of the proxy, particularly for Verity, who regularly drew on Tara's good fortune. Furthermore, Tara was the ideal aspiration, for, as well as having an ID, she also had two other *jobs*: working at the café Sophie previously worked at, for two days per week (earning £10 per

month) and working at a private hotel. Here, for the last 17 years, Tara had worked in the kitchen for two days per week. She had never been paid and this morally ambiguous work will be explored in-depth in chapter eight. Yet, Verity was always excited on Tara's behalf for having so much work. She informed the group most weeks that Tara could not attend because '*...she has gone to work on the bus. The [place] factory and the hotel. Tara has jobs*'. However, for Sophie, Tara's focal point of being in work was a site for tension and envy '*...wish I could get two jobs... wish I could get two jobs like Tara*'. Yet, instead of reassuring the job seekers that Tara's work was not secured through open employment, Sally replied:

Fantastic isn't it. There we are it can be done. There are jobs out there, but it did take Tara a long time to get that job didn't it and she has really stuck at it.

Again, Sophie was kept interested in the possibilities of securing future work, *just like Tara*. This further maintained her interest in job seeking. Moreover, the role of a proxy can be very close to home. Robin was Sophie's fiancé. He was a chartered accountant for many years, and, while extraordinarily different, Sally regularly compared Robin's situation to Sophie's, to add another layer of strength to her case, that Sophie, was most definitely overambitious in her job seeking:

I mean, it's like Robin, you've been very honest. I'm sure when you were 30 years younger, I'm sure he done jobs that were far more demanding.

Robin replied that he had held demanding tax jobs. When he first started job club, I asked Robin if he was specifically looking for paid work. He replied,

I am yeah, I've got a voluntary job [at a charity shop]. I've got enough to keep me occupied. I don't need to be occupied; I need money really... So clerical office work really, yeah. I'll do anything really. Make coffee... I just want some extra money, I'm a bit short of money. Ideally about £20 or £30 a week really. I don't know how many hours that would be for £30? I don't want it to affect my benefits you see. So, maybe a day or a half-day or something... I sold my car about 10 years ago because I couldn't afford to run it'.

Sally replied to Robin, *'It's a bit of a vicious circle, isn't it? Because if you had a little job, a paid job, you could afford a car couldn't you'*. Here then, it is clear that Robin is only interested in paid work, yet, over the course of his nine months at the job club, Robin accepted that he was finding it problematic on how much to declare on his CV regarding his mental health, particularly with the significant gaps on his employment history. In light of this, he too is cooled out over this time, so that he was then receptive to accept unpaid work, as a route to 'retain some status' (Goffman 1952: 11), since, as Robin said, *'the expectations are much higher when you have a paid job... to be more proficient'*. So, for the purposes of his health, Robin was willing to accept what was on offer:

If I don't do anything, I get panic attacks. When I'm busy, I don't... when I'm at a loose end, and I've not much to do, I get panic attacks about 2 or 3 times a week. But if I've got a busy day, I don't get them.

Robin resigned himself to securing more voluntary work, not for the additional experience to then return to waged work seeking, but to act as a filler to his unstructured days. Yet for Sophie, the real tension was not from comparing her personal situation with Robin; it is with Jackie's role as the proxy. Sophie and Jackie were both interested in similar working roles in the small village. Here, without a diagnosed ID or ID status, Jackie may well have been perceived to be closer to the market, yet her position is arguably even more precarious. Her experiences are played out at job club, in front of the job seekers and these experiences are intrinsically intertwined and impact upon the experiences of the job seekers who are in receipt of social care provision. Unlike the other job seekers, as chapter five noted, Jackie and her husband have been transferred to Universal Credit (UC) and she has joined job club to *'get her foot in the door'* of a secure job. For, as she explained, *'[you've got to] get your foot in the door... you've got to get a job first and then people will play with you... if you're not in the system... they won't play ball'*.

Jackie has held a long-term position before, yet this was out of the bounds of formalised human resource procedure. She has not engaged with the structures of large organisations, rather, she has been at the margins of employment

precarity, working as a carer and cleaner for an elderly gentleman over many years. I asked if Jackie was classed as actively seeking work. Sally replied:

Well, she isn't really on the system... she's been in employment. when you [Jackie] had your job with Mr. [surname], were you paying tax? Were you in any system then? Or was it cash in hand each week?

Jackie replied it was cash in hand. Sally reflected:

So, you've not contributed NI or pension... this is why you need to get a job with a proper company... you've missed out... it's going to affect your pension... all this sort of stuff, is really, really important. In the long term it's [cash in hand] probably not done you that many favours... it's hard to know how to play this.

Financial insecurity is the external force that has pushed Jackie to join job club and seek paid work. Here, according to ALMP, this effect is an intended consequence. Facilitated by Sally, Jackie had a work trial at a hotel for four hours per week, over four weeks. Sally informed the hotel manager that Jackie was seeking 8-10 hours work per week after the trial, to make sure she stays under the UC cap (this is incorrect, as chapter five has highlighted). Jackie was very excited at the prospect of potentially securing work, and Sally explained:

It's a very physical job, I do warn you, but I'm absolutely sure that you could do it and the thing that's so good about this place, is that it's such a good team... one of your problems in the past has been having too many people interfering and you getting very confused about it... well, at [hotel], that's exactly what you'll get. You'll have a mentor, one person... a calm environment, where there isn't too much stress and people getting upset... they train their workforce... in a very systematic way... It's very military really.

In Jackie's 'employer information' workbook that Sally had helped her to devise, Jackie described herself as working, '*best in a happy place*'. Sally added:

Basically, you are saying you don't want to work with a bunch of slagging bitches actually. And you haven't got that [at the hotel] ... Ultimately, they expect you to be able to clean a room in 26 minutes... it's quite full-on... [name] is a very reasonable manager... you'd be expected to build up

over months to get to that. She doesn't expect you to go and do it all straight away, but what they do expect is perfect quality.

The trial did not go well. Jackie found the work tasks difficult to complete. She explained, '*I don't like it. I might as well be honest... the people don't really want to speak... I feel like **that** small*' [emphasised as Jackie holds her fingers close together]. Jackie explained that she mixed the cleaning cloths:

Oh my god, there's one for the toilet, there's one for the sink and bath, then one for the mirror. Oh god... she told me off... I felt that small. I'm a lot older than them lot, they are young. Show me up in front of someone else. The girl I was working with showed me up in front of them, felt like that small... I don't understand why they were asking who does the housework and who does the cooking [in Jackie's home]. That's nothing to do with [hotel]... those girls have been there years. I've only just gone in there... it don't feel like I fit in there... maybe I'll be working by myself at the [another work option Jackie is considering]. I won't have all these other ones mucking it down... I will do the 4 [weeks] but that's it then.

Sally asked about the actual labour. Jackie replied, '*bending all the time... toilets, bath, sink, and everything*'. Sally added, '*that's why they pay well. Is it quite hard to learn the different things you've got to do?*' Here, Sophie joined in the conversation, asking Jackie, '*you don't really like it down there at the cleaning job?*' Yet, Sally rebuffed this question, '*well, you're gunna hang on there aren't you?*' Jackie confirmed again that she would complete the agreed 4-week trial. Yet, as the trial progressed, Jackie felt better at the hotel, '*I'm doing well now*'. Midway through the trial, Sally and Jackie had a meeting with the manager to review her progress. Sally relayed the conversation, '*Jackie is fabulous with her quality, so that's nice isn't it* [the group applaud] *but there is a big but, you're not fast enough. She's got to speed up*'. Lucy (job coach), suggested that Jackie could practice her cleaning speed at home. However, Sally began to prepare Jackie for ultimately being unsuccessful on the trial:

You're not used to working in that kind of environment, you need time to speed up... you might decide it's not quite the right job for you anyway... I know she won't offer you a job if she doesn't think you can keep up.

On week 3 of Jackie's trial, a representative from a skills company came along to talk to the job seekers about work preparation courses on offer. Jackie and Sally discussed the prospect that Jackie would be unlikely to secure paid work at the hotel. The representative asked, *'will they give you a reference?... because that is good. If you're not successful... at least you've got your feedback and you'll have a reference'*. At the end of the trial, there was no vacancy. Sally explained to Jackie, *'if they haven't got a vacancy, they can't offer you a job'*. Jackie, then, worked free, for 20 hours, in order to secure a potential future reference from a hotel that would not employ her. Furthermore, if it had not have been for the job club, she would have been financially out of pocket from the experience. Jackie paid £5.80 per day bus fare, which, in this case, was reimbursed. For others without such assistance, with a limited income, this could have been a barrier to participating in the trial. Moreover, if Jackie had been successful in securing the post, with the hours spread out over five days, she would have been working for around 45 minutes per 2- or 3-hour shift, to cover her transport costs. This contrasts with the other job seekers, who, through their disability diagnosis, were entitled to a free bus pass. Jackie noted, while in discussion with the group, *'they won't give me a pass because there's nothing wrong with me, is there'*.

The struggle for Jackie to secure formal employment was too much. Instead, Sally encouraged her to revert back to employment insecurity and cash in hand work, by devising leaflets and offering private cleaning work (this is explored in detail in chapter seven). As the proxy, Jackie's struggle to secure work refuted the *'it can be done'* mantra offered early on in the job club. Frustratingly for Sophie, the consequence for Jackie being unsuccessful in gaining employment is that she continued to be 'parked', while Jackie was 'creamed' (Wiggan 2015). Now, each time Sophie shared the news of the latest vacant position she had found out about, by physically frequenting shops and businesses, Sally listened to the potential vacancy and then directed her attention towards Jackie, encouraging her to apply for the post. When a new local business was under development, Sophie shared with the group that she had been in to speak with them. The manager advised Sophie to take an application form and return it within a few weeks. According to Sophie, this meant that *'they said they would be interested in me working there'*. Sally asked her what jobs were available. Sophie replied that

there would be a pizza bar and a coffee shop. Yet, Sally stopped engaging with Sophie, and instead, talked exclusively to Jackie, maintaining her eye throughout:

What I think you probably need to attach to that is a covering letter saying it.... draft out a letter, we could do that today which I can type up for next week...not all the jobs will be suitable... I don't think you'd be interested in cooking the pizza's, would you?

Sophie was oblivious to the situation that has emerged. She continued to share that she would be interested in waitressing, *'I'm interested in waitressing on tables, like teas and coffees to give to people and maybe help with pizza'*. Yet, no one was listening. Instead, Sally and Jackie were discussing different job roles, working hours, and possibilities. Moreover, Sally informed me [off the record] that the local businesses were *'fed up'* with Sophie continually asking for work. Sally tried to counteract this situation by often telling Sophie that she had, *'quite a few things bubbling away actually, yeah. We've got possibilities'*. Here, the main possibility was to enroll Sophie at the work experience programme in a different city, alluded to earlier in this chapter, and as such, she did not need to attend job club anymore, *'in [city] there are quite a lot of opportunities'*. By this point, Sophie's participation at the job club was unsustainable, and Sally enrolled her in the new one. Within two weeks of this conversation, she was told to stop this job club and start attending the next one.

After over a year of attending the job club, Sophie's last week coincided with a trip out to a potential volunteer venture at a local village shop for the group. This week also coincided with Jackie being offered a paid, 'carved' café job.²⁵ We meet at the café down the road from the job club, as usual. Sophie was excited both at her new plans in the city and visiting the local village shop. Sally was full of excitement for Jackie, yet Jackie did not arrive. Sally called Jackie to see where she was – as she now had a job, Jackie did not think she should come to the job club. Sally tells her to get ready, we will pick her up on the way. Yet this meant that there was now not enough room in the car. Sally told Sophie not to come as

²⁵ Carved employment is defined as customising job duties either to create a specialist job role, thus freeing up the time of specialist staff, or, swapping job duties to make the most of individual skills (Base 2020).

she was '*sorted with [city] now*' so did not need to look at the potential voluntary roles at the shop. Sophie was tearful, she had been looking forward to the visit. She was watching the fuss being made of Jackie unfold and knew that a cake would be purchased to celebrate with Jackie. Yet, Jackie was not looking to work at the shop now either, and Sophie was more than aware. It was an uncomfortable situation. Moreover, Sally was indicating more broadly during the same conversation, to the other job club attendees that they need to be 'moving on'.

While Naomi initially joined job club to find paid employment, by the end of the year, work had not materialised. Instead, to coincide with job club finishing for them, Naomi was offered 6 weeks voluntary work [4 hours per week] in the administration department of the organisation that she lived within and was supported by. Similarly, for Verity, she also secured a work experience role, for 4 weeks at the local non-profitmaking café where we all met before job club sessions commenced. No plans were in place for after either of these placements finished. Importantly, here, then, is according to Goffman's concept, the movement of 'those who fail is one we never see.... person[s] [that] have been rejected...are there by virtue of failure (p. 12).

Cooling the mark has highlighted here, how job club members are being appeased into accepting a lower status. Yet, what happens when individuals are not prepared to accept this position can lead to an exposure of vulnerability. When Naomi and Verity finish their short-term work placements, they were likely to want to re-engage with employment support, to remain on the treadmill of employment engagement, whether this is paid or unpaid. The aim here, then, was to 'transition to somewhere' (Ginsburg and Rapp 2018: 87) rather than 'transition to nowhere' (Silverman 2007: 8). Yet, for Sophie, her failure had meant further exclusion not just from her local labour market, but from the networks of support she had built with her peers and community.

Conclusion

Clark's (1960) use of the observations associated with cooling the mark out to explore the open-admissions system exposed how, in the US, the ideologically driven guarantee of equal opportunities, could not be maintained for all college

students. Failure was both inevitable and accounted for: 'while some students of low promise are successful, for large numbers failure is inevitable and structured' (Clark 1960: 571). Much like Goffman's conceptual framework, this chapter has chiefly dealt with 'adaptions to loss, defenses, strategies and consolations' (Goffman 1952: 11). For this research, the role of the job club had primarily been to 'cool him [or her] out' of something that is ultimately, 'proof of an incapacity' (Goffman 1952: 4). Yet, within employment activation, this process is not static, as observed by Goffman. Rather, it is a fluctuating state that is dependent on funding and/or outcomes (Dowse 2009b), realised through the job seekers moving on to other avenues, to repeat the cycle, by treadmilling around different employment services, in hope of paid work, *one day*.

This chapter has risked portraying Sally as a villain. She is not. Sally has a dual role fraught with emotional labour. She cushioned the blow of disappointment while simultaneously presenting individuals with the knowledge that they were unlikely going to secure paid work, yet simultaneously reinforced the notion they could be successful *one day*. In this lens, she too is being cooled – that is, cooled by the structure and construct of active market policies offering work as available to anyone who keeps striving. As Sennett (2012) discusses, the rise in community-based 'job clubs' results in an 'increasingly difficult task of matching applicants to scant available jobs' (p. 226). This, in turn, requires the professional job councillor to lower the expectations of job seekers. Yet, as he notes, the professional job councillor also must become skilled in handling disappointment, while, at the same time, staying engaged with the tasks in hand, 'even if one feels rotten inside' (p. 226).

The experiences offered from Green Meadow's job club, are, however, too nuanced and multifaceted than Goffman's concepts allow space to explore. Work is ingrained as the route to legitimate citizenship, to the extent that liberalism in the Global North has created a 'shame of dependence' (Budd 2011: 41) for people who cannot attain such a position. So, while cooling the mark is a framework to explore the interaction played out at the job club, it does not explain why people continue on a treadmilling path of seeking employment. To do this, Berlant's (2011) concept of cruel optimism extends the theoretical accounts offered

within this study. In chapter seven I discuss through the lens of cruel optimism the extent to which an attachment to the promise of possibility for paid work is through what she describes as, a fantasy of the good life.

Chapter Seven

Cruelling the mark: barriers to accessing employment

In chapter six, I explored how people are ‘cooled out’ of their aspiration of paid work, and instead, offered the opportunity to at least be a ‘something or a someone’ (Goffman 1952: 4) conceptualised through unpaid work. However, I argue that this process is not necessarily static, as intended by Goffman – rather, it is fluid and fluctuates, depending on the context. As such, Goffman’s insights here did not fully account for the experiences offered in the research field. Berlant’s (2007; 2011) cruel optimism, however, can extend this perspective. Cruel optimism is the term coined by Berlant (2007) to illuminate the attachment or promise to conditions of possibility, only to discover that the realisation of that optimism is *impossible*. It may be ‘a fantasy of the good life, or a political project’ (2011: 1) and even when this possibility is likely to be lost, the continuity of its form provides the endurance of the subject’s sense of what it means to continue and keep looking forward. This chapter, then, sketches out how job seekers at the job club keep working hard, yet paid work never quite appears within their grasp, because instead, it is a fallacy.

Cruelling the mark

Cruel optimism is referred to, here, as sitting on a continuum on an employment cycle – as a process, holding tension. While cooling the mark (Goffman 1952) provides an analytical tool to explore how people accept a lowered status, Berlant’s (2011) conceptual framework adds additional means to unpack the multifaceted experience of the job seekers; for, ‘cruel optimism exists when something you desire is actually an obstacle to your flourishing’ (2011).

The boundary of when optimism becomes cruel is not distinguished. Ehrenreich (2009) explores how optimism, as a notion associated with positive thinking, has ‘fooled America’ with an ideological positivity of how things are now (even when they are not), how things can get better and how being optimistic increases the likelihood of a happy outcome. This stance, then, mitigates for ‘crueler aspects of the market economy’ by material success being achieved through an optimistic

attitude whereby there is 'no excuse for failure' (p.8). As such, 'optimism is a cognitive stance, [and] a conscious expectation' (p.4). In contrast, Berlant (2007;2011) conceptualises her framework of cruel optimism by calling for us to append 'ordinary notions' (2011: 49) of endurance repair work and flourishing alike, and instead, question whether these optimistic attachments are the problem in the first place. Within Berlant's theorising, cruel optimism is the 'condition of maintaining an attachment to a problematic object [of desire]' (2007: 33).

Cruel optimism has been applied to critical feminist theory. Lipton (2017) drew on the framework to explore how Australian universities risk rendering gender inequality as invisible, whereby 'optimistic attachment to gender inequality and diversity policies' (p. 487) are used as tools to improve women's representation, yet, may instead be detrimental to achieving gender equality. Here, while increased participation may be apparent, it does not necessarily indicate 'broader structural change to gendered power relations in Australian higher education' (p. 489). Moreover, this focus on gender representation, by increased monitoring and individualisation, renders women as 'hyper visible and thus responsible for their own success or failure' (p. 489).

Moreover, Rasmussen (2015) studied education policy in Australia through the lens of critical theory and connects it to cruel optimism by arguing that how people perceive the use of technology in education policy is more important than the substance contained within such policy. That is, the optimism and positive effect held about a technology platform curtail accountability rather than allowing space for learning to flourish. Duschinsky et al. (2014) drew on Berlant to explore attachment theory that produces 'obedient and self-sufficient citizens' (p. 229). Allen (2018) applies cruel optimism to masculinity through the lens of queer theory, whereby masculinity can be realised as part of what Berlant refers to as 'the good life' (2011: 11), through the continued belief that it is attainable, yet, as a performance, masculinity is a concept that is continually failed. Allan (2018) drew out Berlant's use of the American Dream and dashed hopes when citizens do not rise as high as their aspirations. More broadly, Brown et al. (2011) drew on notions associated with the American Dream to explore its deep-rooted

fragility when hopes are dashed and inequality is exposed, such as during the financial crash in 2008. Further, Brown et al. (2020) drew on the problematic nature of human capital theory and the notions associated with the American Dream which renders college leavers as over-educated for a scant job market.

Further, cruel optimism has been applied within a critical disability studies framework. Goodley (2014) used Berlant's notions to explore the impossible promises offered within neoliberal capitalism (p. xvii) as 'ableist fiction' (p. 64), as a scene of 'normative desire' (p. 65). Goodley et al. (2017) further these notions whereby the consequences of cruel optimism risks distress 'as one fails to match up to the labour... demands of late capitalism' (p. 13) while exploring the relationship between late capitalism and the ideal body. Here, Goodley et al. question why we emotionally invest so much in institutions that 'discipline our identities and limit our potential to flourish' (p.13).

The foci of Berlant's analysis is that cruel optimism is a project whereby, at its core, the 'moral-intimate-economic thing' that one searches for is attached to cruel optimism as the fantasy that we all aspire to, for the 'the good life' (Berlant 2011:2). We hold on to the 'mistaken desire and belief that we will reach personal fulfilment and happiness through working... hard enough' (p. 13) and attain this good life. When this fantasy is unfulfilled, Berlant (2011) describes:

The compulsion to repeat optimism, which is another definition of desire, is a condition of possibility that also risks having to survive, once again, disappointment and depression, the proacted sense that nothing will change and that no-one, especially oneself, is teachable after all. All that work, for what? (p. 121-122).

It is the 'all that work, for what?' here that resonates. For Goffman, the self is not the cause of the situation, rather, the self is the result of the social situation. No part, no aspect of the self, is untouched by the social world. We are shaped by social norms, and as a constraining tool, we act in certain ways. As such, social norms are deeply embedded and taken as being natural (Goffman 1959). Therefore, the construction that paid work is the pinnacle of acceptance, and fundamentally, citizenship continues as an ideological construct. It is ingrained

to then accept this lowered status on offer of non-paid work (see chapter six). Cooling the mark then, does not satisfy the process of agency of the self, when the attachment to waged work is so deeply embedded. Yet, Berlant describes how the world is pulling us in and pushing us away, as neither ‘an act of conscious intention agency, nor a manifestation of unconscious symptoms in any objective sense’ (2011: 138). Rather, optimism offers a way of ‘participating in ordinary life’ (p. 138). In this sense, as Goodley (2014) notes, ‘labour will save us and allow us to be recognised’ (p. 65).

For those attending job club, this object of desire is the cluster of promises that we want someone to make possible on our behalf (Berlant 2007). This is enacted through Sally acting as the gatekeeper to the promise of work, with regular, weekly questions such as ‘*are there any jobs going for me?*’ by the job seekers. Here, this desire is for work to be the norm, as this cluster of promises can be embedded within a person, a good idea, an institution, and a norm or expectation (Berlant 2007). The object of desire is not confirmed as an irrationality, rather, it is an explanation for our endurance to believe in the object of desire. With this attachment of optimism formed to job club as a group, the attachment could be experienced by one member, yet fear will be heightened for the other members. This fear of loss is the prime scene for optimism. When operating, the ‘potency of desire’ (p.33) contributes to the attachment of optimism of the very thing that is supposed to have been made possible. For, as Budd (2011: 14) reminds us: ‘when we work, we experience our biological, psychological, economic and social selves. Work locates us in the physical and social world and thereby helps us and others to make sense of who we are’.

However, as this chapter will sketch out, it is Sally who struggled to craft opportunities on behalf of the job seekers and invested the time to negotiate on their behalf. Not long after I started attending, I noted in my journal:

While applying normative practices associated with becoming job-ready (health and safety, employer expectations for example), the actual ‘work’ is anything but normative. Normative procedures are a cover to satisfy expected outcomes – the real work is what Sally draws from the club

each week and then actions in between sessions (contacting employers, calling placements).

Hard work

For Jackie, this crafting of opportunity is played out with Sally negotiating with a national hotel chain to offer her the 20-hour work trial explored in chapter six. Sally shared the ‘there is good news, it can be done’ notions with the group, which aligns with the American Dream sentiment that Berlant alludes to, set within a mantra of *work hard and you’ll succeed*. Yet, as we have seen, this good news is attached through the use of a proxy. While Jackie had additional barriers to employment and her experiences as a proxy have been well documented in chapter six, she was, by far, the closest to the labour market at the job club, and therefore, she was the *dream*, the *aspiration*. This sets the scene for the tightrope of confusion that defined a key issue with the job club. On one hand, Sally ignited the imagination and optimism of job seekers that if they worked hard enough, they could secure work like Tara and Jackie (cruel optimism), yet, this held tension with the alternative of recognising individual dis(ability) and realistic job prospects in a supply-side labour market (cooling the mark).

This situation was precarious. Job seekers here were assessed and diagnosed as having an ID that required local authority support. Aside from the proxies, all job seekers were assessed as being within the Support Group (SG) in their Work Capacity Assessment (WCA) (as outlined and defined in Chapter five). Apart from the scrutiny into Karen’s work status (generated through her prolonged volunteering – discussed in chapter five), all other job seekers were stable within their assessments and were not required to regularly re-justify their non-ability to seek paid work. Yet, they chose to engage with work preparation activities. In this sense, the scene of desire was in itself, an ‘obstacle to fulfilling the very wants that bring people to it: but its life-organising status can trump interfering with the damage it provokes’ (Berlant 2011: 227). For, even when a subject has their well-being threatened, the continued desire is within an individual’s sense of what it can mean to live (Berlant 2011), and we have seen this with Karen.

Karen’s GP advised on her records, ‘*patient not able to read, slow at tasks, not to be placed under pressure to speed up as she is likely to fall and increased risk of*

seizure'. Yet, the main reason for her referral to job club was to assess her ability and 'quicken' her up, with the underlying intention to transfer her from the safety of the Support Group (SG) to the increased conditionality within the Work-Related Activity Group (WRAG) (as discussed in Chapter five). Moreover, the non-assessed difficulties Karen faced can now also be unpacked. As she explained, *'I'm not used to coming out of my safe places... going out places... I have a job taking things in that we did... it's always been... since I was a teenager'*. There were multiple examples of where job seekers brought personal barriers to the workplace that could risk their own health and wellbeing. Sophie found it hard to take things in: *'noise distracts me'* she said, and she had previously tried to self-harm. Sophie further recalled, *'I got a knife and I tried to stab myself. It was a new experience where I was. I felt so frightened, so I got a knife. It was scaring me, all the other people'*. Similarly, Naomi had concerns. She worried about what it could be like when a boss tells her too many tasks that need completing:

Too many tasks at the same time. I can't say like, I will put things to dry up, if you ask me to do more, I can't... so like, I dry up and then he says can you put it away or on the side, I can't process it... it's too hard for me to do... It's what has been said to me, I can't take instructions because [support worker] wrote it in my book.²⁶

Yet, what we can perceive as a moment of 'cruel optimism' prevailed as Sally replied to Naomi:

That's a very good point you're making there Naomi... a lot of people with a learning disability find it quite confusing, a lot of information at once. Sometimes, at work, the boss will... help you... one of the key things is actually writing out the [café] orders and remembering who wants what. That is quite a hard thing to do... I think everybody learns differently... you are a human being. We are all different, everybody learns differently, so it's not that you are any worse, you're just fine, it's just different.

²⁶ This conversation, offered by Naomi, also fits in with the framing of the self-fulfilling prophecy (Merton 1936) whereby Naomi claims that she cannot do something because her support worker has told her she struggles with it, and it is documented in her care and support plan.

Yet, while Sally suggested she will be 'fine' and that a future boss may help her, at times Naomi exerted agency. When she was invited to work at The Pop-up café over the summer (see chapter nine), she spoke to her boss at her voluntary job, where she worked two hours per week. Naomi asked to have six weeks off from this job while she worked at The Pop-up Café – for, she recognised that she would not be able to cope with working at both places simultaneously. Three weeks into her Pop-up Café work, where she worked four hours per week, she spoke of how tiring she found it, *'I wasn't too bad at the beginning of it, but as soon as it coming to an end, I get more tired... If I do more than 3 hours, I have to go and have my time'*. Berlant (2011) draws cruel optimism as an 'analytical lever towards the good life, which is for so many, a bad life that wears out the subjects nonetheless, and at the same time, finds their conditions of possibility within it' (p. 27).

However, as chapters two and five explored, there is pressure for individuals to attain 16 hours paid work a week, as then they are *transformed* into net contributors to the state and in 'class 1 employment, where you don't get any benefits, you're not reliant on services and you're fully included' (NDTi 2014: 63). The examples here counter the notions of work and what work means when it is exhausting and debilitating (Frayne 2015; Bates et al. 2017). More broadly, we saw in chapter five the experiences offered by Bob, who also only tends to expect people to work 3 or 4 hours per shift.

These experiences are shared at The Roasted Bean, where staff with an ID work a few hours per day, and at Power, where employees work around 2-3 hours per week. In this sense, the fallacy is in itself, that work will transform people into autonomous, active citizens, contributing towards the state. Rather, it is about managing the tension between ability and working around the system to ensure people can keep their welfare entitlements. As, 'the focus seems to be how you can maximise people's employment without affecting their benefits or other resources they receive' (NDTi 2014: 63). This is particularly precarious for individuals that are in receipt of social care. For, prioritising work participation over security and wellbeing can be hazardous – by obscuring dependency and vulnerability, to the point where 'the social reality' of an ID itself, can be overlooked (Redley and Weinberg 2007).

Throughout my time in the field, there were multiple examples of personal barriers to employment through vulnerable individuals having to navigate their personal health, safety, and wellbeing. For example, Karen lived within an independent setting, with one hours' support each day. One week, Karen arrived at the job club looking pale and bedraggled. She shared how, she had had to move out of her home because a neighbour had, *'hugged me, tried to kiss me [and] lifted up my top'*. Karen's nan had helped her to report the incident to the police and she was staying with her nan while it was investigated. Three weeks later, Karen returned to the job club to share that she had moved back into her flat, *'the police didn't do anything, they were going to try and force him out [this did not happen] I'm a bit worried, walking out the door'*. I did not feel that the advice offered by the job club to *'just keep away then'* could adequately support her with this situation.

Similarly, Sophie and Robin also experienced personal difficulties. One week, Robin did not arrive at the job club, which was unusual. Sophie, his fiancé, tried making contact but there was no answer. She became desperately concerned for his welfare and so, Sophie and I walk together to his flat to check on him. Fortunately, his life was not in immediate danger. However, Robin explained that he had been discharged from his mental health team, yet, he was experiencing some difficulties with his schizophrenia. He had no one to contact and he could not get a GP appointment. While these situations are not directly related to job club, they naturally occurred during the sessions and when situations like this did occur, they tended to dominate the whole session. This then, offers a snapshot into the lives of some of the most vulnerable and marginalised people in our society.

Moreover, these examples operate in a landscape of employment activation that redefines unemployment as avoidable, emotionless, and impact-free. This is conceptualised by a work-for-all approach that de-humanises the lived experience through terminology. For example, worklessness is used to generalise seeking work, and human action is individualised and rationalised to avoid the messy reality of unemployment (Hoggett 2001; Wright 2012). Yet, even while people accessing job club were not required to do so by the state, it is

what Berlant (2011) describes as the cluster of promises that holds ground. These promises are broad and multidimensional. Policies such as the Valuing Employment Now (2009) and the All Wales Strategy (1983), are driven by the ideological yardstick of an ordinary life, leaving little space to understand the extent of employment barriers (Dowse 2009a).

The fallacy of work

We saw in chapter five how Jackie struggled to find employment and instead, she was encouraged to re-engage with precarious work by advertising her availability to work for cash – as a private cleaner. This was in direct contrast to Sally's initial intention to secure formal employment. Sally was concerned that Jackie would not know how to answer questions appropriately if she were to be contacted directly by a potential customer. They role-play a scenario:

Sally: If somebody rings, what would you say?

Jackie: I've done work for Mr. [name] for 20 years and I done everything you know.

Sally: Such as?

Jackie: Hoovering, polishing, front room, bathroom, mopped the floor, dusting, washing. That's all really.

Sally: What kind of a person are you? Are you trustworthy? Are there any other jobs you could mention?

Jackie: I worked as a cleaner in a nursing home for a few months.

Sally: Why did you leave?

Jackie: I was smelling of old people. And I worked in a library as a cleaner, but I left because they kept on at me.

Sally: Don't say that to someone that rings up about employing you. What would you say?

Jackie: [Husband] used to help me with that [the cleaning].

Sally: You can't say that. Pretend I've got a house and I want you to clean it. What would you say?

Jackie: [still referring to the work at the library] They were finding faults with me all the time.

Sally: Don't tell them that.

Jackie: It got too much for me and I didn't like it

Sally: That's not a very good answer... you need to think of something else. What were the hours?

Jackie: In the evening when the library was closed.

Sally: That's better. You didn't like working at night.

Sally: If somebody rings you up, what are you going to say?

Jackie: Well, I've worked in the library and in a nursing home and I cleaned for someone for 20 years and done everything for them. Hoovering, polishing, mopping out, pension on a Monday, shopping.

Sally: Why did you leave?

Jackie: He had a stroke and they took him to [place].

Sally: What sort of a person are you?

Jackie: Reliable and trusted.

Sally: Perfect.

Sally, then, suggested to Jackie that she should make a note of this discussion and place it next to her telephone for any calls that she may receive. As such, Sally offered Jackie 'clues about how to behave more easily with prospective employers' (Sennett 2012: 223) by, putting a potential telephone interview into a ritual that practices behaviour that has been absorbed. However, for Jackie, no calls arrived. Again, this role play occurred in front of all of the job seekers, and each week, Sophie, in particular, asked Jackie if she has heard from anyone who wants her to clean at their house.

Eventually, after attending the job club for eight months, Jackie was successful in securing paid employment. It was a role that had been carved out for her independent of the job club. Rather, it was at the café where she had previously worked for over 10 years, for two days per week, earning £10 per month. Exploring this morally dubious work will be picked up again in chapter eight. Here, however, Jackie was not required to have an interview for the position and the initial job role was altered significantly so that she could then fulfil the required duties. This meant that, for Jackie, she was not required to be a key holder, nor did she have to operate the alarm system, as she would not have been able to complete these tasks. This position was secured without the help of Sally.

In essence, then, the transfer from JSA to UC had, indeed, activated employment for Jackie. Yet, what is also being sketched out here is how working for £10 per

month for many years is perceived to be a success, and considered to be work, in a narrow sense. For people who have an ID and are in receipt of social care, these good news stories and the celebration of employment feed into a broader confusion of how work is defined, and this can now be unpacked by drawing on how such news stories are circulated in social media.²⁷

Social media can be full of good news stories of people successfully accessing work. During the 'learning disability work week' from 5th to 11th November 2018, I undertook a short, simple tracking analysis based on all coverage of the Twitter hashtag #ldworkweek (appendix 1). Here, I explored how many of the good news employment narratives, when tracked back to their original source, shared stories where people are often either not in paid work or are not in receipt of social care. Instead, individuals are more likely to have a learning difficulty rather than a disability, or are classed as Not in Education, Employment or Training (NEET) and therefore are more likely to be closer to the labour market than the job seekers at job club.²⁸ During this short exercise, 49 Twitter feeds of good news were scooped: six were confirmed to be where paid work had been secured for a worker that is in receipt of social care. Of these six, three people were in employment within third sector organisations, one person was working in a fast-food chain and two were employed within a social enterprise. For the remaining 43, it was unclear whether the work obtained was paid.

Moreover, there were often indications that where work had been obtained, it was secured by individuals who were not diagnosed with an ID, nor in receipt of social care. These indications were people sharing their happiness at not having to access Job Seekers Allowance (JSA).²⁹ Furthermore, words like 'work', 'employment', and 'job' confounded the employment narrative, yet following back to the links, the original features are generally based on work experience,

²⁷ NDTi (2014) found a lack of consistent definitions on what an employment outcome is. Interventions such as employment preparation, work focused activities within day centres and volunteering were likely to be perceived as employment in themselves (p.10).

²⁸ A learning difficulty such as dyslexia, dyspraxia, slight or hearing impairments, does not affect cognitive capacity.

²⁹ As chapter two has discussed, JSA is the welfare benefit for those who are unemployed and are assessed as being fit and able to be actively seeking employment and at risk of punitive sanctions if certain criteria is not fulfilled.

volunteering programmes, and internships. This appears to add to the confusion to *what is work* discourse (discussed in more detail in chapter eight), reinforced by organisational language, narratives, and agendas. It is the cluster of promises (Berlant 2011) that work is indeed possible, that Bob also found difficult to navigate. This is evident where employment organisations have already ‘creamed’ (Wiggan 2015) the most able participants, yet still, cannot fulfil the cluster of promise that work should hold. Bob said:

They want to have big figures, to demonstrate what they are doing, but to do that, they have to work with [people with] mild learning disabilities... I’ve only known one person... go with [organisation] and I work all across [region]. He was working at an outward bounds centre... great employment, but it was being paid for by [organisation]. As soon as the funding stopped, so did the work. That’s common place.

This perspective is shared more widely within policy documents. Family members shared stories within the ‘Don’t Hold Back’ report (Children’s Commissioner for Wales 2018) around the ‘false hope’ (p. 33) being offered by work experience programmes, where young people now have the expectation that their work experience opportunity will lead to permanent work, when instead, often individuals were not being paid. Indeed, people having extended work ‘trial’ periods without pay, or had too many hours allocated to them. Kaehne and Beyer (2013) capture how work experience programmes are successful if the employer does not pay the worker, yet, employers will not commit to employing these individuals themselves, due to reduced productivity rates. Pulling together the context offered by Bob and the evidence and literature explored so far, aligns then, with Berlant’s (2011) explicit interest in the power of generalisation. For, it demonstrates how singular, explicit good news features can become, as she notes, ‘delaminated from its location in someone’s story... and [is] circulated as evidence of something shared’ (p.12). This evidence is *felt* at the job club through the proxy roles; *felt* by the examples offered by Bob within his organisation, and *felt* by workers at The Coffee Bean, (discussed in depth in chapter nine). Here, Berlant accounts for the effect of how desires become attached to modes of life (p. 12):

We assume our position as subjects in the world and therefore it is in us as a structuring condition for apprehending anything. Our epistemological self-attachment is all bound up with literacy in normativity, and their relation constitutes the commonsense measure of trust in the world's ongoingness and our competence at being humans. Our sense of reciprocity with the world as it appears, our sense of what a person should do and expect, our sense of who we are as a continuous scene of action, shape what becomes our visceral intuition about how to manage living (p. 52).

Berlant (2011) argues that our visceral response is trained, rather than automatic and our intuition is where what she terms, as the 'affect'. Here, the affect meets 'history, in all of its chaos, normative ideology, and embodied practices of discipline and invention' (p. 52). Therefore, 'our visceral response is bound up in the ordinary, as people make their way through contradiction, laws, norms and imaginaries shaped by events' (p. 53). Applying this historic, chaotic and normative ideology to my research highlights how, instead, the opposite is happening for people with an ID striving for paid employment. Sixty years ago, Goffman's seminal essays in *Asylums* (1961) described the 'total institutions' (p. 15) that would have once been *home* to many people with an ID at that time. Here then, the expectation that people with an ID have shifted from being perceived as holding a stigmatised identity, who in return for welfare support, surrendered their citizenship within a total institutional environment (Meekosha et al. 2013), are now instead, being expected to gain paid employment in the open labour market (Department of Health 2009), is at best problematic. As Berlant writes, 'history hurt but not only. It also engenders optimism in response to the oppressive presence of what dominates or is taken for granted' (p. 121).

Drawing on the 'obesity epidemic' (p. 105) in the US, Berlant connects how bodies, life, environment, and imageries are linked to capitalism. She interprets capitalism as the relationship between the workers and the capitalists (and consumers), and how, capitalist strategies are shifting with a 'net effect' on 'already vulnerable populations' (p. 105). Here, capitalism relates to the experience of production through a cycle of life – institutions, public spaces, and

activities – and, I would argue, organisations, that are now saturated by the logic of the markets. We see this logic of the market's ideology laced throughout specialist employment services, where notions of parking and creaming are rife (chapters three and five). Yet, as we have seen with the simple Twitter feed analysis, there are profound consequences.

Here, policy rhetoric subscribes to 'a model of institutional and individual agency that frames the adjustments as a demotic act' (Berlant 2011:105). This demotic act, in my research, was to keep going, to keep trying, in pursuit of the fallacy bound up in the (un)paid work dichotomy. Yet, exposing the personal barriers job seekers were facing, also exposed over-conflated additional barriers to seeking 'the perfect' job, albeit, without a vacancy or contact with the employers.

Chapter five briefly noted how, one week, Verity (job seeker who requires one-to-one support and lived in a residential care home) and Sally walked around the town looking for the ideal, accessible workplace. They visited various cafes, yet none were suitable, *'too many steps...too narrow...too dark'*. We have also seen this with the suitability of vacancies for Sophie (the public house that would be too dirty; the chip shop that would be full of drunks). Berlant (2011) terms this as hypervigilance through increased alertness. Here, this level of scrutiny supports the fantasy and false logic that continuing on the employment cycle, by engaging in everyday negotiation, together with 'a whole set of abstract value generating relations' (p. 174) would make the bounty of work worth risking; for *one day* the *perfect* vacancy will arise, with the *perfect* manager who will ensure the available work will be *perfect* for the new employee. And this, makes it worth waiting for, worth risking 'amid capitalist...life' (p. 174).

Unpacking (dis)ability

These labour demands were often far out of reach for the job seekers, trying to negotiate open employment, to the point where it was uncomfortable to listen to. Naomi was completing her personal profile, in the hope of paid café work. She was asked, *'can you add up numbers? Can you give change to people? Money?'* Naomi replied yes, however, her support worker added *'you're working on it*

aren't you, you are working on your money skills'.³⁰ Similarly, Verity was attending mathematics and English skills classes weekly. While chatting about this, Sally suggested to her, *'I think that your frustrations sometimes is that you can't take orders because your maths and English isn't there really'*. Apart from Sophie, none of the job seekers would work with cash or financial transactions; they could not 'do' money. Sophie could, but the prices must be in whole pound denominations. Verity explained: *'I can't do money. Count money... I know the pounds and five and ten'*. Sally reassured her, *'that's ok... you're much better with people'*.

Verity, who was seeking café work, could not use a hot tap, kettle, or urn safely, nor could she carry hot drinks to customers. Verity was also often confused when she is at the job club, finding it very difficult to separate work from personal life and, from the purpose of the club. For example, while completing a photograph activity that included matching what people wear to work with what that could indicate their job role may be, Verity identified someone as *'going to the gym or out running'* when an appropriate, anticipated response would have been a physical education teacher or a sports instructor. On a different occasion, Sally asked her, *'what does body language mean'* when discussing how to work in a customer service environment. Figure 4 shows the task for this activity:

³⁰ Naomi has one to one support for all activities outside of her home.

Customer Service

How good are you at?









Smiling at the customer		<input checked="checked" type="checkbox"/>
Making eye contact		<input type="checkbox"/>
Speaking politely		<input type="checkbox"/>
Speaking clearly		<input type="checkbox"/>
Listening		<input type="checkbox"/>
Good body language		<input type="checkbox"/>
Keeping the workplace tidy		<input type="checkbox"/>
Saying thank you		<input type="checkbox"/>

Figure 4. Customer service worksheet

Figure 4 shows the customer service activity worksheet that job seekers completed one week. In response to the question regarding body language in the workplace, Verity replied, *'it's about my body...in the doctors, he checked my body'*. Moreover, Verity could also become upset when she did not know the answers to the questions being asked of her, particularly when activities required her to write down answers. One week, as a group we are thinking about 'what to do when you make a mistake' in the workplace. Verity looked as though she would cry when she was unable to comprehend the task. She said to me, *'I don't know, I don't know what to do... can you write it down for me?'* The discussion was based upon these worksheets:

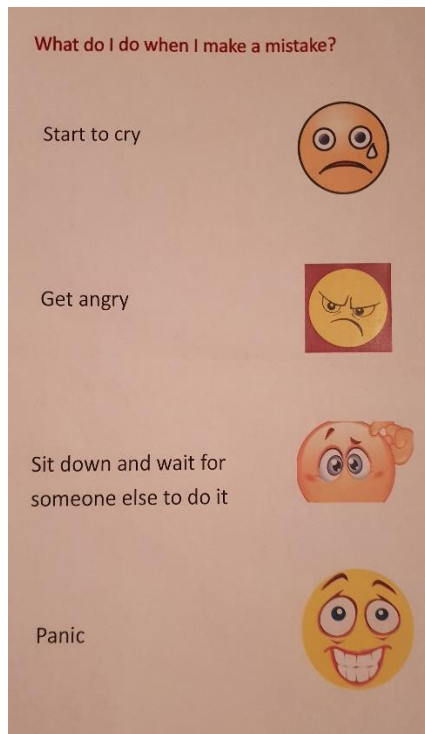


Figure 5. 'What do I do when I make a mistake?' worksheet

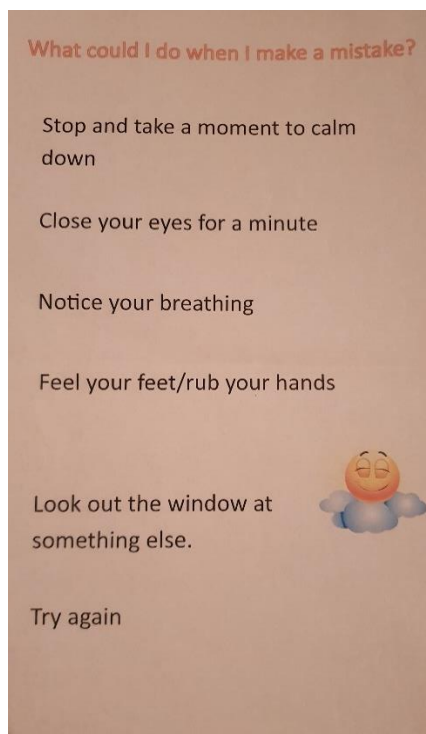


Figure 6. 'What could I do when I make a mistake?' worksheet

Figures 5 and 6 were used as prompts for a group discussion, along with techniques to reduce anxiety in the workplace. These simple steps were ways to, as Lucy (job coach) suggested, '*pick ourselves up and start again*'. The

expectation, is that there will be an opportunity for the workers to be able to engage with this process while in the workplace. Moreover, while Verity struggled with these abstract tasks, she also needed to regularly have it reaffirmed that she should not be encroaching on the personal space of customers if she were to get a café job, such as not to kiss or hug people in the workplace. As Sally reminded her, *'it can be quite personal, sometimes practical, sometimes it's just transport... but often, they are quite personal things that stop people getting a job'*. This position was illuminated with a visit from a local authority employment representative one week. My fieldnotes explain:

[Name] works for the local authority employability section. She has come along to chat with the job seekers. Before she had introduced herself to them, she whispered to me enthusiastically that she 'could get Robin into work'. Robin does not 'look' disabled, nor does he have an ID. He does, however, have significant mental health issues (schizophrenia). She then continues to whisper to me, 'paid work will be very difficult for these guys [the other job seekers]. We are far from paid work'.

Moreover, as well as these intrinsically personal barriers to employment, over conflated barriers are amplified when reliance is placed upon both people and logistics. Information technology, transport, support needs, and the financial costs associated with work, are all prevalent features within the job club. Online application forms are a particular barrier, as Sally shared with the job seekers:

A lot of it is unfortunately online applications and this is just the way the world has changed... the days of popping in and speaking to someone and perhaps telling them a bit about yourself and getting offered a job or leaving your CV with them... isn't there.

This statement by Sally then led to a discussion on internet access. There was no internet connection at the job club and most job seekers attending either did not have internet access at home, or they required support to use their devices safely. For Karen, she would have liked to have used her tablet more often but had been told by support staff that she should only use it when she has a staff member with

her.³¹ This was problematic for Karen, who only had one-hour support per day that was allocated for personal care, help with keeping her home clean, and budgeting. The local library offered half an hour slots for using a personal computer, however, this was not long enough for completing online application forms, particularly as job seekers needed one-to-one support to use the computer. Sophie found a way around this after she had a conversation with a local IT firm. She informed the group, *'the computer chap said to me if I've got a CV, I can put it onto a disc and send it to them... for a job at [supermarket]. I'm going to get a job as a customer assistant'*. Yet, Sophie was not supported at job club with this task.

Transport was also another area of significant frustration. Verity had been accepted to complete a work experience programme some 25 miles from her home. Yet, she had to withdraw after two weeks due to transport issues. For her first two sessions, Sally took her to and from her work experience, and the mileage charge Verity should have made was covered by job club funding. However, Sally was clear that she could not maintain the travel arrangements permanently, and as it could not be arranged by her residential staff, Verity had to withdraw from the programme. For Verity, the only alternative to enable her to maintain her placement would have been for her to pay for a taxi each way.³² She was incredibly upset, unable to comprehend why she could not continue her role. For a long time, she thought that it was either because she had done something wrong, or that she was still working there – often referring to it in current tense. This confusion manifested over many months. One week, some months after she had to stop her placement, she was confused, *'I get worried about my job, coz they keep messing me about'* she said to Sally. Sally asked her what she meant, and Verity replied, *'well the staff told me and that's why they stopped taking me to my job'*. Sally reaffirmed to Verity that, *'transport is the problem actually'*. Confused, Verity did not reply. On another occasion, Verity

³¹ When some job seekers asked for IT skills to be part of the job club, Sally said she could arrange this with Green Meadow, who also facilitate an IT course, at the cost to each job seeker. This was £18 per half day. No job seekers took up this offer.

³² If transport could have been arranged from her home, Verity would have had to have paid mileage payments out of her DLA funds. When Sally was explaining to Verity that they could not provide transport, she said, *'even if we could, you would have to pay [home] to do that and that's going to cost a great deal of money'* [approximately £12 per return journey].

announced to the group, *'I've got a new job, in the [place]. Sally appeared surprised and Verity laughed at her response, saying, 'you said about it!' Sally replied, 'we went to visit it Verity, but that doesn't mean you've got a job, and we decided the transport wasn't gonna work didn't we'.* More broadly, Bob connects with the issues of transport within his organisation, *'because of transport, it is near on impossible to do what they [job seekers] were trying to achieve'.*

Using public transport is considered to be skill development and often linked as a route to both self-determination and independent living for disabled people (Roulstone et al. 2014). For people living in urban areas, transport is less likely to be a barrier, however, for people in rural areas (which job club is, as too, is the areas Bob referred to), limited access to good transport links is particularly problematic and costly. Sally summed it up one week, *'It's like hitting your head against a brick wall... all the logistics'.* Not only are there the personal barriers to employment, but there are also amplified logistical barriers of supporting people who live within structured services to address, further compounded by the vulnerability of accessing open, competitive employment.

This vulnerability is profound when individuals need support from others to complete their work. For Millie, she did secure paid work, delivering leaflets fortnightly around the local area. She got paid £10 for each delivery, which took around 2 hours to complete. Except for Millie, all of the other deliverers were aged 14-16. For Millie, this work was an opportunity for her to work outside, which she enjoyed. However, an additional, conditional barrier was applied to Millie. For, she relied upon her support staff to help her with her round. Sally here, explained the conversation she had with Millie's new boss:

He's quite happy for her to do the job, but he would want her accompanied by someone else, well, a support worker... the key to this Millie, will be getting the right support worker to do this

The suggestion here is that with an unenthusiastic support worker, there was a risk that Millie would not be able to maintain her new job and Sally was often concerned with how staff changes with the community team could prohibit Millie from continuing her round. Sally's concern was founded, an example of this is captured in my fieldnotes:

Millie popped in today. I asked how she is getting on with her round. She is finding the main road really tricky and her support worker has told her it is dangerous, and a risk assessment should be done. I got a sense that this will become a real issue and I asked Millie if she has spoken to her boss to see if she can either pick up a different round or alter her existing one. She returns a few minutes later to say she has been to see her boss [who is based on the same street] and her round has been changed, removing the busy road.

Here, it is possible that without simple intervention, Millie would have been risk assessed out of her job. These examples offered throughout this subsection are not intended to highlight the 'limitations' of impairment, nor are they intended to belittle individuals who were seeking work. Rather, more broadly, it is to expose how we believe that 'labouring will move people out of a state of unhappiness into smooth, rapidly moving and ever-mobile space of the productive worker' (Goodley 2014: 138). This, as unpacked through exploring the everyday interactions offered at job club, is simply not the case.

While a Critical Disability Studies (CDS) framework would argue that these types of barriers can be addressed and removed (Goodley 2014), I would suggest that CDS falls short here, with its foci strongly on notions of self-determination and emancipation. Goodley's (2014) CDS agenda is predominantly regarding consumption and the framework is used as a lever for the reform of public services, with the intention of moving from cruel optimism to 'networks of mutuality' (p. 148) to increase opportunities and develop networks of support and interdependent living. However, for the job seekers, who all lived with a close connection to their support provider, which aimed to work in a personal centred way (chapter two), agreeing to the principles of valuing people (Department of Health 2009), the logistics of these situations could not be negotiated on a daily basis.

Instead, I suggest, in line with Rasmussen (2015), that cruel optimism 'focuses our attention on fantasies that are unachievable and divert our attention from important ethical, social and political questions' (p. 193). For, even if Verity had

been able to complete her work experience, it was unlikely that she would have been able to secure paid work from it. One week, I reflected in my fieldnotes:

Everything is magnified, amplified. What could and should be straightforward is always so complicated, and the additional stress and anxiety for job seekers here is out of kilter with what one expects the barriers to be, namely, personal, cognitive (dis)ability.

Rasmussen (2015) connects her ideas to social policy. It resonates here with her argument that how people feel about a policy has arguably become more important than the substance, even if such policies could actually curtail rather than inspire flourishing. Moreover, cruel optimism happens at its optimum level when 'the loss of what's not working is more unbearable than the having of it' (p. 27). Cruel optimism attends to 'practices of self-interruption, self-suspension, and self-abeyance that indicate people's struggle to change, but not traumatically, the terms of value in which their life-making activity has been cast' (2011 p. 27). It is of 'subtle fashion' (p. 24) operating whereby the fear of loss of the object and the attached promises will 'defeat the capacity' (p. 24) to have hope. Where cruel optimism operates, 'one makes affective bargains about the costliness of one's attachments, usually unconscious ones, most of which keep one in proximity to the scene of desire' (p. 25). Yet, this 'enabling object...is also disabling' (p. 25). Here, this threat to detach from what is not working is double-blind. For, the very pleasure of being within the action and having to sustain that relation bounds itself to a 'situation of profound threat that is, at the same time, profoundly confirming' (p. 2).

Yet, there were instances of refusal on Sally's part, to conform to the expectations and aims of the job club, for example, with Rebecca's situation. Rebecca joined the job club because she wanted to work, and her support team suggested that she should think about a cleaning role. After attending the club for a short period of time, where she completed her portfolio sheets, Sally identified with her that it may be more beneficial for Rebecca to not focus on a paid role like cleaning. Rather, Rebecca's talents and interests were with spending time with children. As Rebecca explained, *'in college, I worked in a nursery. We do plates out, cups out, drinks, snacks, toys out, put them away, bikes in the cupboard'*. Sally then, focused

her efforts on Rebecca engaging with voluntary work at a pre-school. This nuanced example offered by Sally's interaction with Rebecca recognised that Sally is placed within an awkward position. For, she rejected the claims presented to Rebecca for striving to secure paid work in an environment with 'uglier realities' (Frayne 2015: 108) that could be alienating, repetitive, and potentially of poor quality, and refuted the claim that being 'in work leads to a better physical and mental health (Department of Health 2010) which is considered as essential for a better quality of life, in favour of the benefits of volunteering and recognition (Honneth 2012).

Yet, this example creates further tension that requires attention. While Sally has refuted the ID rhetoric (VEN 2009; VP 2009), she had more widely rejected the neoliberal ideology that reinforces notions of employment being a 'normal' state of being. In this sense, Sally also refuted the 'deprivation model' (Frayne 2015: 107) whereby our needs are fulfilled by paid work – structure, status, and self-identity for instance. Instead, she embraced the non-financial rewards of work (Budd 2011). While these ideas are picked up again in chapter nine, Sally has reconceptualised the benefits of volunteering. While engaging in work does indeed have the potential to deconstruct the perceptions of an ID that are considered within the CDS framework (Bates et al. 2017), Sally recognised that this may not always be the best route to guide people towards. For, 'the claim that paid employment is "good for us" is completely without context. It is pure ideology' (Frayne 2015: 109).

Conclusion

This chapter has explored both the intrinsically personal and structural barriers to employment inclusion, by drawing on the lens of Berlant's (2011) cruel optimism. Cruel optimism exists when what is desired impedes thriving, and, when unpacked, this desire is a cluster of promises attached to a problematic notion. Applied to the context of job club, this theory exposes how people search for a good life through the attainment of paid work. The optimism of paid work is, for most, a fallacy, based on good news stories that are shared to demonstrate that it is, indeed, available to everyone, if individuals simply work hard enough.

My analysis has explored how, even when work risks someone's health and wellbeing, the attached cluster of promises of what it means to be in paid work, is in itself, cruel optimism. For, when focusing on individual (dis)ability, it is at the expense of the broader, structural barriers, much neglected within the everyday interactions, that occurred at the job club.

In the following chapter, I explore an underlying theme drawn from this chapter: the non-universal understanding of what *work* is perceived to be to the job seekers, and how work, within this construction, is morally ambiguous. These ideas are bound up in what Berlant (2011) discusses when cruel optimism operates to transform someone's life, particularly when discussing wages. As she notes, 'money cannot make you feel like you belong if you are not already privileged to feel that way' (p. 40). These notions are unpacked through the ideas of un/paid work, work experience, work placements, and volunteering, to explore whether financial reward or the presence within a valued role provides the linkage to *feel* citizenship, or, whether the 'splintering effects' (p. 173) of trying to *feel* ordinary and to have social recognition (Honneth 2012) leads, instead, to exploitation.

Chapter 8

Labels, rocks, and hard places

Chapter seven explored, how, people at the job club were searching for a good life, conceptualised through the attainment of paid work (Berlant 2011). This work was offered through a cluster of promises, that were instead, a fallacy. Yet, these promises divert attention away from the structural barriers and inequality of the labour market.

Chapter eight, presented here, further sketches out these ideas, to capture how people with an ID who are in receipt of social care have constructed an alternative definition of work. This work is instead, based on the historical context of therapeutic work and sits between the paid/unpaid work binary. In the past, most people working in a sheltered work environment in the UK received little pay (or no payment at all), in part, so that they could retain their eligibility for welfare support (Schneider 2008). Yet, this chapter will demonstrate how ‘therapeutic’ work is still prevalent within the learning-disabled community. Moreover, this chapter will explore how, with these nuanced constructions of work, it can invite morally ambiguous dimensions to the opportunity of labour, which can lead to work being misused, distorted, or exploited.

The term ‘work’ has been treated as synonymous with paid employment for most of the twentieth century (Baines and Hardill 2008). Yet, Budd (2011) argues that a broader definition of work is required in order to avoid this simplistic interpretation. Instead, he defines work as lying somewhere between a narrow focus on paid employment and the broader inclusion of activity that is, ‘physical or mental exertion that is not undertaken solely for pleasure and that has economic and symbolic value’ (Budd 2011: 2). It is this intersection between economic and symbolic value that will be a pertinent feature of this chapter.

Chapter five informed the reader that, for job seekers who have an ID and are in receipt of social care provision, they are likely to be categorised within the Support Group of Employment Support Allowance, whereby there is no formal

mandatory requirement to engage with employment and no risks of financial benefit sanctions. Moreover, job seekers within this demographic are likely to be eligible for a Personal Independent Payment (PIP) and have the financial cost of their care and support needs met by their local authority.³³ This, therefore, somewhat alleviates the financial, economic necessity of waged work. Retaining this knowledge, the first part of this chapter explores how some people with an ID do not hold the universal understanding of what paid work is constructed to mean by other members of society, and how, this instead, can lead to alternative notions associated with what work constitutes (and the morally ambiguous associations that this can have). This is particularly apparent when ideas around paid work, therapeutically paid work, volunteering, and work experience become blurred and nuanced.³⁴ First to consider here is why job seekers are searching for work, when they are financially secure and there is no need (at least in the eyes of the State) to do so.

Work motivations

At the job club, most job seekers did not prioritise economic gain as their main motivation for paid work. Similar to broader studies of unemployment (Budd 2011), while Sophie and Naomi did want to attain financial rewards, they also had other reasons to work. Indeed, perceived competence and '*something to do*' was both regularly recorded above financial motivation for work by the majority of the job seekers. This was demonstrated through Verity, who wanted to '*feel better*' by working, and Sophie, who wanted to combat her boredom. Sophie said:

I don't want to be bored at home doing nothing...I want to meet new people and get involved in things... I want to go out and earn some money.

³³ A Personal Independence Payment (PIP) can help someone financially, with a long-term illness or disability. It is an assessed process and awards range between £23.20 and £148.85 per week. This is dependent on how a condition affects an individual, rather than the condition itself (GovUk 2019)

³⁴ In practice, the use of incapacity as an organising principle for benefits along with part time therapeutic earnings ('token gestures' and commensurate payments) reflects the continuing dominance of assumptions based on a medical model of disability (Schneider 2008).

Naomi agreed: *'when I'm at home, I get bored'*. Naomi also wanted to *'get paid, like my family'* through engaging with paid work. Naomi's statement of *'like my family'* identifies with the intrinsic factor of perceived competence which influences employment motivations. Similarly, Karen stated, *'if I get better at things like washing up and putting things away, then I might get some [money]'*. The ideas presented here, draw parallels with research conducted by Andrews and Rose (2010), who identified three major themes that affected their participants' motivation to gain work: social aspects; monetary gain; and; perceived competence. Figure 7 is a (prescribed) self-assessment by Naomi, on why she wanted to work:

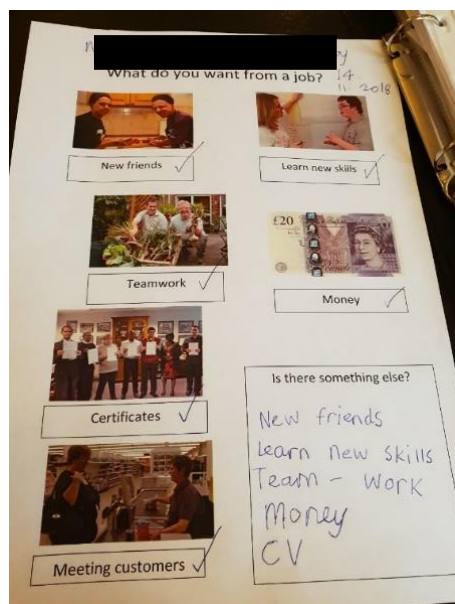


Figure 7. 'What do you want from a job?' worksheet

While not explicitly expressed by job seekers, pressure from others to join the labour market were also apparent. Karen was referred by the Job Centre; Sophie's support workers suggested on multiple occasions that she should *find* a job; and Verity, Naomi, and Huw's parents thought they should be thinking about work options. Naomi recalled a conversation she had with her mother, about work, *'my mum always says, "if you don't work, you don't get paid and if you don't get paid, you don't get the clothes to wear"'*. For Jackie, the pressure to work was also from her family, *'my husband's mum says if you are not working, you are lazy'*. Moreover, Green Meadow also encouraged all of the job seekers to attend the job club once funding had been secured, suggesting to future attendees that work

was, indeed, achievable. Where financial reasons are given for job seekers wanting to find work at the job club, it was not to pay bills. Sophie wanted to save for her forthcoming wedding and Naomi wanted to treat her mother to lunch occasionally. Yet, the financial reward of work was differently constructed and understood by the job seekers. To consider this further, I discuss Huw's situation. At the job club, when Huw, who had behaviours considered to be challenging and lived in a supported living environment with one-to-one support, was asked if he has had paid work before, he was keen to point out he has:

Huw: It's payday on Friday. I'm paid on Fridays.

Huw's one-to-one support worker: They got a proper wage pack every Friday.

Sally: What did you used to do with the money, Huw?

Huw: I paid for a snack, tiffin's, and donuts.

Huw, then, was 'paid' a token amount of a few pounds per week, so that he could experience what it was like to be paid a wage while attending horticultural college. Huw was in his mid-twenties and only finished college a few years previously. While attending job club, he worked unpaid in a library for two hours per week, where his support worker helped him to organise some of the returned books into order and find the appropriate places for them on the shelf. For Sophie, she also has experienced paid work in her past:

Sophie: At [café] I used to work about 16 hours.

Kim: How much did you earn?

Sophie: About £60 [approximately £3.75 per hour] ... I used to get tips as well.

Kim: When you worked at [different café] did you get to keep the tips there?

Sophie: No, I used to get £10 a month.

Chapter seven highlighted how Sophie and Jackie both worked at a café for 12 hours per week, spread over two days. They were paid £10 per month. Tara still worked at the same café and had done for 17 years, working 12 hours per week, receiving £10 per month pay. In addition to the café work, Tara also worked in a hotel, where, for two days per week, she chopped vegetables and prepared the

meat in the kitchen, often for wedding functions. She had worked there for 10 years yet had never been paid. Tara had a third job, working two hours per week at an ice cream factory, where she was paid the national minimum wage. Tara did not distinguish between her roles; they were all her jobs and equally important to her. She regularly shared how happy she was with '*having three jobs*' to the point where, as we have seen in chapter six, some of the other job seekers wished they were as successful with their work as Tara.

More broadly, this position was echoed at different research sites, in different local authorities. At Power, when Steve (a worker/director that has an ID) who had paid work for 2.5 hours per week, was asked about how he felt about being paid, rather than volunteering, he described the physical difference between his roles, and the intrinsic reasons of feeling better and being part of something, rather than speaking of the financial rewards, '*when I am with [organisation] it is more, part of a focus group. With Power, it is more "I am [a] researcher"*'. Likewise, Archie, whose mother has advocated here on his behalf, expressed how having work increased his opportunity to interact:

If you are in work, it's that social interaction. You can go for a drink after work. Archie can do this now, he goes out with 'work' once a month for a meal, or to the cinema.

Archie got paid a small nominal rate from his job and he said to his mother, "*I got money, Mum". It feels nice for him*'. These examples begin to sketch out a non-universal understanding of waged work. For, there is the connection emerging of paid work being a defining feature, central to us as individuals (Noon and Blyton 2007) and an underscore of the tight linkage between work and identity (Budd 2011), yet there is also an emergence of problematic notions of what work is when it is not connected to minimum wage thresholds.

Work as a socially constructed concept

Within the disciplines of economics and sociology, Budd (2011) explores work as having ten concepts: as a curse or burden; as a route to freedom through independence; a commodity where productive effort has tradable economic value; as a form of occupational citizenship – rooted in western citizenship

ideals; for personal fulfilment that satisfies need, self-worth, and self-esteem; as a form of disutility, a tolerated activity to enable goods to be obtained; a social relation that offers interaction with social norms and structures; as a form of identity formation whereby you understand where you fit in social structures; the effort to attend to others through caring, and; as a service, with devotion to others.

More specifically for this research, McGlinchey et al. (2013) cite that the often-complex perspectives on what work actually constitutes are problematic for people with an ID. During their empirical research in Ireland, they interviewed over 750 working-aged adults with an ID. While 6.6% of the participants were in real paid employment (slightly above the UK rates), they found that an additional 7.4% of the participants perceived themselves to be employed when there was either no payment made or, a token, therapeutic gesture was given as a small nominal sum. One reason for this confusion on perceived employment was the historical associations with sheltered employment whereby a small discretionary allowance was made for completing a generally repetitive task. This, therefore, may have blurred the meanings attached to work.

Moreover, in his seminal essay, 'No Profits, Just a Pittance', Reaume (2004) explores how, in the 1960s, a superintendent of a provincial mental hospital in Ontario thought sharing small profits from goods and services provided by the patients was 'therapeutically valuable'. In this case, patients made industrial products for 'pin money' (p. 466).³⁵ During the same timeframe, at another psychiatric hospital in the same State, patients were providing domestic duties on the wards, while others were working full time in a woodwork shop for around \$5 per week. One patient recalls that he found the work to be good therapy because there was no alternative therapeutic stimulation available to him. These anecdotes highlight what was to become a 'major point of contention' (p. 467) for people who, in that province, had been classified as 'unemployable' and therefore, unable to earn a fair wage. Moreover, it also highlights wage

³⁵ Pin money is defined as 'money set aside for the purchase of incidentals'. This notion is gendered, and historically applied in the sense of 'money given by a man to his wife for her own use' (Merriam-webster 2020). The term can also be applied to describe a small amount of money earned by children, or the low paid, for some service (Phrase Finder 2020).

discrimination on the basis of classification of disability. An example, drawn from Reaume (2004), is that of Wayne. Wayne worked seven hours per day, five days a week, earning \$7 per week, as a janitor. He worked so that he could buy a snack from the patient's canteen. This example resonates with Huw's ability to buy himself a weekly treat with his 'wages' in this study.

In Reaume's (2004) writing, he speaks of companies such as Air Canada, who took advantage of such cheap labour costs being readily available, sending products to workshops, inside institutions, to be packaged. Similarly, Roger, from Power, talked of a local situation, whereby people were working putting together packaging for washing machine parts:

There is a lot of historical baggage... being called work because it was mixed up with the old notions of occupational therapy and the therapeutic wage. It's hard to work away from that. And that's as much to do with the place that the people in that service are. I think it changes as more people are coming through mainstream school and getting mainstream ambitions, which is so important for people, but most of the institutional stuff that people are stuck in are those places that really need a bit of a shake. They are stuck in the 90s.

This further resonates with Reaume's (2004) text whereby, with little opportunity to work elsewhere, individuals were surrounded by an environment where 'people were so desperate for some kind of paid occupation and self-worth' (p. 484) that they would take any offer. For, many people here 'had spent most, if not all, of their working lives in a system where getting paid a pittance for a day's work was the norm... even in a highly exploitative system' (p. 484), yet, what was on offer was better than the little opportunity available elsewhere. Furthermore, as Reaume notes, the subsequent advocacy of the People First Movement, exposed how, in their struggle for employment equitability, many people with an ID did not understand the implications of a minimum wage policy and how they were deprived of a salary when compared to non-disabled counterparts, working in similar industries.

Yet, in contrast, there were also many employees working here for a few dollars per week, who did not feel exploited. One family member points out 'low pay

does not mean much to her' (p. 483). These contradictions are inherent throughout Reaume's text: while some workshop labourer's felt exploited, others did not.³⁶ Moreover, this economic vulnerability was able to become prevalent due to the stigma attached to their disability, and the isolation from mainstream society, alluded to by Roger, with his reference to aspirations for people that are, or are not, receiving their education through mainstream provision.

While McGlinchey et al. (2013) suggest that further exploration into perceived employment in the UK is needed, they conclude that it is a historical association that is the legacy of therapeutic wages. My research, however, demonstrates that perceived employment and the historical association with small nominal sums that constitute wages, are not historic, and are instead, prevalent within my empirical findings. Richard, a worker/director of Power (who has an ID), Roger and Margaret, worker/directors of Power, and Mia, a Social Enterprise Officer, explained:

Richard: It [therapeutic work] was part of day centre and they done these sort of training, say woodwork, and that would help with the skills to go into work. But them people are still there, since it started. It's called work, but they get like, two pound a day!

Margaret: Nobody has expected people to do these things. It has been "there, poor thing, they can't help it, it's part of their learning disability that they don't know". No. It is because no one has ever expected standards.

Alan: Especially in special schools.

Margaret: They [people with an ID] are used to it is the 90s day centre or college with the woodwork. You are not expected to have the skills for a workplace, and nobody tried to teach it or enforce it. There is still an awful lot of this. There are a number of people in [place] who still give people £3 per day, for working a full day, or some, who actually make people pay for the privilege of going to work.³⁷

³⁶ A Marxist critique would suggest this to be a form of false consciousness (Pines 1993).

³⁷ What Margaret is alluding to here, is how people in the ID community, now pay to work: when 'sheltered workshops' developed into day centres, and then into 'meaningful opportunities', the local authority often held block contracts with providers. Over time, with the personalisation agenda (chapter two), there was a move away from block contracts and into individual, 'spot'

Mia: It's not so much the enterprises themselves, they are usually settings that are historic. I'm trying to find the right words for it, when we've gone along and seen these settings where people are getting, and it's called a wage. We have advised, you can't call this a wage, for various reasons... it's not legally right.... you find it in the wider sector as well... They'd say... we give them 5 pounds or something, then it doesn't matter if they've had to catch a bus, or get a taxi, or make their lunch, we just give that as their money for the day. I think, no, no, no, you can't do that, but you have to look at it two ways. I don't agree with it, but you've got the person the other side saying that they want that money. It is education and awareness for both sides. One, for the organisation who is doing something wrong and it is illegal and two, for the other person to value you, and what they are doing and for them to understand. They are not a volunteer.

Mia proceeded to describe a setting that, until the early 2000s, 'employed' local people with an ID, under a contract with the local authority (LA). Here, the LA would purchase 'work' for people, who would spend their days, Monday to Thursday, making candles. They were paid a few pounds each day. On a Friday, no 'employees' attended the centre, instead, the 'proper' paid staff then spent the day melting all of the candle wax back down, ready for the 'employees' to return the following Monday to start the process all over again.

This is not isolated, or location dependent. When Archie was asked to start work at The Roasted Bean, the first thing his mother asked the manager, was how much Archie would have to pay to work in the café. She was thrilled to learn that instead of paying for the privilege of work, Archie would himself, be getting paid. Moreover, Bob shares examples of workers that had been working for 7 years, for 21 hours per week, who got paid £3 per day through a LA employment scheme. Here, Bob explained *'the scheme went bust, but they've just continued'* [working there for the nominal rate].

Some eight months after the job seekers started attending the job club at Green Meadow, Sally explored the differences between waged work and volunteering

purchase. Here, the LA either individually purchases a place for somebody, or an individual purchases the place themselves using their individual budget (Boxall et al. 2009).

with the job seekers. The delay here can be accounted for by Sally not being experienced in supporting people with an ID to search for work: her background was supporting people into employment that have mental health issues. Her assumption until this point was that the job seekers already knew the difference between paid employment and voluntary work, and that the job seekers would also hold the knowledge of how much financial gain could be expected in return for their work. Taken from the position of the job seekers, then, there is much confusion on the topic. In conversation with the job seekers, Sally explained:

I think people need to understand the difference between volunteering and paid work, ok. Because it is quite a difference... what do you get from doing volunteering work and what do you get when you do paid work? I mean, paid work, there is one obvious thing you get there isn't there, wages...but you still get things from both, and particularly volunteering... what do you think about when you are going to do either of these jobs?... What do you need to get yourself there? What do you need to prove to an employer?... There are a lot of common things but there are differences and I think that some of you don't really understand the differences...the employers expect different things.

The group then split into two. One group concentrated on this task, while the other look at what stopped people from getting a job. The activity here resulted in this:

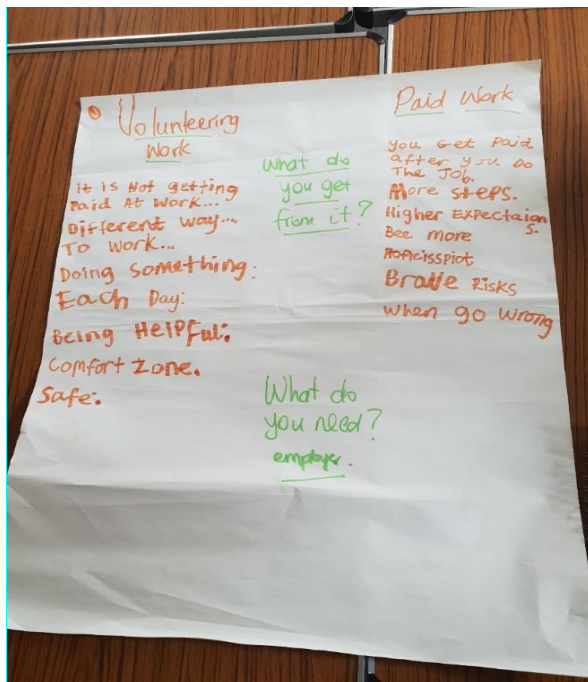


Figure 8. Group work task: what are the differences between volunteering and paid work?

There are two overarching questions in figure 8 – “what do you get from it?” and “what do you need?”. In the voluntary work column, job seekers listed: ‘*it is not getting paid at work... different way... to work... doing something: each day, being helpful, comfort zone and safe*’. In the paid work column, job seekers listed, ‘*you get paid after you do the job. More steps, higher expectations, be more proficient, brave, risks when it goes wrong*’.

In concluding the session, Sally said:

All I was trying to do today, was to try and explain the difference between paid and voluntary and I think for some of you, are you listening, Sophie? Some of you, are very good at saying “I want a paid job, paid job, paid job” but you’re not really understanding how much more is required. What you’ve then got to do to get the paid job. Voluntary jobs are great actually and if you don’t need money, maybe that’s what you should be thinking about really. There is nothing wrong with voluntary work, it still gives you all those nice feelings and achieving things, being a part of a team and some really good things... you need to think very carefully... you all have an income don’t you, you all have some sort of benefit. I mean, it might not be enough, it’s not my business to know, what I’m saying is that if you really want to work with me to get you a

paid job you need to really be thinking about this stuff... the next step for some of you, is to really get a job.

This quote unpacks some of the key differences between the expectations associated with paid and unpaid work. Moreover, the discussion also strengthens the 'cooling the mark' (Goffman 1952) framework (chapter six). Yet, it also aligns towards the importance of what work is constructed as since for labour in this context, whether paid or unpaid, is referred to as work. Therefore, it is hard for people who have an ID and need support with numeracy and budgeting, to necessarily construct the same meaning to work, insofar as associating it with an arbitrary minimum wage. This is because people here are not necessarily aware of how much income is required to maintain their lifestyle. My fieldnotes captured some of these ideas:

On reflection, I sense that people aren't looking for high hourly rates, instead, they are looking to be rewarded for completing a task. Sophie and Jackie worked 2 to 3 days per week at [café] and were paid £10 a month, Tara is still there. To Sophie, Jackie, and Tara, these are wages. They have constructed this to be a paid job. Has no one ever explained what paid work is (i.e national minimum wage?). Instead, job seekers have constructed a financial reward of payment of any size. It is a very different construction of paid work. A keynote – Sally is running around trying to find paid work for people, yet this may not align with the groups' construction and perception of what paid work is to them.

Consequently, this non-universal understanding has the potential to lead to morally ambiguous work, described by Berlant (2011) as the grey spaces associated with capitalism. Yet, these ideas are absent from much academic literature. Budd (2011) sketches out different types of work, based on activity inside and outside of the home, where work outside the home that has no remuneration, is connected to volunteering, civic service, and slavery. The blurred boundaries between work and non-work, are only explored in relation to time and technology. As such, there is a lack of consideration on different interpretations of work, that can have forms of remuneration, yet are not aligned to meeting employment protection legislation, such as the minimum wage.

Volunteering or exploitation?

Budd (2011) suggests that, while typically unpaid, volunteering should be seen as work, as it involves effort and produces benefits for the volunteer and others. Moreover, he suggests that the structures of volunteering are similar to that of paid work in that it can increase motivation and social norms. However, volunteering here is associated with philanthropic or altruistic motivations, rather than through volunteering being a route into paid work. This example, offered by Budd, is similar to other academic literature associated with the broad study of work (Noon and Blyton 2007) that reinforce a simplistic dichotomy between work and volunteering. More nuanced accounts are offered within the literature that connects the benefits of volunteering with a disability and other marginalised groups in society, which will be drawn upon in this subsection.

As a highly valued activity, volunteering is encouraged around the world by government, agencies, and disability service providers alike (Balandin, 2010c; Briggs et al. 2010), with volunteer activities benefiting society underpinned by universal values (Briggs et al. 2010). Volunteering is a key ingredient in community-based and cooperative models of economic exchange and volunteering activities help communities' function better by increasing social capital (Baines and Hardill, 2008; Briggs et al. 2010). Previously characterised as *serious* leisure, volunteering has since been reconceptualised through Putnam's (2000) interpretation of social capital, through its connection with the participation in public life, and as a route to generate and increase social networks and relationships (Putnam 2000; Baines and Hardill 2008; Briggs et al. 2010).

Perceived as a central life interest, volunteering can also be so powerful that it can rival paid work by establishing individual feelings of dignity and self-esteem while simultaneously contributing to community social cohesion (Patterson and Pegg 2009). Moreover, by removing the focus of tenure and wages, the richness for opportunity to become more equal and valued community participants can be realised (Dempsey and Ford, 2009). In this context, volunteering can increase levels of self-confidence and independence, help develop a greater sense of responsibility, and open opportunities to meet new people and develop new

skills. Further, volunteering can be perceived as an enabler to community inclusion, by offering an opportunity for volunteers to be providers, rather than recipients of community-based services. This, then, can address broader considerations of isolation, loneliness, and low levels of community participation (Trembath et al. 2010a). Meaningful volunteering activities increase the opportunity to lift aspirations, participation, and interaction (Balandin et al. 2010a; 2010b) by providing a 'space of hope' (Baines and Hardill, 2008: 315) and with a strong theme of personal identity, volunteers regularly echo each other with claims of 'at least I can do something' (Baines and Hardill, 2008: 313). For people with an ID, a major motivation is the importance of social contact and contributing to their own community (Maguire, 2009).

Yet, what occurs at the job club cannot be considered to be volunteering per se. For, when Trembath et al. (2010a) explore volunteering opportunities that were considered within their research for people with complex communication needs, they articulate that formal volunteering is only appropriate in not-for-profit organisations, whereby the volunteer is in a position that has been specifically designed for volunteers. This is distinguished from informal volunteering (e.g., helping a neighbour with shopping) and paid work. In essence, then, this position describes volunteering as a 'meaningful societal role in its own right that adults with and without a disability are motivated to fulfil' (Trembath et al. 2010a: 214).

Moreover, what has occurred so far in this analysis cannot be considered to be formal work experience, and extending the notion of work experience and/or internships adds another problematic layer to unwaged work. Commonly perceived as a mechanism for transferring from education to work, work experience and internships are characterised as voluntary in nature, as a route to enhance the individual experience and increase future employability (Owens and Stewart 2016). Yet, unless the unpaid work is undertaken as part of a government assistance programme, concerns have been raised with respect to exploitation (Grover and Piggott 2013a). Owens and Stewart (2016) were particularly concerned with programmes that fall outside the boundaries of structured and monitored training schemes, suggesting that those in the open market, which are not associated with any governance and do not provide 'real'

training for people with an ID. Instead, the authors suggest that people are lured into the experience by hopes that it will lead to paid employment, when in fact, few go on to gain permanent and secure positions (Owens and Stewart 2016). With this description, what occurs at the job club is more aligned to work experience, however, without a time limit, this work becomes particularly morally ambiguous.

We have seen these morally ambiguous examples with Karen, working unpaid in a profit-making garden centre; Tara working for 10 years in a private hotel without payment and Tara, Sophie and Jackie, all engaging with work at a café where they were paid £10 per month. This has also been explored more broadly with the examples offered from Power, particularly illuminated through the example of people being paid a few pounds per day to make candles that were then melted down each week by the ‘proper’ staff.

Back in 2006, a prominent ID advocate discussed the fine line between exploitation, work experience, and volunteering in a magazine targeted towards ID service providers (Love 2006). This short article suggested that unpaid work experience should be limited to between 16 days and 8 weeks, further citing that unpaid work is risky unless it is backed up with a clear supported employment strategy. The article concluded that examples of people working for 15+ years in unpaid work experience, masqueraded as employment preparation, is not acceptable (Love 2006). Bates et al. (2017) remind us, that, in some circumstances, what counts as ‘work’ to people with an ID can risk being exploitative. To explore this, a short case study of Archie’s work history captures his employment precariousness and economic vulnerability.³⁸ Drawing on Archie’s case study example, I also show how Love’s (2006) argument that work experience is appropriate when it is provided by a specialist agency can also be contested.

Archie was 29 when I spoke with him. His mother shared some of the experiences he has faced so far. When Archie was 18, he wanted a Saturday job like his sibling. Archie’s mother supported him to attend a disability employment

³⁸ To remind the reader, Archie works at The Roasted Bean café. He is paid a small, nominal sum for his work.

support service. She recalled that, straight away, she knew it was not going to be a positive experience:

There was no space or privacy, it was all open and in front of other people...Archie was belittled... the representative talked to me, not to Archie. He was told he wouldn't be able to manage. He was defeated and kept saying to me 'nobody wants me Mum'... he just curled up and cried.

After this experience, Archie decided not to pursue part-time work while he was at college. Kaehne and Beyer (2013) focus on the importance of work experience being offered to young people with an ID and identify that work experience options are underexplored. As, low employment aspirations reinforce the sparse opportunities for young people with an ID to engage with work experience, while their non-disabled counterparts have the opportunities for this, often having part-time jobs while in education. Moreover, to attain a part-time job while in education, would mean young people with ID would embark on an employment pathway that is typical for the wider population. The authors cite that this would confirm the 'normalisation impetus...increasing the chances of young people to adopt socially valuable roles in life and potentially integrate better in society' (p. 246).

For Archie, he continued with his education and spent four years studying for a BTEC qualification. His aim was to be accepted on an apprenticeship. However, to do this, he required GCSEs as a prerequisite. His mother contacted the LA to see if he could have any support for this. They were told that there was nothing available and that no one in adult services could help with this predicament. Archie then spent a whole year at home without any opportunities. He became very insular and his mother recalled that he was hard to be with at times. Frustrated, she contacted a different supported employment agency. Archie was subsequently offered 'work' through an unpaid placement, working for the local council in the library. His mother shared how Archie worked in silence for a few hours each day, inputting data. The workers were not allowed to talk to each other, so he could not '*build up any kind of connection with anyone*'. When his mother asked how he was getting on, no one shared any information with her, and she was not allowed inside the room where he worked. After 6 months, she

asked if there would be progression or hope of future paid work – there was not, and so, in response, she withdrew Archie from the role. However, many of the other workers had been there unpaid for in excess of eighteen months.

Undeterred, Archie's mother came up with her own idea for employment. She worked at a supermarket and she and her work colleagues felt Archie would be able to manage some paid work there. She contacted her HR department. While sympathetic, the HR department informed her that the only way Archie would be able to be employed by them would be through their 'approved' disability employment agency. She contacted the agency who informed her, that people who were employed through them could only work during office hours, in case there was a problem and someone from the agency had to respond or attend a workplace. This meant that Archie would not be able to be employed on the same shift hours, or weekends, as his peers, which are generally dominant within shop work employment. Moreover, Archie would not be paid at the same hourly rate as his non-disabled counterparts, rather, he would be paid £3 per day. It is not known how much the supermarket would pay the specialist disability employment contractor. His mother recalled, *'he would have had to work twice as hard, for hardly any pay... I said no'*. Archie's mother also recalled another situation where he had some work experience at a job centre:

They loved him there, wrote him a nice letter saying how good he was and for him to pop in for a coffee some time, which was nice. But the irony is that it was the job centre and they didn't then offer him a job! [His mother recalls *'nagging'* social services, local companies, and businesses, seeking to secure work for him] ... Archie had a social worker while he was at college, but this ran dry. The social worker was helpful, gave me some contacts, but I had to follow it all up myself. There is a massive gap. It would have been fantastic for Archie to work, even just for a few hours. A lot of Mum's are afraid to push it when it comes to wages. Some people are like, ok, lets sort some volunteering and that's good, its socially enriching. They may be painting, working on a farm or such like. It's a purpose, a reason to get up. But parents are afraid to ask for wages, in case their child is then stopped from going any more... Out of all of his friends from college, only one has work. All of the others sit

at home every day. I spend my time keeping him busy, but a lot of other parents can't do that... you don't want to be a person on benefits. You don't want to be labelled, but without Archie claiming, there would be nothing.

Ultimately, for Archie and his family, his mother decided to stop working herself to enable him to create meaningful opportunities instead. While she then struggled financially, Archie was able to secure work (discussed in chapter nine) with her support, two days per week. The challenges of seeking work, or indeed, any meaningful opportunities experienced by Archie are reverberated more widely by Bob and he provided examples of people his organisation is in contact with. These include people working for the same supermarket that Archie's mother worked for, where people are still working 16-18 hours per week for £3 per day. Bob's frustration was clear as he talked. He also described an example where someone with an ID worked 10 hours per week in a different supermarket as a volunteer. Bob approached the supermarket manager and asked to see their volunteering policy, however, one was not available. When he asked why she could not be paid, the manager replied, *'no, she'll never work here, she's not quick enough'*. Yet, Bob had witnessed her doing the same tasks as her paid colleagues. He said, *'and, I've just got to hold back'*. I asked Bob how her family felt about the situation. He replied:

Who knows? I went to them [the family], I asked, "on what basis does she go there?" [They said] "oh, well it's either work experience or volunteering". [I replied] "What, for 7 years?" I said, "look, I'm more than happy to speak to [supermarket]", they said, "don't you dare speak to them or they will take her job away".

Here, and similarly themed across this subsection, are examples of situations that could have begun as well-meaning work-like opportunities, yet have instead, become exploitative and then there is the risk of having exploitative practices removed.

The power of work

Drawing on Archie's experiences and more widely on the contributions from Bob, we can identify some key issues. Returning to Berlant (2011) and what she

refers to as the 'grey' economy (p.173), whereby what is a coerced relationship between an individual and employment, where someone may or not be paid, can feel like agency because someone has attained some *kind* of work and they are then playing for the *possibility* within the informal economy. The possibility here is that work can 'provide the social density of citizenship at the scale of a legitimate linkage to the reciprocal social world' (p. 173). The characters that Berlant inscribes are children, unstable within the category of worker or citizen. Her question then becomes whether, through the possibility of citizenship and legitimate linkage, social reciprocity is guaranteed, in a context of adolescents who are on the verge of becoming economic adults. Here, I extend this discussion to include, more broadly, other economically marginalised people, who, like the examples offered by both the job club and Bob, are searching for their possibility of exploitation, as a route to find their place in the world. In this sense, the position of employment exclusion is so extreme, that the precariousness of work does not result in marginalisation. Rather, marginalisation results in precariousness.

Moving on from Archie's case study, this tension between paid and unpaid work continued to manifest. One week, at the job club, I asked Naomi, who, along with her unpaid garden centre work, also worked unpaid in the canteen of a local music club, whether it is problematic to her, that she does not get paid. She replied that '*it's okay with me*'. Knowing that Naomi would understand the difference between a not for profit and a profit-making company, I asked her, if, the music club was running for a profit, whether she would still be okay with working without pay:

Kim: So, if [music club] made a profit from their work and it was a business...would you still be happy to do your job without wages if you knew someone else was making money?

Naomi: Yeah...it would still be okay, I wouldn't mind.

Naomi did have an increased cognitive understanding compared to some other job seekers at the job club. She was articulate and had good numeracy and literacy skills. She did, though, have more support than the majority of the other job seekers. Naomi lived in a registered residential home and had one-to-one

support provided to her when she was in the community, as, she had 'behaviour that is considered challenging'. Yet, teasing out the voices of the job seekers here has exposed some of the multifaceted moral dimensions of value, and what it means to feel valued.³⁹ Mia, who worked as a Social Enterprise Officer, and was part of the focus group at Power, touched upon this earlier in the data when she discussed her role of informing enterprises that it was unacceptable to be paying people a nominal wage because it is illegal and undervalues the individual. Yet, exploring an alternative perspective complicates the picture somewhat. Emma, a representative who provided kickstart funding for The Roasted Bean, as well as 25 other groups spread over Wales and the South West of England, instead suggested:

We are finding again and again that the money isn't important. A little bit of money is nice... but it's the social stuff. No one ever says the money is important, but in some ways, it is a signifier. Instead, it's the support people provide to each other and sharing the skills people have to offer.

Gerry, a worker/Director, encapsulated the overall sense, emerging from Power, by making this comparison:

In the news over the last few years there has been the story of Greece, where, if you were a public sector employee, you weren't paid for several years. But people were still turning up for work. Does that mean they are not as valuable? Or that the state didn't value them? Or, the state just couldn't pay them. And there is that, there is a difference. If you turn up to work and you feel valued, the third sector, the charitable sector, trades on that. You can come and work for us, for two thirds of what you'd get in the private sector, but you get the feel-good factor. So, we know that happens and it is available for everyone. So, when we are looking to provide meaningful work, what happens with people with a learning disability, they end up in, what most of us, looking from the outside, would not call meaningful work. Work that we would only do, when that would be the difference on whether there would be a meal on the table or not. Or, we were young and free.... So, we've already in our head, put those jobs and that work, in a second-best category, at best. And then

³⁹ This will be explored more in chapter nine, in relation to specific research sites.

viewing it from our eyes, when we think about what other people are getting from it. I've got a whole issue in my head. Is it normalisation by another strand? Is it, we want them to have what we think is valuable work, not what they think, is valuable work?

Gerry clarified that by 'we' and 'they', he was referring to '*the people making the decisions, or the activists who are allies, [who] also are looking through it from whatever world view that they have*'. This position, then, questions the normalcy of work for people who may not be able to work at the same rate, and productivity, as others. For Power, this position was accounted for within their business model. Margaret described how this worked in practice:

There is a practical issue around business as well. Social businesses, most of them are to deliver things where there are very small margins. So, if you are doing anything around catering, gardening, anything low margin jobs. If you are going to need a bit of extra time to do a job, or if you need some extra training and there are more than one or two people in the setting who are going to need some additional time or work slower, then you're stuffed. Your margins in a café aren't going to let you pay people a wage. The minimum wage, the margins are too small. Power survives because we work in knowledge, so our margins can be higher, so we can pay ourselves the real living wage despite the fact that it takes us longer as a company to deliver stuff, because it takes us longer to do the work... it takes us longer to get it right... So, we have to be delivering something that has got a higher margin to be able to cope with that. If customers can go to one place and get [product] and it will take 10 hours, they would expect to pay a certain amount of money. If they come to Power, and get a better piece of work, but it has taken 20 hours, they are not going to want to pay double the price. But because there is a good margin, the companies that do it badly, and quickly, they make a really good margin, we can do it and just about cover our costs.

Here, we have a disparity not just in what is and what is not work, but the apparent business costs associated with employing someone who may need to work at a slower pace, and/or have fewer tasks to complete. How, then, can these disparities become aligned?

A moral outcry

In introducing this thesis, an example was offered to sketch out the complexities of work for people with an ID, who are in receipt of social care, through the situation that unravelled at a hustings meeting in the constituency of Hastings and Rye, during the 2019 election campaign. At this event, Sally-Ann Hart, a conservative candidate, suggested that people with an ID should not be paid the same as their non-disabled counterpart, because, 'they do not understand money' and, instead, work in this context provides 'the opportunity to work because it's to do with the happiness they have about working' (Stone 2019). During the discussions, Hart told the crowd that 'it is about having a therapeutic exemption [to the minimum wage] and the article was in support of employing people with learning difficulties, that's what it was. You should read the article' (Busby 2019). The article that Hart is referring to was written by Rosa Monckton. Monckton, whose daughter, Domenica has an ID, wrote the newspaper article questioning why we need to work. Monckton asks, 'is it for the money or for a role in society and to feel we belong? A rise in the national minimum wage is a good thing, but for people with a learning disability it doesn't raise hopes, it dashes them' (Monckton 2017a). Monckton had previously commented:

To have a child with, for instance, Down's [syndrome], is an eternal blessing and joy; but it is also an invitation to a lifetime of challenges, battles with officialdom, and frustrations at lack of opportunity. Making it harder for such individuals to obtain work is a further unfairness and adds to the separation between those with learning difficulties and the rest of society (Cited by Rajan 2016). [Monckton further argued that] Policy makers seem to live in an abstract world, driven by the idea of "ending inequality" without looking at the real lives of people involved. They obsess on the "human right" of disabled adults to receive the minimum wage (Cited by Greenhill 2017).

Much like some of the examples offered within this thesis, Monckton comments that the stories of people with an ID searching for work, tell a familiar tale of exclusion and loneliness. In response, she called for a therapeutic exemption from the national minimum wage: 'It is so obvious to most parents in my position that a therapeutic exemption from the minimum wage would have a transformative effect' (Cited by Greenhill 2017). While the national minimum

wage (NMW) legislation is designed to protect people from exploitation and ensure a basic living standard, in this instance, she perceives it to be a barrier to employment inclusion.⁴⁰

In response to Monckton's position, there was a frenzy of media attention, with a key response theme arguing against a NMW exemption based on how it would disingenuously affect other marginalised groups in society, rather than focusing on the unique position of people with an ID. Moore (2016) responded, 'if you legitimise wage discrimination against them, how long before you legitimise it against people with physical disabilities, like me?'. Yet, as this chapter, and others have demonstrated, the nature of ID is a paradox of contradictions, and cannot be compared to other groups. Monckton replied to these concerns:

Policy is not being formed around the needs of disabled adults and their long-term future, but around financial and ideological convenience. We are not talking about a homogeneous group but about individuals with different needs and aspirations (Monckton 2016).

The situation at the hustings event caused a similar outcry in relation to Hart's support towards Monckton's article. Here, the Labour shadow disabilities minister branded her comments as 'hateful', and suggested that anyone with such views had 'no place in Parliament' (Stone 2019). While Lawrence, a Campaign Support Officer with Mencap, who has an ID, commented:

People with a learning disability, like me, can work and make really fantastic employees with the right support. We have the right to be treated and paid equally – it's the law. I'm proof that... all is needed is for employers to make small and cost-effective reasonable adjustments in the workplace to open up doors to employment for people with a learning disability' (Stone 2019).

⁴⁰ When interventions in the labour market such as the introduction of the NMW occur, they can be perceived to distort the labour exchange and impact on labour market competition. Within narrow constructs such as this, workers are not exploited as they are paid according to their contribution. This perspective is found frequently throughout neoliberal market ideology (Budd 2011).

Yet, as chapters five, six, and seven have explored, this situation is nowhere near as clear cut as Lawrence suggests. Before Monckton's media attention, there had been some limited discussion on whether the structure of the NMW is dis-serving people with an ID. MP Philip Davies and Lord Freud have both previously suggested that NMW may be making paid work harder to access for people with an ID. Back in 2011, Philip Davies said that the NMW:

May be more of a hindrance than a help [...] we need a sensible conversation. The politically correct brigade wants to close down that debate [...]. It is a scandal that only 6% of people with an ID have a job. If legislators are not prepared to accept that the minimum wage is making it harder for some vulnerable people to get on the first rung of the jobs ladder, we will never get anywhere in trying to help them into employment (Cited by Monckton 2017b).

Lord Freud expressed a similar stance. In 2014, when he was the Parliamentary Under-Secretary of State for Welfare Reform, Lord Freud was asked his thoughts on helping people with an ID into successful employment. He replied that he knew that there were people not 'worth' the minimum wage that needed additional support (BBC 2014). Following the comments, heated political responses called for his resignation. Yet in a further interview, the full conversation was contextualised (Kearney 2014). Here, Lord Freud spoke of vulnerable people with limited ability who wanted to feel valued and have an opportunity to give back to society. Returning to Reaume's (2014) key literature on the history of workshops for people considered to be unemployable is important here. For, like Monckton, the call for an increase in sheltered workshops came from parents of people with an ID to increase opportunity. As Sennett (2012) notes, 'the principle of a workshop was to promote equality of employment, as they were open to everyone' (p. 44). However, the historic legacy and struggle by the People First movements to secure equitable wages and employment for people with an ID, and associated unfair labour practices, continued well into the 1990s and it is met with vehement disapproval (Reaume 2014).

Returning to my data gathered at the job club, without some kind of mechanism to increase employment inclusion, Sally was initially hopeful that she would be able to approach potential employers and 'carve' out a potential vacancy for the job seekers. This conversation located her perspective:

Trickiest thing about most jobs is the customers, and people don't really understand that... and I think the key to paid work for you guys, if you want to get paid work, is carving out what you can do, coz I think jobs have a whole range of things you need to do, and if we are being really honest with ourselves, it's really working out what parts of it you can do. So, like you [to Naomi] have worked out that you are really good at cakes aren't you [cutting and plating the cake slices]. Not bad at drinks, but cakes you are really good at... and Verity is very good at talking to customers and she's very good at getting people laughing, communicating with customers... everyone is different, we've all got different strengths really and if you are going to do a paid job, it's about finding what you are really good at. We are all different and it's pointless trying to go for jobs that you clearly can't do... and my job sometimes is to go to employers and say, "I've got this person, these are the things they are good at, what jobs have you got in your business that maybe might match up and getting paid for". And I think what Karen said is really important... you feel safe in what you are doing as a volunteer, but to move on, to take a risk.

Yet, Sally was unsuccessful with her quest to carve out any work opportunities. In the statement above, Sally is addressing two issues. First, to encourage Karen away from the garden centre where she had worked unpaid for around 7 years, but also, for Sophie, to understand why she was struggling to find paid work. I asked Karen what she felt about paid or unpaid work and she used her work at the garden centre as her point of reference:

Karen: If I got paid, I'd have to show people, explain where the plants is.

Kim: But you've got that knowledge haven't you.

Karen: Yeah, but I can't.

Kim: Why? Is it the customer contact? At the minute you do your thing, look after the plants and tidy up, but the difference with paid work is you'd need to have contact with the customer?

Karen: Yeah. I just can't.

Taken in this context, the contours of work are not linear, nor are job seekers perceiving themselves to be exploited, even if they are morally ambiguous. Sally too, touched upon this one week after I had been away at a conference. The job seekers knew I was presenting some of the findings from this ethnographic site and asked what I had talked about. I spoke about the line between paid and unpaid work, how volunteering is more because you enjoy it, but now policy is pushing volunteering as a way of increasing the chances of getting a job. Sally then added:

So, there is a fine line... a fine line between somebody volunteering and the definition to modern slavery actually. And employers are very reluctant, some employers just don't want to know about it.

Linking the job club activities to modern slavery highlights many complexities. This position is so convoluted, nuanced, and morally ambiguous, that I can now also explain why, as explored in chapter four's methodology section, I decided not to approach any of the employers, who allowed Karen, Tara, or Sophie the privilege of working without pay. For, like Gerry from Power described, we are applying our world view of what is, and what is not, acceptable onto other people. It was not appropriate for me to draw attention to a situation that may then, present a problem for the job seekers, who all value their own opportunity to *work*. Put simply, drawing attention to their situation as exploitative may cost them their 'work'.

Attitudes of disablism

While, so far, this chapter has exposed some morally ambiguous practices, there are more implicit experiences of disablism at play. Piatak (2016) asks if unemployed people can contribute to reversing the trend of a decline in volunteering. However, his research found that unemployed people are much less likely to be asked to volunteer. Adding the complexities associated with having an ID places another multidimensional layer of discrete, everyday disablism. For, as Sally described, *'it is surprising actually.... even getting a job as a volunteer and you're not getting paid is quite a challenge actually'*.

During my time at the job club, a local village shop (a Community Interest Company) situated in an affluent, rural area, planned to open a small coffee shop at the same site.⁴¹ Initially, Sally suggested that the job club could supply the volunteers for the new venture, and she approached the organisers. However, the club attendees were marginalised. Sally explained:

They've got to train some other volunteers before they will move on to us. It might have potential, but it will always only be voluntary work for us. Some people there might get paid, they do pay some workers, but they have been very honest with us, they don't try to pretend. It's a lovely setting and it's on the bus route.

Aligning to chapter six's exploration of cooling the mark (Goffman 1952), this statement offered from Sally highlights how, while the job seekers will never be paid here, it could, instead, offer an opportunity to volunteer in '*a lovely setting*' that is '*on the bus route*'. Yet, unpacking this statement also alludes towards a richer and more discursive analysis for interpretation. For, job seekers who are offering their time unpaid, like other local citizens, are 'parked', while others in the community are 'creamed' (Wiggan 2015) and offered a more favourable position. Moreover, Sally also suggested that, while some people there may be paid for their work, it '*will always only be voluntary for us*'. This discreet marginalisation and disablism is spoken matter-of-factly and is not an isolated occurrence. Tara took her CV into a different café one week and spoke to the manager. On her return, she informed the club:

They won't pay us. All the other staff get paid there, but for people like us, don't get it [paid] in there.

This construction of 'us and them', continued to be reproduced at local level, within everyday interactions in the community. Beyond the disappointment of being unlikely to secure waged work through volunteering or work experience, there is cheap labour being used that may otherwise have led to a paid member of staff. More broadly, as Owens and Stewart (2016) discuss, there is also the

⁴¹ A Community Interest Company (CIC) is an enterprise where profit made is for the benefit of the community.

reinforcement of the perceived perception that certain work has little or no value. Sally was mindful of this position:

The problem with volunteering is, unless an organisation organises it well, volunteers just don't feel valued... doing boring things.

Here, not only are people failed in their quest to secure employment, additional disabling barriers include volunteer coordinators underestimating the abilities of the prospective volunteer; difficulty in matching a volunteer to a role with their own unique contribution; existing staff feeling unable to support a volunteer with different needs (including issues with literacy and hygiene); issues with accessibility, and; disabling attitudes amongst existing volunteer staff teams (Trembath et al. 2010a). Additional barriers highlighted by Trembath et al. (2010a) include an increase in the personal cost of volunteering (transport and subsistence costs) and the fear that a volunteer would increase the workload for existing volunteers and paid staff. These negative attitudes and disabling misconceptions decreased individual motivation to volunteer and limited the opportunities available to them.

Returning to the job club, Karen paid to go to work. While she used her free bus pass to get there, the bus times were not suitable for her return journey.⁴² For seven years, twice a week, she had paid for a taxi to take her home after work. Karen took her own lunch with her and got a 'free' drink. In the winter, when she had been working outside in the cold, she received a small discount in the staff canteen to get some hot food. Sally spent the best part of a year trying to coax Karen away from the garden centre and she regularly tried to suggest an alternative, at a community garden where Karen could have a small piece of land to grow her own vegetables and flowers:

If you're not getting paid for it, you need to enjoy it. If there is no payback, do it to get involved in something and get something else from it and be

⁴² Karen got the bus to the garden centre, yet it was not safe. The garden centre was on a very busy main road and she had to navigate down the main road and cross over. To do this, Karen waved when she was stood opposite the garden centre to catch the attention of a worker, who would then come out and help her to cross safely. This, however, can take time as there was often only one member of staff near the till point and this staff member needed to have served all of the customers before they can help Karen. Karen then, was often waiting in excess of 10 minutes to cross the road.

involved... have a go, try it out... sometimes, trying something else can give you confidence.

While Karen often said she liked the idea, she never took up any other offer suggested to her, even after, as a group, we all went to the community gardens one week to accompany her to have a look around. Naomi, however, did secure a short work placement towards the end of the year, for a few hours a week working in the Green Meadow head office. Sally informed her:

When you start, you have an agreement. What you will do and what we will do for you. It's important you make the commitment before coming over, what will be expected. Because it is quite a commitment from us in the office to give you this experience.

With the reality of a self-perceived real job, Naomi became petrified that she would not be able to manage, saying, *'I can't do this, I can't do this'* repeatedly. Over two weeks, we worked together to identify five things that she would like to achieve during her time there. There was also a report, that had an evaluation of progress attached. Figures 9 and 10 (below) are her work experience job description and outcome sheets:

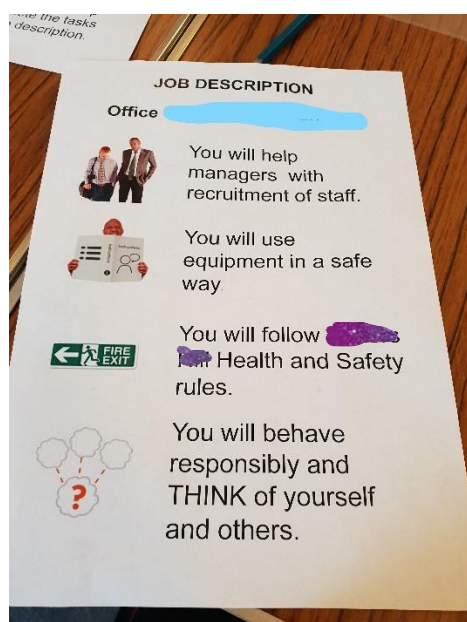


Figure 9. Naomi's work experience job description

Work at [redacted]

My outcomes – What I want to achieve in the office at [redacted]

Name: [redacted]

My Outcomes from:	Aiming for	Achieving	Maintaining	Exceeding
I want to use the shredder safely and shred documents.				
I want to check the first aid boxes and report what is needed.				
I want to check the tea/coffee supply and report what is needed.				
I want to photocopy documents and take to the right person.				
I want to do word processing tasks for staff.				

? Telephone – long term

Figure 10. Naomi's evaluation process sheet

In figure 10, the outcomes that Naomi would like to achieve from her work experience were – *'I want to use the shredder safely and shred documents; I want to check the first aid boxes and report what is needed; I want to check the tea/coffee supply and report what is needed; I want to use photocopy documents and take it to the right person; I want to do word processing tasks for staff'*. These tasks are then split into 'aiming for; achieving; maintaining; and exceeding'. Naomi did consider adding answering the telephone to her aims, however, after a discussion she decided this was a longer-term aim for the future. Naomi did complete her experience, yet by this time, her cohort from the job club had been moved on and she returned to her day opportunities package. Sophie, however, did manage to secure her own local volunteering role. She informed us one week that she had good news:

I'm going to be working with [name] over at the Florist, it's voluntary for a little bit... she heard I have lost my job at the [café] and I asked her if she had anything going.

Sophie said *'for a bit'* even when the owner of the florist shop has repeatedly informed her that she could not afford to take on an employee. A month after she started her work at the florist, I asked Sophie how it was going. She replied, *'alright at the moment. I like it at [shop] but I'd prefer to have a paid job'*. This precarious work, then, begins to repeat itself in a cycle, similar to how Tara and Karen became volunteers at private companies.

The problem of pretending

For Sophie, the problematic nature of ‘pretend’ work that has been highlighted by various participants – Sally at job club, Margaret and Gerry at Power, Mia with the example from the workers in the candle factory, and Archie’s mother at The Roasted Bean – caused her anxiety and emotional upset. We saw in chapter six how she aspired to have three jobs like Tara, even though only one of these could be considered to be a ‘real’ (paid) job. Margaret and Sally went further with their claims towards the notion of pretend work, when it is instead, unvalued and underpaid/non-paid work. Sally, said that the new café at the village shop, ‘*do not pretend*’ to offer something they cannot [or will not], Margaret reflects more broadly:

It’s calling a spade a spade. So if what you have got, is it is voluntary work and, for historical reasons we give you a nominal, small payment to cover your expenses, that’s a problem, but at least it is clear it is volunteering and expenses, rather than calling it a job and there is a wage. Then you’ve got the problems, that some of it, that is called volunteering, isn’t actually volunteering because it is just a day placement that has been purchased for you. Because if you want to change, somebody who was helping with setting up Power, was in the position where he was told he was volunteering but when he said, “that’s fine, so I am going to stop and go and volunteer somewhere else”, he got told no, he can’t because social services has got a contract for you to be here. So, it’s not even volunteering. It was a block purchase and the person could choose to be there, or could choose to sit at home and watch daytime TV, not choose to volunteer somewhere else.

Chapter seven outlined how social media is full of good news stories of people succeeding in their quest for work. We can now consider how these stories have a direct impact on individuals. With the simple backtracking of these good news stories, I was able to demonstrate that, often, the work secured was unpaid or, where it was paid, it was likely that the successful new employee was not in receipt of social care, and therefore closer to the labour market.⁴³ These good

⁴³ To recap, chapter four demonstrated that out of 49 twitter feeds of ‘good news’ only six were identified as for people with an ID in receipt of social care. Of these six, three were within the

news stories feed into the rhetoric of, as Berlant (2011) describes, the search for the 'good life'. This position then feeds into a 'what is work' discourse that is reinforced by the language used by organisations and their own agendas. As we have seen, Sophie, Verity, Karen, and Huw were often confused by what work is, what it entails and how it is confused with therapeutic type work, (as described by Reaume 2004) volunteering, and work experience. For some people then, seeing others around them secure paid work, similar to Sophie watching Tara find work, exasperates the situation of trying to obtain work of any kind.

Yet, this position also encapsulates policy documents that directly affect commissioning practice. The NDTi 'Cost Benefit Analysis of Paid Work' (Greig et al. 2014) is presented as a report for commissioners, based on evidence best practice. Throughout the document, 'employment experience' is a term often referred to and a section is devoted to raising the profile and visibility of people with an ID working within a public setting. Indeed, one person with an ID refers to his volunteering position as a 'meet and greet' as his first job (p. 57). To unpack this further, I return to the critical disability studies CDS framework of professionalisation.

As chapter two highlighted, bureaucratic remedial policy attempts to integrate people with disabilities as an 'exclude-able type' (Titchkosky 2003: 518). In this position, disabled people are made to matter within an excluded and marginalised context. Remedial programmes and their administrators rely upon disability being framed in this way and it generates narratives around the consequences of disability that, in its very nature, legitimises the existence, content, and control held within such policy. Moreover, from this position, being an 'exclude-able type' within a policy paper, legitimises and rationalises the need for professionals to continue to make a living through disability, by providing specialist services, such as employment support (Titchkosky 2003).

Further, the discussion in chapter three explored notions that question why initiating notions of *normal* citizenship, conceptualised through paid work, is perceived to be the route to social inclusion and normalisation. By returning to

third sector where they received their support, two were within a social enterprise setting and one was in a fast-food restaurant.

the rhetoric of active citizenship and its attachment to workfare ideology, this position can be illuminated by Rebecca and Steve's relationship with un/paid work. For Steve and Rebecca, the nature of the volunteering work supersedes the call for wages. Steve, who had paid work with Power and has an ID, is quick to point out that his voluntary work was not problematic to him, and that it provided more than what could be quantified through a monetary value:

There is nothing wrong with being part of the [organisation]. When we went to [city] and they were talking about photography for people with learning disabilities... I told them all the stuff I have done in practice, each of them thought I was gold. I get more out of being part of the focus group [compared to his paid work with Power].

Steve previously had paid work in a supermarket. When discussing this, in comparison to his current volunteering role, he again preferred volunteering:

I'm just coming back to the supermarket thing. Because before now I have worked in a supermarket. [What I do now] It's around meeting people. Research, interviews, proofreading documents, and paperwork. Meeting people, local government, social workers, health board, being a part of something. Instead of being in the same square meter doing nothing almost, stacking shelves, doing the travelling, you know, I was in [city], [city] all those areas.

Similarly, for Rebecca, she had the opportunity to explore meaningful volunteering over what would be, for her, paid, manual work. We saw in chapter seven that Rebecca had expressed a desire to seek employment. Her support workers had suggested that she would make a very good cleaner and that she should explore whether she could find a few hours of work per week as a domestic. Yet, instead, Sally suggested that she could explore a more personally satisfying role, of volunteering at a local children's nursery.⁴⁴ Rebecca had never considered such a 'job' as possible and was thrilled at the idea, even when Sally

⁴⁴ Sally is fortunate that she does not have hard outcomes needed to secure funding, yet this is somewhat unique. For, if there were hard outcomes, such as how many people have entered paid employment, she would have had to explore cleaning work as a clear possibility for Rebecca. Instead, without such fixed outcomes, she was able to explore an area that Rebecca would love to work in, which is working with children.

informed her that the role will be unpaid and was unlikely to lead to paid work. Here, as Ransome (1995; 210) notes,

It seems highly probable that the key reason why people continue to express such a strong willingness to participate in the labour process, stems more or less directly from the fact that there is no practical alternative available to them.

In these circumstances, then, as an alternative to the formal employment process, non-exploitative volunteering is also dependent on the nature of activities being undertaken, even if it would be in a profit-making nursery business. Yet, from a policy perspective, wrapped up in notions of active citizenship, this disparity is problematic. In the NDTi document (Greig et al. 2014), one stakeholder rhetorically questions whether ‘including volunteering [is] pragmatic or building in failure?’ (p.63). Drawing on the examples from Rebecca and Steve, one could not consider these situations to be failures, yet, according to the political discourse, they fall within such parameters.

A note on (un)intended consequences

While chapter five explored the landscape of employment activation in-depth, it is appropriate here to capture some complexities that are caught up within the work discourse. This, then, is concerned with the outcome for people who do not need to actively engage with paid work, yet do so out of choice. This chapter has demonstrated that volunteering is a complex and wide-ranging topic, whereby the motivations for volunteering often intersect with waged work. This is particularly apparent when it is not always a matter of personal choice, and instead, repackaged as work experience within a ‘conditioned...dense web of social relations and structures’ (Kelemen et al. 2017: 1252).

As a policy response to combat social exclusion, volunteering has been cast as a form of self-improvement and training to enter (or re-enter) the workforce (Baines and Hardill 2008). Yet, when presented as an opportunity to increase skill development, contacts, and credentials, volunteering becomes framed within a workfare ideology and aligns to welfare-to-work focused policies (Baines and Hardill 2008). A critique of this agenda is that non-marketised

activity tends to be devalued (Lister 2004) and instead, re-branded in 'ways that privilege its association with employment' (Baines and Hardill 2008: 308).

The paper by Baines and Hardill (2008) is dated, and, at the time, acknowledges concern with the future direction and relationship between volunteering and waged work, with emerging pressures from the welfare-to-work agenda and policy interventions. However, Slooties and Kampen (2017) extend these emerging ideas within a more contemporary context by exploring migrant women's experiences of volunteering as a route to empower individuals and increase employability prospects, as a route to empower migrants to become the 'ideal citizen' (p. 1900) by achieving workfare volunteering goals. Rather than supporting this idea, the authors, instead, suggest that the reverse is happening, and two mutually reinforced reasons actually disempower the volunteers.

First, is the lack of opportunity for volunteers to ever actually attain paid work as an outcome of their volunteering activities, and secondly, with such a focus on attaining paid work as the 'ultimate form of integration' (p.1900), the contributions made by the volunteers as active citizens often result in disempowerment. In this context, a policy goal of workfare volunteering is often failing to achieve the planned goals. Similar to the UK's policy position on citizenship ideals being conditionally dependent on paid work activity, the empowerment and employability agenda can hold tension by either opposing or amplifying each other. Self-confidence and autonomy may increase employability, yet within the contested notions of citizenship, comes less focus on citizenship empowerment, and more demand and attention directed towards obligation and responsibility (Slooties and Kampen 2017: 1905).⁴⁵

This perspective is further drawn out by Honneth (2012) who explores the theory of recognition. Here, he unpacks how the social recognition of volunteering activities merely 'serve the creation of attitudes that conform to the

⁴⁵ An example of this is the Right to Work (from 1997) which was a New Labour policy intended to have a dual role of helping to reduce unemployment for young people and avoiding more expensive work-related interventions such as the WP. Yet, while 'work experience' was 'paid' at JSA (plus expenses) rate, the surplus value accumulated by the employer through the productivity of the worker was extracted from participants was privatised to the host company. In a time of personal and public austerity, capital was profiting (Grover and Piggott 2013b).

dominant system' (p. 75), subjecting them to domination, rather than empowerment. As such, the positive connotations attached to such activity is lost and replaced by a 'mechanism of ideology' that is 'repeated [through] rituals [to] conform to the system of expected behaviour' (p. 77). Moreover, Kampen et al. (2013) take a discursive perspective to volunteering, highlighting how it can intersect with the fragility of self-respect and the emotional labour of volunteering when it is connected to workfare. In a meritocratic society, both success and failure are tied to one's individual responsibility, and the embedded policy imagination frames the self-respect of those at 'the bottom' (p. 428) as the 'losers' in society (Kampen et al. 2013: 428). As such, volunteering is perceived to be 'individualised adaption to labour market failure' (Baines and Hardill 2008: 315).

However, in the Netherlands, compulsory volunteering is prevalent. Building upon Foucault's body of work, the ideal citizen is the worker-citizen and citizens become self-governing, exploited to perform unpaid work and 'even feel happy about it' (Kampen et al 2013: 429). Yet, rather than adopting this position, the authors explore through the lens of the participant, by ethnographic methods, how workfare volunteering can be emotionally liberating. Focused on self-confidence, with the main goal of future employability, this research found that people went from 'being a nobody' to 'being a somebody' (p.431) with a new role and status in society. Further, the authors demonstrated how people felt part of something *bigger*, with an example of someone now being able to say, 'I am a coach', rather than 'I am unemployed'. This example resonates with Bates et al. (2017) who drew on an '*I am active, not passive*' stance (chapter three), by overcoming feelings of uselessness in a more inclusive atmosphere that may not be found in paid work.

Yet, as we have explored, for the people at the job club, the picture painted by Kampen et al. (2013) is not so clear-cut. These dichotomies of volunteering operate within a backdrop of the connections to active citizenship (Balandin et al. 2010c) that emerge as problematic within the volunteering sphere. So, while volunteering was a key component of citizenship until the market-driven discourses took hold in the 1980s, for marginalised groups now to become

actively included in the citizenry, there is tension. For, even within the context of ID specific strategies, these policies operate in line with workfare ideology that devalues volunteering as a route to active citizenship by participation and contribution and instead, alienates some people further away from mainstream society (Baines and Hardill, 2008, Balandin, 2010c).

Conclusion

This chapter has sketched out some of the tensions that intersect across, and within, the conceptualisation of work. To do this, different forms of work have been explored, rooted in the experiences of the job seekers, and how a non-universal understanding of waged work has manifested through the legacy of therapeutic/pretend work. More broadly, frictions with volunteering have also been explored. Volunteering may have captivated policymakers (Social Action and the Big Society, for example), yet it remains under-theorised within academia in relation to its boundaries with waged work. As Keleman et al. (2017) note, new forms of employment, such as unpaid internships and benefits-to-work schemes, do not fit into the binary understanding of what does and does not constitute work. My findings extend this noted absence to account for token/therapeutic nominal work that is not afforded space within contemporary scholarship and discourse.

Volunteering can lead to the exploitation of people who are looking for paid work (Trembath et al. 2010b). However, this position is much more nuanced and multifaceted for volunteers who have an ID and perceive themselves to have a *job*. Moreover, this is further amplified when people are encouraged to find work, particularly when the structures of welfare-to-work and nominal wages are at play. Some people are not necessarily seeking the expected income associated with paid work. Rather, there are instances of community connections and social capital being offered through work, whether that be paid or unpaid.

In contrast, work experience is offered as a mechanism to employment, by providing the opportunity for people to learn basic skills and workplace behaviour, such as asking for help and problem solving (Lindstorm et al. 2014). However, again, there is a disparity here. Work experience generally lasts up to six months, whereas the experiences offered by the job seekers at the job club

demonstrate that this work experience can last 17 years in Tara's case. As Bob and Archie's mother have contextualised, there is also a risk here that if this ambiguous work experience is questioned, the probability is that the position will be terminated, further reducing the opportunity individuals have to interact in their local community. Scholars researching both volunteering and work experience for people with disability (Baines and Hardill 2008; Baladin 2010; Trembath et al. 2010b; Lindstrom et al. 2014) all suggest that for those seeking paid work rather than volunteering, dedicated employment programmes and agencies should be used, as they are likely to be more beneficial and less exploitative. Yet, as chapter three demonstrated, it is unlikely that people who fit the demographic of those accessing the job club would be able to secure entry to specialised employment programmes.

As a consequence, this chapter has sketched out how morally ambiguous work has become prevalent in the learning-disabled community, to the extent that people with an ID express how their lives have been enriched by work, even if this work can be reasonably conceived as exploitative. Chapter two of this thesis explored the reduction of day opportunities on offer for people with an ID, a result of both austerity and personalisation. Held together with this chapter, the reduced opportunity to build a sense of community and social networks has resulted in the individualised, non-collective space, whereby people are creating their own path. Here, I argue, that there is an inherent risk that the morally ambiguous work discourse will become more prevalent within contemporary society. Moreover, those denied access to appropriate support from specialist employment provision, namely vulnerable people with the highest support needs who do not 'fit' into existing structures of work, and are furthest from the labour market exchange, are more likely to be navigating open employment. Here, those most vulnerable are at further risk of precarious and hazardous unpaid exploitation where work experience/unpaid work is offered instead.

Chapter nine, presented next, continues the discussion associated with the key themes presented here. However, it does so by exploring alternative approaches to employment activation – for people within my study. I also broaden out these

discussions to contextualise alternative employment inclusion, from outside of my empirical data collection.

Chapter nine

Is there a *better* way?

‘People fit in different things and I want to fit in a job’.

Lucas, worker at The Roasted Bean

So far, the four previous empirical chapters have explored how employment in/exclusion is, understandably nuanced and complex. No matter how much policy attempts to encompass diverse groups, inclusion will always generate exclusion (Simplican and Leader 2015). This chapter, however, presents some alternative perspectives on the future of work for people with an ID who are in receipt of social care. While still drawing on empirical analysis, this chapter also offers a broader contextualisation of how people can experience employment *inclusion*. First, however, the trajectory of employment activation needs to be explored to demonstrate how national policy intends to attend to future employment inclusion.

The future trajectory of employment policy

Chapters three and five presented how people with an ID, who are over 25, and in receipt of social care, face extreme employment exclusion and rejection from the formal economic exchange system. These chapters also sketched out how the focal point of policy for disabled people, more generally, is often at the expense of those with more profound support needs and instead, afforded in practice towards people with learning difficulties or mild ID (Simplican and Leader 2015). Clegg and Bigby (2007) explain that by only attracting those closest to the labour market into the workforce, supported employment programmes can contribute to an ‘illusion of inclusion’ (p. 796) that sits in a grey area of inclusion and exclusion by offering the appearance that employment activation is occurring for certain disadvantaged groups. This position looks set to continue, given the current and future policy trajectory on employment activation.

A report from the All-Party Parliamentary Group on disability (Connolly et al. 2016) highlights how the aims of the then soon to be published ‘Improving the Future of Work, Health and Disability’ (2017) strategy, of raising the

employment rate for people with a disability from 48% to 64%, is not expected to be met by 2025. In real terms, the gap had narrowed by just 1.3% between 2013 and 2016 and, at this rate, it is expected to take until 2065 to narrow the gap by the target of 16%. Learning Disability Today (2016) responded by highlighting the repeated multiple failures of both the private and public sector organisations in their attempts to address discrimination against disabled people. Moreover, the response is also critical of the service provision available to disabled people to help create, gain, and retain employment.

The inquiry further found evidence of ‘institutional disablism’ whereby organisations are failing to provide appropriate support in the workplace, citing in-work support as inadequate, and recruitment and retention policies as not inclusive. Rather, the employment gap is a ‘continuum of a collective failure’ where organisations are not held to account in meeting their targets (Learning Disability Today 2016: np). These figures, reports, and responses cover all forms of disability, yet, as this thesis has demonstrated, the employment rate is significantly lower for people with an ID in receipt of social care, and moreover, it is declining.

In addition, the ‘Improving the Future of Work, Health and Disability’ (2017) policy absorbs people with an ID within the categorisation of learning difficulties and mental health issues. This broadness detracts from the specific needs that people with more complex requirements for employment support require, risking further alienation for people with an ID and in receipt of social care. Mainstreaming people with an ID into a broader disability category leaves little space to focus on how their needs may be different from other disabled people, which had been previously somewhat attended to within the former Valuing Employment Now (2009) strategy. Disbanded in 2011, the Valuing Employment Now (2009) document was heavily criticised at the time for its misconceptions of capacity, its admissions criteria, and its low participation rates, particularly for people with higher support needs (Dempsey and Ford 2009; Melling et al. 2011). Yet, calls have been made to bring the initiative back into play, for people with an ID are now left ‘marooned’ (LDT 2016: np).

However, researching the relationship between ID and employment does have the potential to redefine the ‘window dressing’ (Kellett 2010: 32) notions associated with the complexity of the ID landscape and employment activation. This chapter will now sketch out a broader, and possibly *better*, approach to employment inclusion by scoping out examples both from my empirical research and more widely, whereby employment inclusion is approached using different models for people with more complex ID. Grassroots approaches to employment inclusion for people with an ID have emerged over the last decade. From a not-for-profit restaurant in Southern Spain (Bergen 2019) to the world’s first ultra-accessible theme park in the USA (Friedlander 2017), innovative and inclusive employment developments are resisting the individualised policy direction of mainstream, open employment inclusion. Closer to home, first to consider, is an alternative approach offered by Sally at Green Meadow.

Tea and bunting - sketching out new forms of work

Frustrated with deploying the methods associated with cooling the mark (Goffman 1952) (explored in depth in chapter six) Sally, the work manager at Green Meadow, attempted to reverse some of the difficulties experienced by job seekers towards the end of spring 2018. She proactively presented the job seekers with the possibility of being a trainee at a Pop-up Café over the summer. Instantly, the atmosphere within the job club altered, fostering a positive, exciting space. The Pop-up Café became a distraction from the everyday mundane negative associations of open employment job seeking. Sally explained the aim of The Pop-up Café was to offer ‘*a simple afternoon tea in a nice gentle marquee with music playing and bunting flowing*’. Themed on the 1950s, The Pop-up Café intended to attract customers from local nursing homes that had previously requested to visit the lush rural grounds on offer at Green Meadow.

All of the job seekers intended to apply for a vacancy available within the café, which was framed as a work experience opportunity. Worksheets reflected this shift, with, ‘what I want to get better at’ focused outcomes. These were listed as confidence, teamwork, listening, feeling better about yourself, following instructions, and work rules. Here, then, it is necessary to alter the term job seeker, to trainee, reflecting a newfound identity and shift in social position. This

terminology was adopted within the job club interchangeably with 'worker'. The vacancies on offer were either 'front of house' or 'kitchen porter' roles, with both posts having a job description drafted. Trainees were invited to complete an application form and attend an interview. While these processes are well associated with a standard application process, in practice, the procedure differed somewhat from the expected human resource structures. Sally and I supported the trainees to complete their forms, before she 'interviewed' them, as a group, within the job club session. During this interview, Sally spoke to Sophie:

Sophie, you're quite good at money, and not many people are. Write down 'I can do money [a few minutes later, Sally continues] ... Now Sophie, you're interesting because you are the only person that has ticked that they can do money because you really can give change.

Sally then tested Sophie by asking if she can add up £2 and £1. Sophie replied that she could and that, '*£2 and £1 is £3*'. Sally continued, '*brilliant, perfect. I knew you could do that. So, if someone gives you notes and coins, you can work it out. We can put some prompts by the till... you might be our till lady*'. The dynamics profoundly shifted here from chapters six and seven, whereby Jackie was the proxy to paid work, as a source of envy and upset for Sophie – for, even though Jackie had more work experience and did not have a diagnosed ID, she was not confident in working with money. Sophie's money handling ability provided a confidence boost, since altering the structure of work, offered her an opportunity to exert her own agency within a working environment.

Next for Sally and the trainees to attend to were 'user-friendly' tools. The cost of items on the menu was formulated to whole pounds. The note pads for trainees to record the orders had photographs that correspond to the items available. Tables were dressed for how they would be presented during the café opening hours, with photographs taken as a visual prompt for trainees for when they were expected to clear the tables and lay them for the next customer. While appearing straightforward considerations, these alternative modes are fraught with time-consuming challenges. There were many issues to overcome with the menus, as the photographs of drinks (to aid trainees with limited literacy ability)

all looked similar. Sally captured this: *'they all look a bit alike don't they. I made the coffee a bit frothy. Orange squash, that looks more like orange juice but never mind. Chocolate cake or flapjack, that's all that's on the menu'*. Helping trainees to visualise the differences between tea and coffee, even with photographs and written words, took multiple attempts over many weeks. A group decision was also made not to offer decaffeinated alternatives as this would limit the duties that the 'front of house' staff could be actively involved in. Overall, as Sally encapsulated, *'what we are saying is, there are ways to make things easier for people'*.

For three consecutive weeks, each job club session became a café stage and performance, using the kitchen area of the church hall. Here, a safe and inclusive environment enabled trainees to practice their roles, with us all taking turns in role-playing the front-of-house staff, kitchen porters, and customers. This 'trial and error' approach supported the trainees with their confidence and hands-on experience. Sally asked the trainees to *'smile, make eye contact and be very polite'*, even when they were unsure of what to do. Trainees were given keywords to take home and practice, such as *'welcome to our café'*. Everyone was very excited, and Verity practiced:

Here's the menu and I'm gunna tell you, it's tea, coffee, juice, it's cake or flapjack...and I will say to you, thank you after you order. I pay you after you've finished your drinks and I say thank you.

Risk assessments were completed, identifying such things as a tray must be used for all hot drinks to avoid burns from spills and only Sally or Lucy (job coach) could use the urn. The comfort, health, and wellbeing of all trainees was paramount, which is so often absent from low-wage, entry-level job roles (Frayne 2015). Here, it was identified that, for the two hours duration of each café session, all trainees must have a break, with a chair and water available to them. Further, the restricted opening hours of The Pop-up Café was intended. For, as Sally noted, *'it is only for a set amount of time. For some of you, you can only do that short time. For a job to go on and on, it's too much, too difficult to sustain'*. What we see with this inclusive approach adopted by Sally is that everyone had

the opportunity to work, if they so wished, and moreover, the structures to employment can be altered to offer a truly inclusive workspace.

Set-up costs were minimal. Sally and Lucy's wages were covered by the employment preparation programme; the land for the café was owned by Green Meadow and Sally '*begged and borrowed*' crockery, tables, and other necessities from her own friends and family. Moreover, the project was innovative, commissioning the cakes from the Green Meadow baking club and offering tables to the woodwork club for them to sell their wares. However, with no particular funding for the project, there was no budget to pay any wages.

While chapter eight demonstrates that wages are not generally associated with work experience opportunities, which is what this project aligned towards, early on, trainees asked if they would be paid. This suggests that their expectation was to earn a wage from their work, similar to the findings offered by Ineson (2015) in her paper documenting a path to paid work for a participant with a complex ID. Ineson (2015) notes: 'two of the first questions the participant asked when introducing the concept of work were "how much [wages]?" and "what colour [uniform]?"' (p. 62). These questions, therefore, demonstrate that the participant fully expected such work factors to apply to herself. This second consideration of uniform is also conveyed within my data and will be explored in due course. First, however, is the continued theme of wages, as Sally explained to the trainees:

So, our job will be to serve the teas and cakes and they will pay us money. And if there is any surplus money at the end of it, it will be shared out amongst all of you trainees... proportionate to hours you have worked. So, the more hours you do, the more money you will get.

Sophie asked how much money they might make. Sally had done some projections and suggested it will be around £10 each in total, based on each person working three of the six available sessions. Sally added, '*take your friend out for a coffee or something, but I don't think its gunna be a huge amount of money if I'm honest*'. Sophie was satisfied with this, replying, '*yeah, that'll be nice*'.

The Pop-up Café ran once a week, for two hours each time, over six weeks during summer 2018. Around three-quarters of the visitors to the café were already

known to Green Meadow in some way and the best weeks takings were £148 over a two-hour period. There were some operational issues, particularly around the till, calculating bills, and giving change. Yet, everyone was pleased they had 'got through their targets', by accomplishing their own, personal objectives, and more collectively, that individuals had had the opportunity to be part of something new and valued. During the evaluation process, the group met one evening to give their feedback on the café and have the opportunity to reflect upon their experiences.⁴⁶

Here, Sally arranged for each trainee to be presented with a certificate and their wages. Each certificate was personalised, highlighting a particular identified strength that the trainee had improved upon during their experience. For instance, Jackie's was her commitment; Sophie's was for trying her best; Naomi's was taking on feedback; Verity's was for *'bringing her sense of humour and selling lots and lots and lots of strawberries'*. Sally congratulated the trainees, *'you all worked hard. Some of you done long hours [four hours with set up and cleaning], very long days'*. I produced a simple visual picture to highlight the words most used by trainees during the evaluation evening, presented here, in figure 11:

⁴⁶ An evening induction is arranged, for 1.5 hours. It clashes with 'Thursday' club, so the time is brought forward. Sally and Lucy arrange everyone's transport, re-arrange clashing support times and reassure people who are anxious about the evening. They provide people with a light snack so they can go straight to Thursday club afterwards. Karen is worried she will have to pay the mileage to attend the evaluation evening and be out of pocket. Sally reassures her *'no, you won't have to pay mileage on this because it is part of the project. You won't be paying anything, it won't cost... so don't worry about that'*.



Figure 11. Capture of most transcribed words from trainees

Moreover, along with the certificate, a small brown envelope that contained each person's wages was handed out and signed for. The trainees intended to use their wages to reward themselves. Verity informed the group that she would treat herself to a cake. Yet, she had no idea how much she had earned as she was so preoccupied with her certificate to look at her wage pack. Instead, she told us that she was going to telephone her father and share her news. Naomi informed us she would take her mum out for coffee – I asked Naomi if it mattered to her, how much money was in there. She replied, '*no, it was just because it had money in it*'. Sophie was so proud of her certificate that she did not mention her money, even though, for Sophie, the wages had always been important to her throughout her job-seeking experiences.

The highest wage was for Jackie, who worked five of the six available sessions. In total, she was paid £50, equating to around £3 per hour. She decided to treat herself to some perfume. Moreover, the trainees put together a video to send to the project funders. Asking Sally if there were specific outcomes for this element of the funding, her reply was:

No, not specific... making money isn't important to them although they will like to see it going towards something sustainable, I suppose. But they just want it to have a positive impact on the people working there... and they understand how difficult it is for people to find work... So far, they have been very positive about everything we've been doing.... there are six people, all retired accountants, and chief executives... There was a very rich person, [that set up a charitable trust from the interest of their capital] it now makes about a quarter of a million pounds a year profit and they give that money away to projects like ours.

It is difficult to fully capture the outcomes of such a project without personally witnessing the individual growth and development of the trainees. During the evaluation process, I produced a simple feedback evaluation based on what the trainees offered as feedback on their experience from my recorded transcript. Figure 12. shows some of these quotes:

"I thought I felt good in myself seeing all the people, meeting new friends"

"I thought everybody enjoyed themselves and I think we should have another coffee shop like it"

"I enjoyed doing the money and serving the cakes"

"I think we should do some more days"

"I think it would be nice to have it on the weekend"

"I loved it, wearing the uniform"

"Since I've been doing The Pop-up Café, I've got to know the rest of the guys and that's really good, because it's just made my confidence grow huge"

"Friendship, friendship. It's more like, friendship"

"I really enjoyed it"

"I've listened to what people say all my life and I want to be more independent"

"I did what I wanted to do"

"Doing The Pop-up Café has built my confidence up"

"We made it as a team"

"I'm ecstatic! This is my wages!"

"I haven't ever been paid before. My Mum, my Dad, my sister all get paid. I'm the only one who hadn't been paid"

"I want to say, that everybody, I enjoyed the café, I enjoyed it and I want to do more at next year. I enjoyed it both the people here, they done a lot"

"It's fantastic"

"You see, I can get paid!"

Figure 12. Quotes from Trainees

Figure 12 offers some of the direct quotes gathered at the evaluation evening, from trainees who took part in The Pop-up Café. Sally also shared with the group:

The thing is, we are all different. A lot of people work, they do a job, they get the money, but for some people, it doesn't have to be like that. What is work? Work is going and being part of something. Being in a team, feeling good that you've done something and have a purpose. And if you need a project like this to be successful, then that's what we all need to do then really... We had to make sure that YOU done the work, you done the drinks, you did the cakes and you took the money and you sold your strawberries.... everybody had a job to do and that's absolutely critical. I get the impression in some of these community cafes that the able-bodied are doing all the work and the people who need the support, who have got a disability or difficulty, aren't doing a great deal and that frustrates me.

The themes raised within the data analysis from Green Meadow are echoed more widely, particularly from my observations at The Roasted Bean, a Community Investment Company that has many similarities with The Pop-up Café. Here, practical adaptations such as the menus being in a friendly format and a petty cash tin instead of an electronic till are apparent. Moreover, the importance of wages is threaded throughout the accounts offered by the workers at the community café. Like Naomi, who commented at The Pop-up Café that she was ecstatic at having been paid for the first time, Lucas, a worker at The Roasted Bean shared, *'now I get a wage, it's important now I earn the money. I feel better getting wages. I don't mind how much, but I've earned it'*. Yet, more than the 'user friendly' or wage similarities, there is a sense that social identities are being crafted. These subtle, nuanced notions of identity modification occur at both The Pop-up Café and The Roasted Bean and can now be explored under a broader *rites of passage* umbrella. Sennett (2012) explores these notions of rites of passage through rituals that confirm an individual to now be a valued member of the community.

Crafting identity

Garfinkel (1956) noted in his analysis of formal ceremonies and rites of passage that identities are redefined (or removed) with new attributes assigned and how these formalities reframe a collective identity work (Atkinson 2015). The

contours of such a concept can be applied here too. The subsection above has highlighted how the trainees at The Pop-up Café held an informal ceremony to celebrate their individual and collective success, with certificates to reinforce their achievements. Yet, other more discreet examples can be encompassed within a symbolic ‘rites de passage’ (Atkinson 2015:87) framework that demonstrates work not simply through wages, but as a form of status and approval (Budd 2011). First, at both The Pop-up Café and The Roasted Bean, employees are paid in cash. This visual representation of value could well have not the same impact if, like most contemporary positions, the pay was electronically transferred into a nominated bank account (Worksmart 2019). For, to hold money that has been earned is a signifier of worth (Kaehne and Beyer 2013), evident at the evaluation of The Pop-up Café and The Roasted Bean alike. As an example, I was with Lucas when he received his wages one day. His face lit up with happiness to physically hold his earned money.

Next, still within the rites of passage realm is a uniform. By wearing a uniform, membership to notions of work are attached. When Sally initially asked who would like to work as a trainee at The Pop-up Café, the first conversation to take place for the group was what they would need to wear. Jackie went straight out to buy a new blouse, while Sophie worried her trousers and shoes would not be smart enough. All trainees wanted a name badge, and all were very pleased that they were required to wear an apron. At The Roasted Bean, Lucas extended this, *‘I love it, wearing the uniform’* he exclaimed. More broadly, Zappella (2015) discusses uniform as a representation of equality, with difference concealed. Considering these two ideas together, a participant drawn from Kaehne and Beyer’s (2013) work suggests while the physical money is important as a visual symbol, a uniform is more of a powerful determinant of holistic development. As the advocate of a participant notes, ‘the money doesn’t mean anything at all but the putting on a uniform and going to work and having something she’s actually expected to do [that does]. I don’t think it’s a coincidence that at the same time her attitudes have moved, and she’s sort of being more responsible’ (parent B) (Kaehne and Beyer 2013: 245).

The spaces of opportunity offered here shift self-perception away from being a user of services, and instead, providing services, is ever-present within my data. Following on from her Pop-up Café trainee experience, Naomi actively adopted a ‘helper’ role at the job club, attaching herself to new job seekers to show them the ‘ropes’, while at The Roasted Bean, Jessie not only worked in the café but also self-identified as a helper to other employees. She says, *‘I help the others, on a Monday. I help them’*. These symbolic ‘rites de passage’ (Atkinson 2015:87) are afforded to so many within our society, yet for people who fall into being within the category of the 5.2% employment rate, their occurrence is cause for extended celebration and ceremony.

At Power, their stance and ethos have a direct significance on readdressing the visual representation of theories of membership.⁴⁷ Here, a small collective decision challenges the critique made of critical disability studies (CDS) by Vehmas and Watson (2014), that CDS does not have analytical power (discussed in chapter two).⁴⁸ As Margaret explained:

We made the decision that, all Power workers would wear smart shoes when they are working. It doesn’t matter if we are dressed casually for work, jeans are fine. But businesspeople, even when they dress casually, they have smart shoes on, don’t they?

Without the need for a uniform, Power made a conscious decision to shift the binaries so intricately associated with CDS by disrupting the *dishuman* framework (Goodley and Runswick-Cole 2016). Within this lens, as the authors remind us, ‘a dis/human position means that we recognise the norm, the pragmatic and political value of claiming the norm, but we seek to trouble the norm’ (p. 5). Here, the aim of Power was to alter the membership category assigned to workers, from dis/recognise and dis/ability. For, other professionals and potential clients would first draw upon the appearance of the worker, before assigning them to a *dis* category, and therefore challenge and trouble normalcy,

⁴⁷ To remind the reader, Power is a Community Investment Company, specialising in consultancy work and the knowledge economy. The founding workers are all worker/directors. This structure is composed of a mix of people with and without, ID.

⁴⁸ The authors here, question the value of CDS, suggesting that to neutral difference is a false premise, as impairment has demonstratable effects on people, that cannot ‘be explained away by deconstruction’ (p. 646).

assumptions, and expectations. Coleman-Fountain (2017) refers to these interruptions as 'practices of ordinariness' (p. 775), redefining 'damaged identity' (p. 768), while Altermark (2017) scribes the position of challenging the social practices of diagnostics and classification, by unsettling the 'uniform identity' (p. 1327) of people with an ID.

Both Altermark (2017) and Coleman-Fountain (2017) explore this social shift to ordinariness, through a lens offered by Goffman (1959). Altering the frame of reference at Power, whether discreetly with the example of the shoes, or more explicitly with the decision for all core workers to also be company directors, enables an understanding of how performance is modified to fit (or disrupt) the expectations within society, 'where reality is being performed' (Goffman 1959: 45). In this frame, the performer redefines their social role by presenting different parts, to disrupt the 'impression of reality' (p. 28), with an individual revealing the performance of social status or multiple statuses. This concept of status, here, is unclear, 'for example, there are many statuses in which membership obviously is not subject to formal ratification' (p.68). Instead, there is an opportunity for an 'idealised impression' (p. 72) to be offered by 'accentuating certain facts and concealing others' (p.72). In the case of Power, this point of reference has reframed the use of the team, rather than the individual 'performer, as the base unit' (p. 90) with true co-operation offered here to 'maintain a particular definition of the situation' (p. 96).

Yet, even with these examples of positive employment inclusion, for some, wearing a uniform does not detract from other examples of entrenched disablism. At Green Meadow, this was practiced by the new providers of the organisation (who had not funded the employment provision) using The Pop-up Café experience as a good news story for their support services. Here, the service was able to exploit how it was the 'go-getting' attitudes of the support workers and employment support team that enabled the trainees to experience work, rather than the agency, hard work, and determination of the individual trainees themselves. Moreover, at The Roasted Bean, one example details the ingrained attitudes of the wider community towards an employee. My fieldnotes explain:

I am standing at the café counter about to order. A gentleman in front of me asks for some hot water, to top up his coffee. He does not ask the worker; he asks the worker's supporter. The worker's supporter then has to take on the painstaking role of negotiating boundaries, for the benefit of both the customer and the worker. The supporter repeats the request to the worker. The worker takes the cup, fills it up with the requested hot water, and passes it to the customer.

This experience, where the worker was not directly asked to re-fill the customer's drink, highlights the dis/ability framework, this time through a negative example. For, the customer had appeared to see the workers (dis)ability, before their membership to the worker category. Moreover, it also highlights the need for strong, advocative networks, that prioritises the requirement for the worker to perform their employment duties, rather than the supporter taking over and topping up the hot water themselves. In this case, the employee at The Roasted Bean would be unable to hold such a position, as a worker, without the assistance of an unpaid supporter, often, a parent.

Networks, enablers, and barriers to employment inclusion

Monckton (2017) (discussed in detail in chapter eight, regarding her stance with the national minimum wage), is mother to Domenica, who has Down's syndrome. So frustrated with the lack of work opportunities, she set up Team Domenica, a social enterprise charity supporting employment opportunities in the South of England. Similarly, Gordon and Rachel set up The Roasted Bean as a route to channel their frustration at a lack of opportunities in South Wales. Archie's work at The Roasted Bean could only be achieved when his mother sacrificed her own job and financial security to enable him to develop his role as a worker. This importance of networks then, is paramount for success. Indeed, Stevens et al. (2011) remind us that social resources and capital can lead to in-equitability for those who do not possess such support, 'members of disadvantaged socioeconomic groups can suffer from low levels of social capital if their networks do not extend to individuals with greater resources' (Budd 2011: 110).

Blum (2015) explores these ideas whereby parents (usually mothers) tackle 'multiple bureaucratic obstacles' (p. 29) to remedy institutional failure. Within

my research, such examples are nuanced and varied. These examples, however, do shine a light on the acquisition of resources, time, and capacity dedicated to the 'lone quests for justice' (p. 29). At Power, Margaret shared a 'success' story referring to a 'tiger mother'⁴⁹:

Someone pulled some strings by talking to the employer about corporate social responsibility.⁵⁰ Job was carved out around her daughters' skills and what her daughter wanted to be doing and then they took the creative step in recognising that in that situation, bringing in a job coach wasn't the right move. It would be better for the young woman to be getting some additional support from other staff that she would be working alongside. So, they used some of her direct payments to purchase support, but it is done, like a wage subsidy. It isn't perfect, but it means the employer isn't losing out financially or getting irritated because another member of staffs' time keeps being taken up with providing additional support... but the power of having her there... She is in a visible job in a well-respected setting and, yes, it's public sector, where you wouldn't expect to see somebody with a LD [learning disability], working. She is breaking barriers. In order to do it, the support side is paid for through DP [direct payments] but the getting the job, is down to a tiger mother, who refused to accept the supported employment agency who said "it's a shame her hopes are too high" and an employer who isn't afraid of corporate responsibility.

This insight from Margaret returns us once again to the financial implications around a wage subsidy. In her example, personal direct payments act as a mechanism to levy an informal wage subsidy. While, as Margaret shared, this was '*not perfect*', it did enable someone to be employed by finding a route *around* policy. As capitalism and austerity can bind people together, it can offer space to think creatively about work and to work the spaces of capitalism (Bates et al.

⁴⁹ In this context, 'tiger mother' is a term used to denote a mother who fought for her child to be included. However, the term is controversial and contested, by its association with a 'neoliberal racial project' to rationalise the social arrangements of power (Rhee 2013: 561).

⁵⁰ The mechanism for equality in commercial entities has not led to a social justice route of embracing diversity, rather, it is perceived to be a source of advantage competitively. Budd (2011) notes that 'corporate diversity programmes are at best, of limited value and at worse, a public relations play' (p. 140). Honneth (2012) argues that notions of social justice are democratically controlled by the state and as such, commercial entities cannot be drawn upon, or made to be responsible for, 'the implementation of justice' (p. 39).

2017). The Pop-up Café and The Roasted Bean, however, had a somewhat precarious route *around* policy, fraught with concern on the payments of cash that are not accounted for by the Department of Revenue and Benefits, or the legalities of not paying workers above the national minimum wage threshold. Gordon, the co-founder of The Roasted Bean, summed this up, when he shared how he is unsure if what they do would fit in with, *'any questions from HR Revenue and Benefits'*. However, he resolved this by claiming, *'I am sure that they have got more going on with Brexit at the moment than to worry about us distributing a few pounds'*.⁵¹

While this comment was made in good humour, it acknowledges the conscious peculiarities of current practice and the (potentially problematic) legality of this situation. Workers are legally expected to be paid at least the national minimum wage under the National Minimum Wage Act (1998) and this legislation applies to all individuals over the age of 21.⁵² Yet, what is apparent and threaded throughout The Pop-up Café and The Roasted Bean is that the experiences align more closely to an apprenticeship, rather than work experience that is usually short-term and focused on increasing skills, or volunteering that is generally performed without a financial reward (Budd 2011), or paid work. The concern here, however, is that if these opportunities were to be formalised and attached to a training centre, the risk is that those furthest from the labour market would, once again, be displaced and excluded from the (un)intended consequences of employment activation – indeed, as explored in chapter five, the requirement of arbitrary pre-requisites and endemic employment creaming and parking tendencies. Yet, on the other hand, this position would function as a legitimate route to the part-wages associated with apprenticeships during the trainee experience.

⁵¹ The National Minimum Wage Act (1998) states, that for voluntary workers, employed by a charity, no monetary payments, of any description, or no monetary payments except in respect of expenses can be received.

⁵² The Act allows for lower payment thresholds that are age dependent. e.g. younger people can be paid lower rates, and these are staggered until the age of 21. There are certain exceptions to the National minimum wage – fishermen can be remunerated in respect of sharing the profits or gross earnings of the vessel. Certain religious workers are exempt, as are prisoners, detained persons in immigration centres and reservists for the Ministry of Defense.

More broadly, an exception to the national minimum wage, however it is repackaged, fuels debate. While it could be an effective labour market policy designed to enhance employment opportunity and facilitate integration, it can also perpetuate the cultural attachments and meanings of reduced worth, as a portrayal of disability embodiment of non-productivity and dependency (Soffer et al. 2011). As an alternative, some scholars have explored the use of *serious leisure* as a route to employment like replacements.

Exploitation, by another name?

Patterson and Pegg (2009) and Aitchinson (2003) enter a debate around 'serious leisure' for people with an ID by aiming to shift the deliberation of community inclusion and citizenship towards an inclusive model of contribution. Here, Patterson and Pegg (2009) wish to address that 'economic rationalists have argued that people with disabilities have been a continual financial drain on society's resources... reliant on some form of government support... regarded as non-contributing citizens' (p. 388) by continued rejection, which has served to discourage people with an ID from the labour market, through consequential detachment. Similar to Aitchinson (2003), the authors seek to reframe the alternative by considering leisure activities as a 'possible substitute for paid employment' (p. 390), whereby a greater emphasis for funding by social policy and researchers is placed upon experiences. For Patterson and Pegg (2009), their research points towards the pursuit of amateur hobbies and volunteering through the acquisition of knowledge, skills, and experience.

Moreover, their research found examples of people having positive volunteering opportunities, whereby it did lead to paid work (after some two years). Their study also documents the experience of a participant who volunteers at a supermarket. While the analysis offered within my empirical research has not been connected to positive experiences, such as leading to paid work, the difference here, is that the participant they draw from does not take on a role that is a function of paid counterparts. Rather, the volunteer acts as a meet and greet, helping people with their shopping and interacting with staff and customers alike. In this sense, a role has been carved out, whereby positive experiences can offer a work-like alternative and, the presence of people with an

ID is felt within the community. In essence, then, 'serious leisure' can be an important remedy to the stagnated precariousness of unemployment, if, the individual has a position unoccupied by a paid worker.

Hall and McGarrol (2012) take an alternative approach by suggesting that while segregated employment spaces are being reduced in favour of mainstream employment contexts, those with an ID operate within a 'separate sphere' (p. 1276) from other marginalised groups within society due to the ongoing need of social care support, heavily dependent on a shrinking social care sector. Their position is to increase the grassroots work like alternatives, like what is offered by The Pop-up Café and The Roasted Bean, through a 'third sphere' (p. 1277) of social capital building and local networks. Here, a relational process based on interdependence can be sketched out with networkers of partnerships between the individual, their families, professional carers, and organisations. Overall, this perspective offers to bridge a gap between social care and people with an ID.

Yet, my research highlights how this experience is not necessarily optimistic in practice. Gordon and Rachel had great difficulty in the early part of setting up The Roasted Bean with their local authority (LA). Considered as not to in line with the aims and objectives of the LA, no funding could be secured, even without alternative meaningful and satisfying roles being offered through LA provision.

Instead, Gordon and Rachel were supported by kick-start funding and now that the café is near sustainable, the LA have indicated that they wish to explore possibilities of 'purchasing' work for people in the county. Moreover, The Roasted Bean is set to expand to run canteens across the area for some emergency first responders. The rationale in this opportunity is that there is not enough profit from the canteens to sustain a profit-making company, but there is an opportunity to become a self-sustaining work option while ensuring those first responders have the availability of hot food. Here, interrelated forms of 'work' and 'care' can form senses of attachment and belonging with a fluidity of space between work and the security of care (Hall and McGarrol 2012). This fluidity of care is evident with the next example of Ignition Brewery in London.

Ignition Brewery employ and train people with an ID to 'brew great beer' by drawing on people's strengths, rather than their limitations, like The Pop-up Café and The Roasted Bean. Workers tend to take on single function roles, such as focusing on the hops *or* production *or* cleaning. For instance, one trainee wanted to be the delivery driver, so the company is helping him learn to drive. Yet together, they all make a collective contribution, and the not-for-profit company pays the London living wage to all trainee brewers. The brewery, as O'Shea (2017) explains, was set up in response to the lack of opportunity offered to people with an ID locally. Again, this resonates more widely within both the literature and experiences from The Pop-up Café and The Roasted Bean. Their ethos is to be aspirational, to not be anyone's 'pity project', and to make good beer that everyday consumers would purchase.

Moreover, adopting an activist approach, the company intends to 'shake up the social care system' because, as O'Shea discusses, 'I don't think what we do is always good enough' (O'Shea 2017 np). Here, he explores the significant barriers that the brewery team had to endure, from within the social care sector, where 'negative disablism' was enforced through risk assessments and key performance indicators (KPI's) limiting people's life choices. In response, O'Shea (2017) suggests, 'let's be done with pity, get rid of the risk assessments and get to work' (np). Yet, fundamentally, O'Shea (2017) calls for a profound shift in the conceptualisation of how support is delivered to people with an ID. He cites that, if a trainee were to be reliant on a support worker for one hour, their local authority would pay £12. Instead, once confident in a supportive, inclusive, and understanding workplace, a support worker could begin to withdraw this level of support, saving the LA that same £12. Moreover, the worker would be earning £10 per hour, and the gap here then, is £22, per hour. O'Shea then challenges the LA to take 10 percent of the social care budget, and spend it differently, for the care and support budget would begin to decline, and the existing funding streams would be replaced by inclusive work environments.

Mahoney and Roberts explored some of these co-occupational ideas back in 2009. Here, the proposition was to pay support staff to enable people with an ID to sustain employment, as an ongoing position and the authors suggest that

funding this could be done by diverting social care funding to a community enabler as a method to reduce both 'occupational injustice' and 'occupational deprivation' (Mahoney and Roberts 2009: 170). This, then, is what Gore et al. (2013) refer to as 'continuous social support' (p. 232). While the examples presented here so far are considered to be segregated, they all include social contact within their local communities.

More broadly, these innovative and alternative spaces of opportunity are emerging from other, non-segregated areas too. The extraordinary lengths that Power went to, to secure Richard his working position, have provided a profound route to a life-altering, rich, and stimulating opportunity for him. As we have seen in earlier empirical chapters, Richard was paid, whether there was work available to him or not, to satisfy his welfare benefit administrative requirements. Moreover, to afford this, all members of Power only paid themselves the living wage, to ensure there was enough finance available for Richard to have a guaranteed wage, and to allow for the additional time it takes for the enterprise to complete contractual obligations. Richard explained the impact this has had in his everyday life:

I think Power gives me more using my talents and skills that I wouldn't be using in a supermarket. But I have been offered work at my local pub because one time I collected glasses. And the manager there said, "do you fancy a job" and I went, "thank you for the offer, but I am already working, thank you very much".

Richard laughed and glowed with pride as he recalled the conversation. More widely, his work offered an opportunity to interact in new ways, with people in positions of power. He recollected a situation where he was at a meeting about a work programme, where representatives were, as he put it, 'negative' in their conversations. Richard was proud to introduce himself:

I said, "hello my name is Richard and I am worker director of my own company" ... And I said, "I am a person with a disability as well". [It] felt good. Something to always remember. Somebody who I had went to see at the job centre was there!

The significance of his work was so eloquently captured by Richard here:

I'm part-time, I'm not full time, but I class myself as a worker, so I feel in myself, as a citizen, part of the community that is working in the community. When I'm at my local pub, I chat to people in there, a friend of mine and I chat. "How was your day going?" and I can have that kind of chat.

Overall then, despite low wages at The Pop-up Café and The Roasted Bean, what occurred at Green Meadow, The Roasted Bean, and Power alike, is the community-based benefits of being valued (Lindstrom et al. 2014) and recognised (Honneth 2012). In these cases, it seems that it is the ability to work, the ability to be part of a team, and the support to complete tangible tasks, that really means people with an ID are self-perceived to be valued citizens.

Conclusion

This chapter has presented some alternatives to employment policy based on the empirical data analysis of The Pop-up Café, The Roasted Bean, and Power. While broad employment policy for people with an ID advocate mainstream open employment, this thesis has demonstrated that this can be at the expense of those who are over 25 and in receipt of social care. The position and structure of the open labour market are at the detriment to those who may need additional support to enter a *workplace/workspace*.

This chapter has sketched out, through both empirical analysis and wider examples, some alternative ways of *doing* work, some of which is what would be considered as segregated employment. Yet, these solutions created within the structures of employment activation and citizenship are perceived by the people with an ID, and their networks and advocates alike as a *better* alternative to seeking paid work in the open employment market. While these opportunities may not satisfy those who consider segregated work as unacceptable, this is a grassroots approach located within a space where contact with the local community is a daily occurrence. These work arrangements have been set up by people with an ID themselves, their families, and advocates, without the support or financial assistance of local authorities. Moreover, this resistance to 'occupational injustice' and 'occupational deprivation' (Mahoney and Roberts 2009: 170) has seen many people heavily investing their own time and skills to

support and enable people to develop their own sense of self-worth and enter the rites of passage of work, against a backdrop of seeking routes *around* both current policies and accepted good practice.

Chapter ten, presented next, is the final chapter of this thesis. It presents a brief summary of the key discussions of each chapter and considers the broader implications of this research project. Moreover, chapter ten articulates my academic contributions and highlights a general direction drawn from the research, that requires future attention.

Chapter 10

Conclusion

My thesis has offered insight into the everyday lived realities of how people with an ID, who are in receipt of social care, navigate and interact with the structures of employment. In its introduction, I stated that the employment rate for people within this demographic is at 5.2% (Hatton 2017). I also highlighted that there are disparities in the reporting rates, due to the significant variations within different local authorities for recording such statistics. Some local authorities only record employment of those working 16 hours or more per week, others document any paid work, while some also record employment as an outcome for people who are engaging with volunteering, unpaid work and work preparation, or anything in between. Drawing out these disparities matter. The rhetoric of employment policy pitches paid work as being available for anyone, yet this study has exposed the problematic nature of such narratives.

As this thesis progressed, issues around the definitions of a 'learning disability', particularly with its intersection with work, also arose. Academic literature and policy evaluation documents alike highlight how support is targeted and prioritised towards those who are closest to the labour market. By default, this prioritised demographic is dominated by people who have a borderline/ mild learning disability, or impairments, rather than overall difficulties with learning new skills and communication. Further, groups considered to be 'at risk' or vulnerable to social exclusion, such as young people classed as not in education, employment or training (NEET), are all absorbed within this targeted employment support. Similarly, people with mental health issues are also captured within this grouping.

As such, this thesis explored the tensions inherently associated with the entry criteria of employment programmes for people who do have an ID and are in receipt of social care. Such programmes are often based on payment by result (PbR) models of employment activation, where a payment can only be secured on the outcome of a successful placement of paid work. As consequence,

‘creaming’ and ‘parking’ issues are endemic (Carter and Whitworth 2014). These forms of exclusion are felt through entry barriers of being under 25 years of age, and able to satisfy the pre-requisite entry criteria, based on the ability to work a set amount of hours/days as well as literacy and numeracy competence.

Those who do support people with an ID, who are in receipt of social care, have a very different experience of the employment landscape. Limited literature presented within chapter three, instead, paints a picture of negative experiences, including occupational injustice, perpetuated stigma, and negative language aimed at individuals. In response to Ineson’s (2015) quest to support someone with a complex ID engage with paid work options, ‘specialised’ employment programmes offered ‘cold calling’ supermarkets asking for work, or, considering more *realistic* ideas such as volunteering at a charity shop: thus, the 5.2% employment rate is not increasing and nor will it, given existing arrangements (diagram in appendices two).

The early part of this thesis unpacked theoretical considerations to contextualise both the historical and contemporary position of ID. Here, with a broader awareness of societal exclusion, marginalisation, and discourse, I explored how historical policy and practice *treated* people with an ID, through medicalisation and pathologising a disability that, in itself, is not a medical condition. Theoretically, the position of supported employment has similar contours to the concepts of social role valorisation (SRV) and the principles of normalisation, so dominant within the ID story. Rooted in this context, I explored how notions such as these make assumptions about what *normal* is perceived to be, by the promotion of principles that people with an ID should strive to be as ‘culturally normative’ (Wolfensberger 1972: 28) as possible by occupying more socially valued roles, such as having a job. These notions were allowed to flourish, due to a lack of influence from the social model of disability for people with an ID.

Today, people with an ID occupy a paradoxical role, whereby capacity is consistently called into question, while, simultaneously, the individual should be striving for autonomy. Here, this thesis engaged with a broader connection to employment policy, and its interplay with concepts of citizenship. Running parallel to the specific ID policy agenda is a wider relationship with the welfare-

to-work trajectory. As such, a recurring theme threaded throughout this study, is the key neoliberal tenets of choice, freedom, responsibility, and individualisation, which are weaved throughout the fabric of modern welfare states, to the extent whereby citizenship attainment and waged work have become interwoven.

The individualised activation of the welfare-to-work agenda is at the expense of the demand side structural barriers to work – that is, job availability and discrimination which cannot be controlled by the individual (Patrick 2014). Further, strengthened by the transfer of individuals from unconditional welfare support (Income Support) to conditionalised assistance (Employment Support Allowance), the attachment of welfare benefits to employment and models of citizenship, is problematic. While liberal citizenship contests traditional dominant images of disabled people as being passive welfare recipients, the transfer of power from the state to the citizen, individualises social problems. Here, the individual experience of marginalisation, alienation, and social exclusion is personalised, by the assumed responsibility of someone's own welfare, through paid employment.

However, chapter three also explored how, even with these changes in status and legislation, the majority of people with an ID are still placed within a dependent, devalued narrative. As Goodley (2014) reminds us, the attraction of normative desires to aspire to work readiness within the neoliberal agenda and models of citizenship, are troubled when a person needs help and support to communicate and to be a part of their community. This discussion was extended by exposing how the underpinning ideology of supported employment lacks critical engagement. For, supported employment makes positive assumptions around what work means to individuals, when the reality may not fit with such assumptions. This, then, offered the justification to explore such notions and ideas through my empirical research.

Drawing on methods aligning to critical ethnography that seeks to contribute to social change, observations from a job club, specifically set up to support people with an ID engage with work preparation, addressed a *what it is* and *why we do it* research position, by unpacking the nuanced and multifaceted motivations to

seek employment, and, in turn, the consequences of such decisions. In addition, three different sites of data collection were accessed to complement the ethnography. The Roasted Bean, Power, and contributions from Bob, a work manager from a support provider, all differed in their geographical location, engagement with employment preparation, and perspectives on mainstream versus segregated work activities.

The data-driven analysis began by connecting how job seekers at Green Meadow experience employment activation policy. Here, the (un)intended consequences of employment activation were explored, exposing the tightrope that requires navigation in response to the conditionality attached to both the Work-Related Activity Group (WRAG) and Support Group (SG) of Employment Support Allowance (ESA). A particular focus, here, was on Karen's experiences of categorisation for welfare assistance and the potential conditionality of WRAG, due to her unpaid work at a garden centre. The lack of understanding by the Department of Work and Pensions (DWP) on how Karen could work in this capacity, yet was not able to seek formal paid employment, connected more broadly with the controversy associated with the binary of who is, and who is not, fit for work. Underlining these interactions is the financial implications of re-defining the binaries of such categories, as a cost-cutting exercise by the Treasury in times of austerity.

Further, chapter five also explored how, with the lack of eligibility to established sites of employment support, people such as those attending Green Meadow are being encouraged to engage with the open labour market. Here, people who are the most marginalised within the labour market are aiming to engage with paid work in settings that are not associated with the networks of established supported employment sites. Rather, people are seeking work by individually applying for vacant positions. This position is extreme. In other words, individuals that have been rejected by the specialist employment support providers (who have partnerships with large employers, models of intense support, and carved work opportunities) because they are not deemed close enough to the labour market to be likely to succeed, are in effect, encouraged to apply for vacancies where they will be competing for jobs alongside other

applicants who are not experiencing any such adverse barriers to employment. Sennett (2012) considers situations such as these, to be the 'acid of personalised competition' (p. 82). Moreover, job seekers at Green Meadow were not necessarily being provided with adequate financial advice on how paid work could affect their welfare assistance and potentially, their eligibility for social care support.

As a result of these individual and structural barriers, chapter six framed the data analysis through Goffman's 'cooling the mark' (1952) concept. Here, the conduct and practices of Sally, the manager at the job club, aligned to the strategies offered within Goffman's concept. By drawing significantly on Clark's (1960) interpretation of the framework, I showed how, in essence, job seekers were cooled out, accepting volunteer and unpaid work as a work-like alternative to paid employment. Individuals were encouraged to detangle their involvement from notions of paid work, and instead, accept their lower position in the economic market and, in society. This reframing, however, had tensions. First, it distorted the understanding of what work is for the job seekers, when ideas around becoming 'someone' were linked to work not equating to financial reward. Secondly, it began to unpack a non-universal understanding of wages. The lack of knowledge/awareness/appreciation of the protective employment mechanisms, such as the national minimum wage is nuanced and complex when intertwined with eligibility for welfare assistance. Finally, there were tensions for Sally to negotiate since she had to maintain enough interest in the job club to justify its running. As such, theoretically, Goffman's cooling out concept did not fully account for the experiences at the job club. Instead, I extended this concept by suggesting that these strategies at play are fluid and fluctuating dependent on their deployment and context.

To further unpack this nuanced and complex data in a way that allowed for the process as a continuum, Berlant's theoretical concept of 'cruel optimism' (2011) was introduced in chapter seven. Rooted in critical studies drawn from race, history, and English literature, the fallacy of paid work can be explored. In this context, I captured how work was not only an aspiration but also a fantasy. While there may be occasional good stories of people with ID in employment within the

media, these stories are circulated as evidence, detached from their location from someone else's story, and shared as evidence to maintain such a fallacy. Moreover, a simple track of such good news stories, using contemporary social media, further reinforced that, in most cases, the successful individual either did not have an ID and be in receipt of social care, or if they were, it was an unpaid, voluntary position that had been secured, yet shared as a 'work' success. These accounts further reinforced the non-universal definitions of employment, yet simultaneously offered a superficial fallacy that this good life is within someone's grasp, if they simply keep trying and working harder.

The chapters, at this stage, have connected the analysis to theoretical concepts. However, it also exposed further areas requiring attention around the specificities of work. Chapter eight, then, unpacked this through exploring the non-universal understandings of work and employment. Here, the importance of work was considered, within a broader discussion on its conceptualisation, as much more than financial reward. Rather, it was considered holistically, with attention afforded to its tight linkage to identity, economic and symbolic value, and establishing the 'rhythms of our lives' (Budd 2011: 11). These accounts of why work is so important provided the backdrop in which to unpack the non-universal understanding of work and how, when it is synonymously discussed with unpaid work, the tensions of financial reward, exploitation, and morally dubious work engagement were exposed.

This non-universal understanding of work for people with an ID (and other marginalised individuals and communities) has 'historical baggage' – a legacy attributed to sheltered workshops and sites of rehabilitation that offered therapeutic wages, where 'people were so desperate for some kind of paid occupation and self-worth' (Reaume 2004: 484). While considered to be outdated, this position is not absent from the contemporary employment landscape. Sophie, Jackie, Tara, and Karen all experienced morally dubious work, that, under scrutiny could be considered to be exploitation. Moreover, broader experiences from participants at all of the complementary research sites were able to resonate and engage with such discussions. Yet, the confusion and oversimplification of the paid/unpaid work binary were only identified at the job

club some eight months after it was established. This position was reinforced through nuanced conversation and acts of discreet disablism, whereby paid opportunities were not available. As Tara commented, *'they won't pay us. All the other staff get paid there, but for people like us, don't get it [paid]'*. Yet, job seekers continued to be encouraged to seek paid employment. As such, the two theoretical connections were combined to consider this a moment of 'cruelling the mark'.

Chapter nine considered how this employment landscape is context-dependent. When 'token pay', as in, small therapeutic nominal sums, were offered at The Pop-up Café and The Roasted Bean alike, it was perceived as an opportunity to offer a work-like situation rather than as a form of exploitation. These accounts differ from those associated with profit-making organisations, where work value is extracted for a profit to the company. Moreover, I extended this analysis by offering alternative routes for the future of work for people with an ID in receipt of social care. While the future trajectory of employment policy is set on a path of uncertainty, grass-root activists are sketching out ways *around* policy. These ideas vary – from small traineeship programmes that do not address issues around national minimum wage, to crafting identity in social enterprises, where such establishments offer the opportunity for people with an ID to be treated as an equal.

Chapter nine also included broader examples from elsewhere. The call to re-design the social care system by reallocating social care funds to inclusive employment sites from O'Shea (2017) is radical, yet its point of departure is profound. This shift in the conceptualisation in how social care is administered and delivered, to allow for a redistribution of funding, offers space for opportunity to actively co-create service delivery. These examples are all difficult to navigate through policy, yet they do offer the opportunity to work the spaces around neoliberal capitalism (Bates et al. 2017). As such, consideration is also afforded to exploring alternative contributions of cooperation, value, and recognition by the state that people can make contributions to the fabric of society, by weakening such fixed conceptualisations, based on economic worth.

Moreover, chapter nine demonstrated fundamental principles, not necessarily explicitly linked through employment research, yet evident within the data collection – namely, the importance of collectivism. Networks, support, and friendships, and the opportunity to feel connected, are weaved throughout the accounts offered by the job seekers and complementary data sites alike. The job club evolved into a site of collective activity, replacing other such spaces that had been lost through the closure of day centres and a lack of funding through measures of austerity. Job club became a hub, an opportunity to meet and socialise for people often experiencing social isolation. Here too, Sally as the manager regularly adopted a nurturing role, such as reminding job seekers to wash their uniforms. It is unfortunate, that the only space afforded for this is under the premise of a job club, operating within the boundaries of employment activation and labour markets.

Contributions

This thesis has made four contributions by locating the ideas associated with work to a broader discourse of why work matters. First, by contributing to rethinking the concept of work. Work is often ‘reduced to oversimplified tenets of work as a necessity or a source of income’ (Budd 2011: 13). However, in contemporary society, this narrow explanation is insufficient, with its boundaries collapsed (Budd 2011). Instead, offering a broader framing of work has afforded the space to explore the wider complexities of the ethical and moral issues associated with such conceptualisations. Moral elements, such as these, have, according to Honneth (2012), ‘all but disappeared from the theoretical vocabulary of sociology’ (p. 98). By avoiding a simplistic interpretation of work where it is only synonymous with paid employment, and a work/non-work, paid/un-paid binary, and instead aligning to the notion of work being undertaken for either economic or ‘symbolic value’ (Budd 2011: 2), work is not framed solely as a commodity. Rather, work is framed as fundamental for identity (Jahoda 1982) and essential for the human experience (Budd 2011), in all its forms.

As such, wider considerations of citizenship and its changing nature and relationship with the state require attention, especially for those who are unable

to attain paid work. Times of welfarism and state protection have diminished, there is now a race to define people by need, through the deserving and undeserving categorisations. We live in a neo-liberal society, yet this does not necessarily define the future. This thesis contributes to such a discussion, by strengthening the voice from the experiences of marginalised, often invisible people, to support a reframing of active citizenship that refutes its simple attribution to paid work. In this sense, the positive, idealistic notions of work are also refuted. As this study has demonstrated, work is not always good and nor does it always live up to its neo-liberal promise. For, there is a 'gulf between social reality and utopian expectations' (Honneth 2012: 57) whereby theory is so distant from the real conditions of work, which has resulted in the 'acid of personalised competition' (Sennett 2012: 82), yet, to be without it, lies 'internalised rootlessness' (p. 257). These debates are the crux of this thesis, that is, exploring the grey (Berlant 2011) and the grey spaces between work and unpaid work.

The second contribution of this thesis is the benefits of interdisciplinary thinking. An interdisciplinary research approach can, as this study has demonstrated, enhance the breadth of discussion. This thesis has drawn upon ideas and concepts from disability studies, critical disability studies, medical sociology, social policy, sociology, history, critical race studies, work and employment, and citizenship literature, without expressing an alliance to one or more such positions, to offer the fullest picture of a complex, nuanced, and context-dependent social situation. This was a purposeful intention – for work is not solely a commodity experienced through productive effort with tradable economic value. It is also how we experience our social selves and locates us in the social world (Budd 2011).

Taken together, this instead offers a broader and more diverse intersectional approach, where work in this frame can engage with conversations and debates around how inequality, marginalisation, and exclusion is experienced by different social groups. For example, drawing on multiple lenses to explore (dis)ability illuminated the intersections between the social and the self, rooted in its historical and political context. As a consequence, thinking across

boundaries and drawing insight from multiple disciplines has enriched the conversation and offered a unique and comprehensive understanding of the observed.

The third contribution of this thesis is addressing the theoretical themes and connections gathered from the research sites, to inform and extend two key academic concepts. First, through Goffman's much neglected 'cooling the mark' (1952) framework. Here, I applied the cooling strategies in an empirical context to understand how current welfare and employment policy is systematically unjust against disabled people. Moreover, I modified Goffman's static strategies by demonstrating how they can also be fluid and fluctuate, depending on the context. Next, the theoretical offerings from Berlant's (2011) 'cruel optimism' extended this inquiry by encompassing a broader, ideologically driven position bound up in critical studies exposed 'the good life' as a fallacy, and out of reach for most people. In connecting these two differing perspectives of cooling the mark and cruel optimism, together, as a continuum, the complex and nuanced processes at play could be explored, to sketch out, *cruelling the mark*.

The final contribution of this thesis has been to draw attention to the under-theorised notions associated with therapeutic pay, and how this is still prevalent within the learning-disabled community. This is in contrast to many existing accounts which consider this to be outdated. In this sense, people are 'falling through the cracks' (Berlant 2011: 63) of employment protection, in search of attaining the status of a worker, and a 'legitimate place in the world' (Berlant 2011: 162). This legitimacy is conceptualised by individuals undertaking work in its tightest sense of the word yet being rewarded in its loosest sense. That is, work is undertaken for financial gain, albeit often under the national minimum wage threshold, and then rewarded for all its additional benefits of conceptualisation, such as to structure a day, increase social inclusion, and to meet new people.

Moreover, I have filled an academic research gap. McGlinchey et al. (2013) called for further exploration into perceived employment, and in response, my findings demonstrate that not only can individuals perceive themselves to be in employment when they are not, but that people also do not share a universal

understanding of what work is. Further, this position has also contributed to Keleman et al.'s (2017) call to expand research into what does and does not constitute work. My findings extend this noted absence, to account for token, nominal work that is not afforded space within contemporary scholarship and discourse.

What next?

I would not be so bold as to suggest that this thesis can claim to offer 'solutions' to such complex and nuanced situations – and my intention is not to propose specific policies designed to improve practice. Rather, the aim here is to offer different options and ideas, drawn from my research, that demand further attention. This study has highlighted the need to clarify definitions and recording practices within local authorities to ensure data collection is consistent across the UK. Clarification on what counts as employment for recording purposes could significantly alter the current statistics. Moreover, definitions between policy and practice require attention, particularly within sites of employment activation that draw on differing definitions of 'learning disability' that result in further exclusion.

More broadly, while national frameworks support employment as the route to secure active citizenship, at a local level, the structure of local governance does not support the labour market inclusion trajectory. There are isolated examples of local authorities supporting such innovation, yet, most work options are funded by securing grants, both at a local and national level. For localities that do not have links to external organisations, there are few pathway options for young adults with an ID and these are centred around day opportunities and leisure. As such, young individuals are generally 'placed' with support providers, or connected to the third sector, and are then often set for a life in which they rely on welfare. In other words, the rhetoric of policy is not supported at ground level sufficiently and leaves people underserved. Thus, welfare dependency is perpetuated and reinforced for people who have an ID.

More specifically, shifting the ethos of service design and delivery will go some way to conceptualise some of these considerations. A local transformation project based on co-productive research methods to redesign service delivery is

currently under development in Torfaen, South Wales, based on the Gwent Better Future Lives (Torfaen People First, Barod CIC and Wright 2017) and A Good Day (Barod CIC and Torfaen County Borough Council 2020) reports. Here, local learning-disabled people have been employed as co-researchers to explore new opportunities, including work, education, learning, and leisure, and to evaluate (and hold to account) the implementation of the project's recommendations by the local authority.

Other research that this thesis readily lends itself to more broadly is around the national minimum wage and employment policy. Within my research, there has been a focus on the national minimum wage legislation and its mechanism to act as a barrier to employment inclusion for people who are not necessarily able to satisfy the breadth of a job description or work with lower rates of productivity. While an exemption to the national minimum wage is not the solution, and caution should be applied to any such notion as a simplistic response to policy, a wage subsidy could be a potential route to increase the presence of this demographic in the workforce. This debate would go some way to attend to the responses on the nature of work and its relationship with pay.

Moreover, this option would support grass-root initiatives that do not follow the supply side employment position taken by the UK. Research in this area is under-theorised, yet topical. There is an opportunity here to research how this could be implemented, without additional cost to the state, through a redistribution of social care funding. Here, highly innovative models of reorganising social care provision within a model of co-working with support workers, rather than individuals traditionally being 'cared for', could offer a dynamic and unique research opportunity. As such, there is scope to reduce the exploitative practices currently prevalent within the learning disability community, which sees people working unpaid for many years, in the hope of one day securing paid employment. On a similar research trajectory, this thesis lends itself as a springboard to unpack notions associated with a universal basic income. A model of universal income could alleviate the interwoven connection between citizenship and the expectation to engage with waged work to be considered a full and active citizen. With pilot programmes in parts of Scandinavia and Canada

currently under evaluation, this research area is fresh and topical within academia, social policy, economics, and employment activation.

Additionally, there is space to further the debate and contribute to the theorising of the citizenship framework. Patrick (2017) calls for a challenge to the assumed relationships between responsibility, inclusion, independence, and participation in the paid labour market. Instead, she suggests a more inclusive understanding of citizenship needs to be broadened out, taking into consideration other definitions of 'work' that can assist people in fulfilling their citizenship responsibilities, such as volunteering, informal aid, and support. Patrick also calls for the 'welfare dependency' notion to be replaced as a descriptor that is only ascribed to people claiming out-of-work benefits, for as she explores, we are all dependent on various forms of social welfare at one time or another. Furthermore, Patrick (2017) aligns with Dean (2004) and Williams (2012) in calling for the 'mythical' (p211) independence term to be understood instead, as interdependence, as a positive feature of the human condition and as the basis for all human interaction (Patrick 2017).

A final note

Drawing on labour market policy, underpinned by citizenship theory, exposes the relationship between the political trajectories in the UK, and its impact upon the learning-disabled community. In this light, inequality has illuminated difference. By disrupting and troubling the ease at which employment services are considered to be the *best* way for people with an ID to become *normalised*, my research exposed some of the highly exclusionary practices that do not allow for people, who do not fit neatly into the boxes and categories (Bowker and Star 2000), of being close to the waged labour market.

People with an ID, who are in receipt of social care, and want to engage with work, do so through an 'illusion of inclusion' (Clegg and Bigby 2007: 796). Here, good news stories of people being successful with employment activation are detached from their context and then shared as a positive experience. Yet, for the most part, this experience is often unpaid work, masquerading as employment. Or, where successful work is attained, it is often secured by people who do not fall into the demographic of needing social care. Instead, people here, are usually

considerably closer to the labour market. Moreover, the normative assumptions of work are continually offered as a route to the 'good life'.

Instead of reinforcing such fallacy, this thesis aimed to consider how it is reasonable to expect people to not enter such personalised and individualised, insecure, and precarious work options. These options are based on principles of normalisation, with little consideration or regard to understanding why paid work is the default – that is, why this is a normative position associated with self-worth and active citizenship. Rather, we need to consider other sources and routes to non-competitive recognition, cooperation, value, and social justice. Most importantly, I have shared the 'other voices' so often absent from social policy to demonstrate how multiple realities need to be recognised and better understood, in short, to recognise how individual labour market 'failure' is not simply someone's own fault.

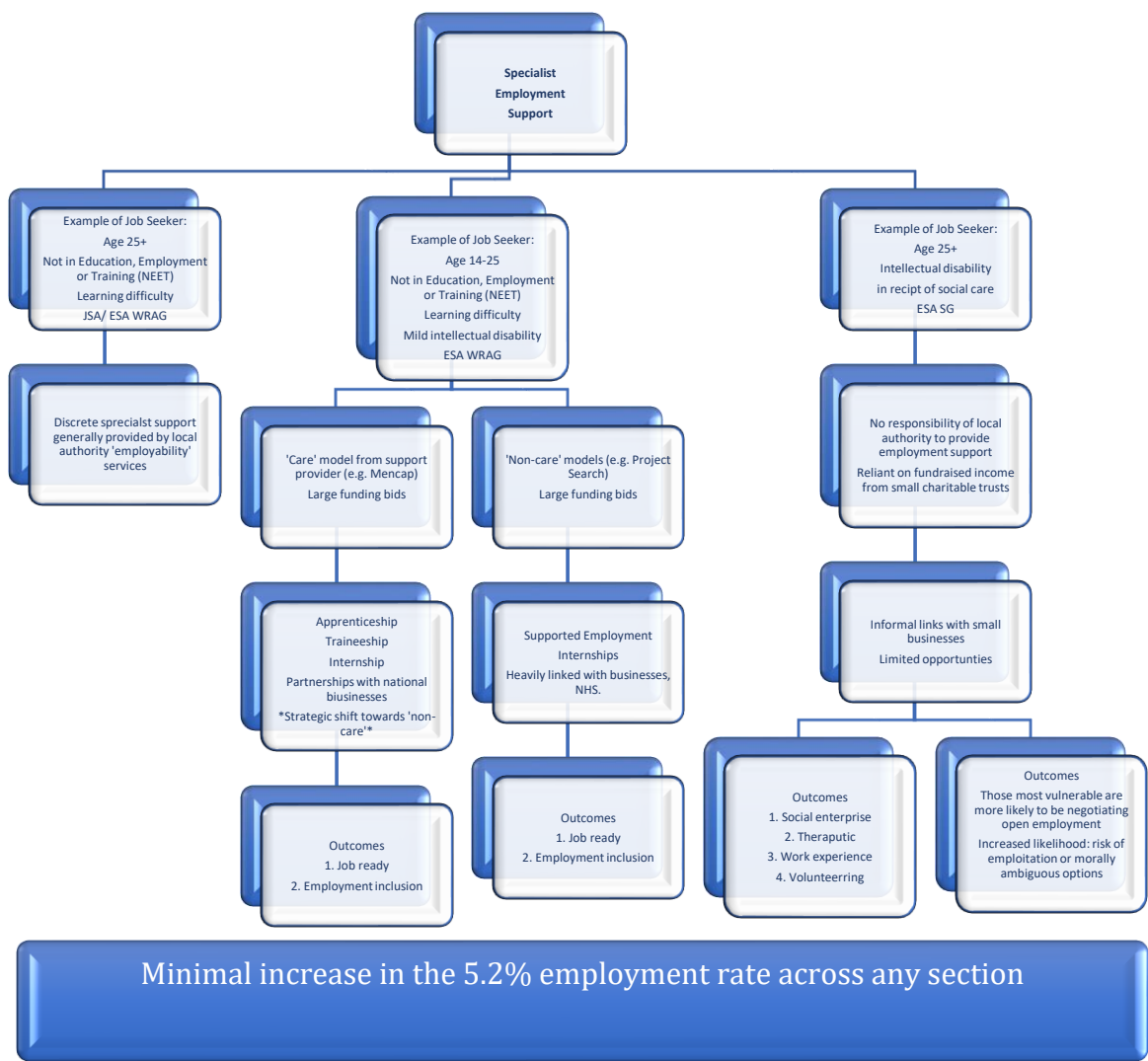
Appendix 1: Analysis of #ldworkweek 2018.

#LDWorkWeek 5th - 11th November - 'good news stories' (set up by Mencap) - showcasing/sharing/promoting good practice. Other organisations encouraged to contribute										
Support org.	Employer	Employer description	Job role	Route	Paid?	Increasing 6%?	Employee	Adaptions	Comments	
1	Mencap	Sewell FM	Partnership (business/charity)	Cleaner	8 week trial	Yes	Yes	coordination	Visual	Employer won Impact on soc.
		Aim- individuals from Mencap in every cleaning team across Yorkshire					disorder/autism	instruction cards		award for benefit to soc. Social responsibility initiative
2	Mencap	Financial times	Corporate	Internship	Unpaid	No	? NEET			2 case studies, second one NEET
3		Lead the Way project	Service provider (day centre?)	Project	Application	Yes	Yes	Roy (see detailed sheet)		Post is within Cloverleaf Advocacy. Not for profit org. Supported by Council, NHS clinical commissioning and
4	Mencap	Young Vic theatre	the NHS plan to employ more people with LD. This ensures they have a more inclusive workforce...thank	Usher	Traineeship	Unknown	Unknown	Young person		
5		Gig Buddies	Part of Stay Up Late org: "Grass roots charity"	Quality Checker		Unknown	Unknown			In post for 2 years
6	ARK (previously Action for Kids)	Savers Health & beauty (shop)	Business	Shop Assistant	Unknown	Paid	Unknown	Young person Under 25		
7	Mencap	Me and My Body		Co-trainer			Unknown	Unknown		
8	Mencap NI	McDonalds	Business	Assistant	Employability	Yes	Yes			"I was losing hope of paid work, because I had never had a paid job. I now feel proud of myself for how far I have come"
										Project - funded by European Social Fund; Dept. of Economics; Dept. Community
9	Mencap	Mencap 'Treat Me Well' campaign	Charity status	Campaign Assistant		Unknown	Unknown	Unknown		
10		KataKata	Independent café	kitchen	Unknown	Unknown	Unknown			"I am so grateful finding this opportunity"
11		Ignition Brewery	"More beer, more jobs"			£9.70ph	Yes	All in receipt of social care		See further information
			See further information							
			A brewery with a difference							
12	Mencap	Asda	Business			Yes	No	JSA/ESA claimant		
										Building Better Opportunities programme (Big Lottery)
13	Mencap	British Heart Foundation	Charity status	cleaner	Work experience	No	No			"a great little cleaner in the mak
14	Teamwork Trust	Nursery	Private	Assistant	Work experience	Yes	Unknown			"having an extra person has really helped us"
		Screen workshop	Unknown		Work experience	No	No	Unclear		3 year programme; various volunteering
		Unknown			Work experience	No	No	Building Better Opportunities programme (Big Lottery)		
15	Mencap	Local library			Work experience	No	No			
	"interns & Outcomes"									

16	Mencap	Fortis Living	Platform housing group		Work experience	No	No			Helping with 'Music Monday'									
17	Mencap	Mencap		Intern	Work experience	No	No												
18	Mencap		Volunteering UK visited the workhub group		Work experience	No	No			"volunteering helps us learn new work skills, gain experience and give back to your community!"									
	"interns & Outcomes"																		
19	Mencap	NHS	Kidderminster Health Centre	Waiting room coordinator	Placement	No	No												
20	Mencap	Bristol Museum		Assistant	Unknown														
	Support org.	Employer	Employer description	Job role	Route	Paid?	Increasing	Employee	Adaptions	Comments									
21	Mencap	Retail				Yes	Unknown												
22	Mencap		Community Project	Litter picking		No	No												
23	Voyage Care	Hickley Day Care	Support provider	Admin	Volunteering for 'quite a while'	Yes	Yes			Ben is one of three people who have been volunteering here for more than 3.5 years. He has a 10 hour per week contract "Started to save his wages to buy little treats"									
24	Mencap	NHS	Dental practice			Yes	Unknown	NEET?		colour coordination for equipment Help with remembering security codes									
25	My Ark	Bike Shop			Looking for a placement	No													
26	My Ark					Yes	Unknown			I have LD's									
27	Advert	The NHS	The NHS plan to employ more people with LD. This ensures they have a more inclusive workforce...thank you NHS NHS is using Project Search - this is based on internships and work experience																
28	Mencap	Hotel	Business		Internship	no	no			Setting up a boardroom									
29	Mencap	Café			Internship	no	no												
30	Mencap	The Range UK	Retail	Sales ass		Yes	Unknown												
31	Mencap	Mencap		Office work	Volunteer	No	No												
32	Mencap	Mencap		Receptionist		Yes	Yes												
33	Foxes	Hotel			Work experience	No	No												
	Academy																		
34	Mencap	Advert	92% of customers interviewed in a large study felt more favourable towards companies that hired people with disabilities. What's more, 87% specifically agreed that they would prefer to give their business to companies that hire people with disabilities Stats for general disabilities, not LD (LD included but often not referred too in disability employment policy)																
35	Mencap	A clean Sweep	Cleaning cooperative ran by people with LD		Placement	No	No												
			Grahame Morris - Labour MP "1 in 50 people in the UK have a LD but shockingly, just 6% are in paid employment" - incorrect stats																
36	Mencap	Prime People		Business Supp	Traineeship	No	No												
37	Mencap	Sainsbury's	Retail			Unknown	Unknown												
38	Mencap		Photography exhibition			Unknown	Unknown												
39	Foxes	Hotel			Work	No	No			"I'm good at working behind the bar & I can make drinks for guests. I made a gin and tonic . Work is really important to me and I'm getting going to get a paid job after"									
	Academy				Placement														
	Support org.	Employer	Employer description	Job role	Route	Paid?	Increasing	Employee	Adaptions	Comments									
40	Mencap	Debenhams café	Business	Assistant		Yes	Unknown												
41	Mencap	NHS	Newham Hospital	kitchen		Unknown	Unknown												
42	Mencap	Council	LA	Grounds Maint	Placement	No	No												
43	Mencap	National Trust	Charity status		Placement	No	No												
44	Mencap	Clintons cards	Retail			Yes	Unknown												
45	The Advocacy Project			Trustee		Unknown	Unknown			More barriers to negotiates (CEO)									
46	Mencap	Seewell FM								Since 2017, 30 people have been helped with 5 receiving paid jobs so far									
47	24/7 & Mencap	Distribution	Disability confident	Warehouse	Working interview	Yes	No			Unemployed'									Mencap provide the job coaches
48	Mencap	Positive futures	Learners group	Litter picking		No	No												
49	Mencap	Mencap		Receptionist	Team	No	No												
					apprentice														

Appendix 2: Employment Diagram.









Employment Support



Minimal increase in 5.2% employment rate across any section

Appendix 3: User friendly participant information sheet.

Research Project: The Impact of Work

My name is Kim Dearing.	
I am a researcher at Cardiff University. I will be at job club for a year.	
I am doing a project about work, especially paid work. I am interested in finding out why paid work is important to you.	
If you are happy, I would like to record what happens using a voice recorder.	
The voice recorder saves me having to write lots of notes in the club. After, I can listen back and then write my notes.	
When I write my notes up, I will not use your real name.	
It is fine if you change your mind and decide you don't want to be involved in the research.	
When I have finished my research, you can have a copy of what I found out.	

If you have any questions or worries,
please ask!



Appendix 4: Further information for participants.



Research Project: The Impact of Work

Some questions you may have for me:

Why is this research being done?

My research is funded by the Economic and Social Research Council. I want to understand how you feel about work, especially paid work. I hope to use my research to make it easier for people to find work in the future.

How will the research be done?

I will come along to the job club for a year. I will watch and listen to what people say about work.

With your permission, I will voice record what happens. Then I will type up what has been talked about. I will change your name so no one outside of the group will know what you have said.

Sometimes, I will ask if I can chat some more with you. If I do this, I will ask you to sign a form like this one again.

What will happen to the information from the job club?

The research will be written up as a PhD thesis (like a short book). I will also write a report. You can have a copy of this. The research may also be published in journals and books. No-one's real name will be used in any of my work.

Who am I?

I am a fully trained social researcher at Cardiff University. Before this, I worked for a long time helping people who needed support. The reason I am doing this research is because paid work is very

hard for people who need support to find and I think that this is unfair.

Do I have to take part?

Not at all! Even if you agree to take part to start with, you can change your mind. You can also decide to take part in some, but not all, of the research.

Please speak to me if you have any worries or questions about the research!

Appendix 5: User friendly consent sheet.



Research Project: The Impact of Work Consent sheet

I understand the information sheet for this research project	YES / NO
I understand that I do not have to be involved	YES / NO
I agree that I would like to be involved in the research	YES / NO
I understand that I will be voice recorded at the job club	YES / NO
I understand that I can ask not to be involved in the research at any time	YES / NO

My name: _____

My signature: _____

Date: _____

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