

**THE LIVED EXPERIENCE OF WORK  
FOR PEOPLE WHO HAVE AN  
INTELLECTUAL AND  
DEVELOPMENTAL DISABILITY**

A thesis submitted in partial fulfilment of  
the requirements of The University of  
Brighton for the degree of Doctor of  
Philosophy

**Diana Ramsey**

**March 2020**

## **Abstract**

This doctoral research thesis explores the work-related experiences of people with intellectual or developmental disabilities. Akin to the experience of people with other types of disabilities, the barriers are many and varied, including social, organisational and personal factors. The political and policy environment of the United Kingdom promotes employment for all. However, existing literature suggests policy failure as employment rates are low for people with intellectual or developmental disabilities. Furthermore, their perspectives and 'voices' appear only fleetingly or are absent in the literature reviewed.

This research illuminates the lived experience of six people with intellectual or developmental disabilities engaging in employment. It provides insights into the employment support for people with intellectual and developmental disabilities relevant to their support networks, employers and professionals (including occupational therapists). Using a hermeneutic phenomenological methodology, an exploratory inclusive research method was applied, involving a creative collaborative partnership between the research collaborators, researcher and a photographer. Six work stories composed of narratives and visual images were created and five collective narrative frames emerged through this collaboration. These included: 'the quest to do', 'navigating bureaucratic seas', 'finding a good fit', 'the forging of identity' and 'finding both friend and foe'.

The findings indicate that people with intellectual or developmental disabilities have important stories to tell about their journeys towards and within paid employment. Their stories reveal the extensive barriers they faced, whilst recognising that people could experience a good, as well as a poor fit with their work. This research recommends that skilled personalised support and a positive social working environment is crucial to providing a good fit for such individuals in employment. The creative collaborative partnership was found to be a valuable innovative method in supporting collaborator involvement and inclusive research principles.

# **Contents**

Abstract	2
Contents	3
List of tables	6
List of illustrations	6
List of reflexive accounts	7
List of appendices	7
Acknowledgements	9
Author's declaration	10

## **Chapter 1. Why work?**

1.1 The research aims and focus	11
1.2 The centrality of voice and the researcher position	14
1.3 The research problem in practice	18
1.4 The research methodology and methods	21
1.5 Thesis overview	23

## **Chapter 2. Work for people with intellectual and developmental disabilities: a literature review**

2.1 Introduction	26
2.2 The focus on work: the policy context	27
2.3 The role and function of work	32
2.4 The factors that help people find and retain work	41
2.4.1 Predictive factors for the employment of people with IDD	42
2.4.2 Outcomes of being in employment for people with IDD	49
2.4.3 Research in collaboration with people with IDD	52
2.4.4 Work-related occupational therapy research with people with IDD	55
2.5 Summary	59

## **Chapter 3. Methodology**

3.1	Introduction	61
3.2	Methodological considerations	61
3.2.1	Inclusive research	61
3.2.2	Qualitative methodological considerations	64
3.3	Phenomenology	67
3.4	The research position	72
3.5	Hermeneutic phenomenology: the research application	75
3.5.1	A commitment to the use of interpretation	76
3.5.2	Reflexivity: reflecting on the researcher's involvement	79
3.5.3	Beyond science: towards the humanities	81
3.6	Communicating the lived experience: narrative and visual methods	81
3.7	Summary	85

## **Chapter 4. Method**

4.1	Introduction	87
4.1.1	Research aims	87
4.2	Phase 1: research development and recruitment	89
4.2.1	Advisory group involvement	89
4.2.2	Recruitment of photographer	90
4.2.3	Ethical considerations	90
4.2.4	Collaborators' recruitment	91
4.2.5	Consent considerations	92
4.2.6	Collaborators' payment	95
4.2.7	Research funding	95
4.2.8	Academic supervision	95
4.3	Phase 2: data gathering	96
4.4	Phase 3: data analysis	99
4.5	Phase 4: data dissemination	103
4.6	Summary	103

## Chapter 5. The work stories

5.1	Introduction	105
5.2	The data gathering process	106
5.3	Jo's story: a cleaner and café worker at a family country park	112
5.4	Ruth's story: an administrator in the public sector	116
5.5	Mark's story: an assistant caretaker, groundsman and volunteer	127
5.6	Tabitha's story: a school catering assistant	134
5.7	Jennifer's story: a waitress, charity shop worker and cleaner	144
5.8	Kenneth's story: a cleaner	150
5.9	Summary	162

## Chapter 6. Work[able]. The quest for paid work

6.1	Introduction	163
6.2	Applying the hermeneutic reduction	163
6.3	Five narrative frames	167
6.3.1	The quest 'to do'	167
6.3.2	Finding 'a good fit'	170
6.3.3	Navigating bureaucratic seas	174
6.3.4	Finding both friend and foe	178
6.3.5	The forging of identity	181
6.4	The group meeting	184
6.5	Summary	187

## Chapter 7. Discussion

7.1	Introduction	188
7.2	'Understand me'	189
7.2.1	Beyond self-identification: the personal is political	189
7.2.2	Work[able]	198
7.3	Belonging versus stress and striving	201
7.3.1	The nature of doing	201

7.3.2 A good fit: belonging	205
7.3.3 A poor fit: stress and striving	208
7.4 Redevising work and employment support	212
7.4.1 The contradiction of complex employment support	212
7.4.2 The importance of social factors in supporting employment	218
7.5 Summary	223

## Chapter 8. Conclusion

8.1 Introduction	225
8.2 The contribution of the collaborators' work stories	225
8.3 The contribution to occupational therapy practice	231
8.3.1 My Work Plan: an assessment tool in draft	233
8.4 The contribution to policy and service re-design	240
8.5 The contribution to inclusive research methods	243
8.6 The limitations of the research	246
8.7 Summary	250

<b>References</b>	252
-------------------	-----

## List of tables

4.1. Research process overview	88
5.1. Data gathering process and collaborator demographics	109
6.1. Analysis overview	165

## List of illustrations

Illustration 1. <i>Here I am: understand me</i> , Mencap media campaign, (October 2016).	12
Illustration 2. 'Will Britain get through this recession?', ' <i>I signed on but they would not give me nothing</i> ', 'I want to care about people, not about my job', <i>Signs that say what you want them to say and not signs that say what someone else wants you to say</i> , by Gillian Wearing (1992-93).	15

Illustration 3. The job story map	97
Illustration 4. A day in my working life	115
Illustration 5-9. Work plan confidential	122
Illustration 10-15. Working man	131
Illustration 16-18. Never think doing a job is easy	142
Illustration 19. Waiting to bloom	149
Illustration 20. Working with an analytical eye	160
Illustration 21. Kenneth self-portrait	161
Illustration 22. Occupational adaptation	194
Illustration 23. Visual representation of the model of occupational therapy as a complex, dynamic process	196
Illustration 24. My Work Plan: an assessment tool in draft	236

## **List of reflexive accounts**

Reflexive account 1. Literature review	39
Reflexive account 2. Methodological considerations	71
Reflexive account 3. Recruitment criteria	92
Reflexive account 4. The job story map	98
Reflexive account 5. Constructing the narrative	101
Reflexive account 6. Creative collaborative partnership	108
Reflexive account 7. The intersubjective experience	111
Reflexive account 8. The hermeneutic circle	164
Reflexive account 9. Fusion of horizons: Jennifer	170
Reflexive account 10. Fusion of horizons: Ruth	184
Reflexive account 11. The group meeting	193

## **Appendices**

Appendix 1. Research letter of invitation	274
Appendix 2. Research fact sheet	275
Appendix 3. Research consent form	283
Appendix 4. Dissemination activity	886
Appendix 5. The literature search summary	287
Appendix 6. University of Brighton ethics approval	293
Appendix 7. UKOTRF grant acceptance letter	295

Appendix 8. Semi-structured interview	297
Appendix 9. Initial interview 1 <sup>st</sup> edit – example	299
Appendix 10. Job story map – example	309
Appendix 11. Crafted narrative with link words – example	310
Appendix 12. Employer consent form	317
Appendix 13. Easy read findings summary	319

## **Acknowledgements**

Thank you primarily to the six research collaborators, named in this thesis as Jo, Ruth, Mark, Tabitha, Jennifer and Kenneth, for sharing their stories. It has been a privilege to listen to their experiences and witness their courage and resilience.

Thank you to their families and their employers who have supported their engagement in the research.

As with any undertaking like this there are those who provide incredibly valuable support. Thank you to the local self-advocacy group for helping me in the early stages of forming my research idea and materials. Thank you to the supported employment provider and work consultants for being partners in the recruitment process for this research. Thank you to Sharon Boothroyd, photographer, for her creativity and curiosity in engaging fully both with me and the research collaborators.

Thank you to my academic supervisor's Dr Josh Cameron and Mr Bill McGowan for their foundational encouragement and tireless support throughout this research journey. Thank you to the Royal College of Occupational Therapists for the Research Career Development Grant that has supported this project financially. Thanks also to my employer Kent Community Health NHS Foundation Trust and particularly my manager Matt Dodwell for being supportive of my PhD studies. Finally, thank you to the family and friends who have encouraged me, specifically my partner David and daughter Evie, for walking alongside me.

## **Declaration**

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree and does not incorporate any material already submitted for a degree.

Signed:

A handwritten signature in black ink, appearing to read "John Doe".

Dated: 16<sup>th</sup> March 2020

# **Chapter 1. Why work?**

## **1.1 The research aims and focus**

The focus of this thesis is the experiences of people with intellectual and developmental disabilities (IDD) in paid work. This is a phenomenological study that was conceived in my occupational therapy practice and in the healthcare environment impacting the lives of people with IDD. It was honed through the first year of my PhD studies in conjunction with an advisory group of people with learning disabilities. A hermeneutic phenomenological approach was applied, involving the adoption of a phenomenological attitude to data collection and a reduction in analysis, together with my reflexive account as researcher. A narrative and visual exploratory method was used, forming what is known as a creative collaborative partnership between the research collaborator with an IDD, the photographer and myself as the researcher. These partnerships supported the research aims by maximising the collaborators' involvement in the data gathering and analysis, as well as supporting the communication of their lived experience of work as phenomena.

This chapter outlines the research aims and terminology used in this thesis, in conjunction with an overview of the background to the research. It highlights the centrality of the voices of people with IDD in the research and sets out my position as researcher. It then contextualises the research within occupational therapy practice and policy in the United Kingdom (UK), prior to introducing the methodology and method used and providing an overview of the thesis.

### **Research aims**

- To illuminate the lived experience of having an intellectual and developmental disability and engaging in paid work as a phenomenon. [L  
SEP]
- To gain new knowledge that will inform practices supporting people with intellectual or developmental disabilities in relation to employment.

In the early phase of research development, the research question emerged as 'How do people with an intellectual and developmental disability experience paid work?', with the two research aims as detailed above. Heidegger (1962) described the hermeneutic structure of the question as 'fore-conception'. He stated that when composing a question our intent in asking the question is

revealed and this is dictated by our understanding and presumptions (Heidegger, 1962). Furthermore, this intent is equally proposed to determine what we discover from our question (Heidegger, 1962). In this introduction to the research, an exploration of the fore-conception of the research question will be considered reflexively, in conjunction with a review of the political and clinical practice background to the question. Due to the importance of the reflexive position both to inclusive research and the broader methodology, I will refer to myself in the first person and have included extracts from my reflexive diary in text boxes throughout the thesis.

The process of decision making required in research has been described as similar to ‘going exploring’, in that it necessitates considering a variety of options (Finlay, 2006, p.3) equally from positions that have cultural, social and political influence or implications. One of the first decisions required in this research relates to the terminology used, namely the IDD label. This was not a straightforward or neutral term, as encapsulated in a campaign by Mencap (Illustration 1), as each community and individual makes decisions regarding the terminology used to define IDD.



Illustration 1. Here I Am: Understand Me, Mencap Media Campaign, October 2016 (Original in colour)

International terminology adopted in the academic literature is ‘intellectual disability’ and ‘developmental disability’. The terminology adopted by a leading self-advocacy group in the UK, People First, is ‘learning difficulties.’ This group believes, in accordance with the social model of disability (hereafter referred to as the social model), that it is society that is disabling rather than the impairment (People First, 2017). As there is ambiguity regarding the term ‘learning

difficulties' due to its potentially broad application, I initially adopted the term 'people with a learning disability' (LD) or 'people with learning disabilities', as these are used in national policy in the UK and in my clinical practice. A person with a learning or intellectual disability (ID) is defined in ICD-11 (WHO, 2019) as a person with a disorder of intellectual development. It is diverse etiologically, occurring during the developmental period (prior to age 18 years) and characterised by a significantly below average adaptive functioning and intellectual impairment (WHO, 2019).

I chose the term LD initially because I understood that this would be identifiable to the collaborators in the research. I also wished to conduct research with people that identified with this term, as I work as an occupational therapist in learning disability services in the National Health Service (NHS) in England. However, it became evident when I formed a partnership with the employment support provider (ESP) to recruit research collaborators that the service commissioned by the local council was for people with a learning 'difficulty' alongside people with a learning 'disability'. As the ESP did not apply rigid eligibility criteria, I extended invitations to everyone they supported to take part in the research. I subsequently used the terminology 'learning disability' within the research letter of invitation (Appendix 1), the research fact sheet (Appendix 2) and research consent form (Appendix 3). I recognised that potential collaborators might refuse to take part in the research if they did not self-identify in some respect with this terminology. During the research recruitment process, the wide-ranging nature of the collaborators' self-identification with labels relating to their disability became clear. It was therefore necessary to broaden the consideration of the literature and change the terminology to people with 'intellectual or developmental disabilities'. As I used 'learning disability' with the research collaborators and with reference to my employment, this term will be found in the research collaborators' stories and when I discuss my work. The terms learning disability/intellectual disability are also used throughout the literature review. However, at every other point in the thesis and in acknowledgement of the range of terminology used by the collaborators 'people with an intellectual and developmental disability' (IDD) has been used.

Additional decisions were required in the choice of terminology about employment structures and occupational therapy. When talking about the participants' employment, I used the terms 'work', 'job' or 'employment' and

make explicit reference to ‘paid work’. Within employment services there are a multitude of different terms used, so unless otherwise specified, ‘open employment’, ‘competitive employment’ and ‘integrated employment’ refer to the labour market for the whole population. ‘Supported employment’ largely refers to an individual gaining increased support within open employment, although some countries’ definitions vary, and this will be stipulated when it occurs. ‘Sheltered employment’ or ‘sheltered work’ describes an environment where people with IDD work alongside peers with IDD or other disabilities in an employment setting that may be subsidised, where workers may be trainees or receive minimal pay.

I will use the term ‘employment support provider’ (ESP) to refer to individuals or organisations that are established (as in the case of the provider partner in this research) to provide specialist employment support to people with an IDD. This does not include the job centre itself or support by a disability advisor within a job centre. I will also use the word ‘occupation’ as it is used in occupational therapy, to reference all activities that occupy our lives, including work (Taylor, 2017a).

## 1.2 The centrality of voice and the researcher position

Central to this research was the aim to examine and give a voice to the experience of people with IDD in employment. As will be outlined in Chapter 2, the voice of people with IDD either appears fleetingly, or is absent, in the relevant literature. The artist Gillian Wearing produced a series of artworks called *Signs that say what you want them to say and not signs that say what someone else wants you to say* (Wearing, 1992-93), consisting of photographs in which people as individuals are given control over what they want to say at a given moment (see below). I am sharing three images from this body of artwork that relate to employment, as I find them effective in communicating something individual, public, simple and yet complex when interpreted by me, as viewer, from my own social, economic and political position. The subjective (and intersubjective) interpretive stance is important in this research and will be explored further in the methodology.



Illustration 2. 'Will Britain get through this recession?', '*I signed on but they would not give me nothing*', '*I want to care about people, not about my job*', Gillian Wearing, 1992-3. (original in colour). *Signs that say what you want them to say and not signs that say what someone else wants you to say.*

The literature review focuses on research that draws on the opinions of people with IDD. I acknowledge that the information gained from these studies is not representative of all people with an IDD but is rather a reflection of the comments and observations made by those whose opinions have been collated. Similarly, just as I interpret Gillian Wearing's images from my specific perspective, the research findings are interpreted from my perspective as a researcher and as an occupational therapist who works within learning disability services. I recognise that while I have aimed to put the person with IDD and their voice on work at the centre of this thesis, my perspective as a white, non-disabled therapist will have affected my selection and observations of their lived experience of employment as a phenomenon. In acknowledgement of this, the reflexive position is important in order to ensure examination of my bias as researcher. Furthermore, the centrality of 'voice' in this research also extends to my voice and the voices of collaborators within academia and disability studies specifically. This research agrees with the position set out by Bjornsdottir and Svensdottir (2008) in their article '*Gambling for capital: learning disability, inclusive research and collaborative life stories.*' which states that 'researchers with a learning disability are often not taken seriously and non-disabled researchers tend to be met with scepticism' (p.263) within the field of disability studies. This will be discussed further in Chapter 3, Methodology.

When considering the fore-conception behind my desire to examine the lived experience of paid work for people with learning disabilities, it is relevant to note two significant national events that were formative at the time the research question was being developed. In 2007, Mencap released the report *Death by indifference*, which exposed the premature deaths of six people with an IDD in acute hospital settings in the NHS. This report shared the lives and deaths of Emma, Mark, Martin, Ted, Tom and Warren, asserting that there was widespread institutionalised discrimination in the treatment of people with IDD in the NHS. This was followed by the report of the independent inquiry into the deaths *Healthcare for ALL* (Michael, 2008) and the report of the subsequent confidential inquiry into the premature deaths of people with IDD in 2013 (Heslop et al.). Both inquiries found that the support for people with IDD in health and social care was deficient in numerous areas and had led to premature deaths. Widespread recommendations were proposed.

In 2011, while the confidential inquiry was in progress, a BBC Panorama documentary was broadcast, providing an exposé of systemic physical and emotional abuse of people with an IDD at Winterbourne View hospital. This facility was a short-term assessment and treatment hospital for people with IDD and mental health and/or challenging behaviour needs. All the regulatory systems, such as local authority safeguarding and care quality commission review, were found to have failed to identify the abuse or respond to concerns raised by whistle-blowers. These failings led to a comprehensive review of all mental health and challenging behaviour services for people with learning disabilities and the implementation of a national initiative to support people with learning disabilities, when appropriate, to leave inpatient settings and return to the community and their families (Department of Health, 2012b; Department of Health, 2015). Subsequently, this led to learning disabilities being made one of the key priorities for the Department of Health (DH).

Both *Death by indifference* and the BBC documentary about Winterbourne View were followed by inquiries and policy development, resulting in significant reverberations, reflections and changes to learning disability services. As I work within community learning disability services and am employed by the NHS, I have felt the experience of these failings profoundly. I recognise that, in part, I aim to address these failings through my work, and also that this research was motivated by my desire to refocus on the reason I started working with people

with IDD as a therapist: because I believe fundamentally in people having the right to live a fulfilled life.

My interest in employment as a subject in my clinical practice will be explored in more detail below, in section 1.3. However, I acknowledge that the political and healthcare environment contributed both positively and negatively to my position as researcher. Similarly, while the method detailed in Chapter 4 seeks to support the founding principle of this research, enabling research collaborators to be partners in this research, I acknowledge the tension between my aim to support the collaborators' voice whilst achieving an academic qualification. This has been challenging throughout the research, exemplified specifically in the sense of struggle I experienced in switching between communicating with the collaborators, my reflexive writing and my academic writing. I sought to conduct this research inclusively, aiming for 'research in which people with learning disabilities are active participants, not only as subjects but also as initiators, doers, writers and disseminators of research' (Walmsley and Johnson, 2003, p.9). In acknowledgement of these principles, the people with IDD taking part in this research are identified as research collaborators as opposed to participants, expressing their partnership in the research process and dissemination. However, this thesis recognises its limitations in relation to inclusive research, acknowledging that a fully inclusive project is not possible when conducting a doctoral project due to the academic requirements (Bjornsdottir and Svensdottir, 2008). Although this research aimed to research as inclusively as possible, I acknowledge that it is not fully inclusive in the terms defined by Nind and Vinha (2012) and Walmsley and Johnson (2003). Subsequently, the terms 'doing research inclusively' (Nind and Vinha, 2012, p102) and 'applying inclusive research principles' will be used throughout this thesis to describe the research position. Additionally, in the thesis in order to differentiate between this research and other research studies being discussed I will refer to 'my collaborative research' in acknowledgement of the partnership undertaken with the research collaborators.

### **1.3 The research problem in practice**

The challenges to entering employment for people with an IDD, like those for people with other types of disability, are many and varied. They include social barriers, such as stigma and prejudice, organisational barriers, such as inflexible practices, as well as personal barriers, such as a lack of skills or reduced self-determination (College of Occupational Therapist [COT], 2007). These challenges amount to occupational marginalisation and whilst not always leading to overt discrimination are described as operating invisibly, often as normative standardised expectations of when, where and how people ‘should’ participate (Townsend and Wilcock, 2004).

With the green paper *Valuing people* (DH, 2001), followed by *Valuing people now* and *Valuing employment now* (DH, 2009a and 2009b), I, along with many occupational therapists working in learning disability, felt encouraged by the central position accorded to ‘independence’ and ‘employment’ in a health document. In the context of the wider revelations in healthcare highlighted above, we recognised and embraced this policy document as reflective of an enablement approach. This resonated with our core beliefs and training regarding the central role that occupation plays in the life, health and wellbeing of people with learning disabilities.

This enthusiasm was quickly tempered by the limited financial investment available to realise these ambitious goals and the level of challenge present in the social model underpinning these papers. Mike Oliver, the key proponent of the social model, states that the individual is disabled by barriers in society rather than by their impairments (2013). There is broad consensus that the social model has redefined the concept of disability and facilitated empowerment for people with disabilities. This has helped to transform the imposed cultural roles of victim or patient as historically defined by the medical model. However, in their critique, Shakespeare and Watson (2002) state that, particularly in the UK, the social model has become a received orthodoxy. They argue that it fails to acknowledge limitations or its potential to deny impairment and difference, and that this is damaging.

Instead, Shakespeare (2014) argues against a singular understanding of disability as being either medical or social. This theory would include every

aspect of a person's experience, whether cultural, bodily, social, psychological or political. However, Oliver (2013), in reviewing the social model 30 years on, cautions against moving back to an individualised model, as this risks becoming de-politicised. Within this thesis, I have aimed to balance these two perspectives, adopting Shakespeare's model of disability (2014), while acknowledging the social model in relation to the structural factors impacting people with IDD.

In addition to the challenge of navigating models and ontology in practice, there has been ambiguity about the role of occupational therapy in addressing the work-related needs of people with learning disabilities. Specifically, while occupational therapists identified that supporting people with IDD in work was a key part of their role, they also communicated a lack of clarity as to how they do this (Lillywhite and Haines, 2010). Currently, ESPs, often from the charitable sector, are contracted by local government to provide bespoke support for the employment of people with IDD across the majority of the UK.

Lillywhite and Haines (2010) provide guidance that states while ESPs can support most employment needs, the occupational therapist's skills should be used in a 'consultancy' capacity when there are more 'complex barriers' to individuals getting work. This position of ambiguity is one that I identify with as a practising occupational therapist working with people with learning disabilities. I recognise the centrality of productivity and work, both when it is absent and present in the lives of people I support, whilst also finding that it is rarely a commissioned aspect of 'health' provision or a community team's contract.

I also recognise an uncertainty in my practice regarding how to apply an occupational therapy intervention, when supporting work for people with learning disabilities, within the limitations of my clinical environment. I have also been aware of the desire for work-related activity in those that I have supported, and national statistics showing a significant discrepancy between the 6% in work (DH, 2018) and the 65% desiring work (DH, 2012). Nonetheless, while my uncertainty sparked my interest in this area of clinical intervention, my research question regarding the experience of people with learning disabilities in paid work emerged during a series of clinical interactions and the completion of the literature review during the initial phase of my research.

One of these clinical interactions occurred during the delivery of a work skills group, Steps Towards Work. This group included six young men with learning disabilities who were in their final year of college and who aimed to build work-related skills and awareness. As part of the group, individuals were encouraged to discuss their interests, strengths and potential barriers to employment with those who knew them. What was striking to me at the time was that the experience of having a learning disability and its potential impact on getting and sustaining a job was not mentioned by any of the individuals with learning disabilities, or by their family members or carers.

A further occasion that prompted questions was when I worked in a forensic unit with a father with a mild learning disability, mental health problems, a substance misuse history and sexual assault as his index offence. On arrival at the unit, I began my clinical intervention with him as he was reported to be sleeping all day and not engaging in any self-care or unit-based activity. In all our discussions, the only thing he wished to talk about was his work history and his desire to return to work; this was not something anyone in the staff team had acknowledged as important or worthy of attention but it became my focus and was transformative in his recovery.

In these two situations, I recognised that I was drawn to listen both to what was and what was not being said about having a learning disability and working, as well as to considering the potential impact of not having paid work on the individual's future outcomes. During the literature review, I became increasingly aware that only a small proportion of studies had actively worked with people with learning disabilities in their methodology or sought the experience of people with a learning disability directly regarding work. When a study included quotations from people with learning disabilities, ideas pertaining to inclusion, humanity and belonging were highlighted but not examined (see the literature review in Chapter 2).

My occupational therapy practice perspective and the well-documented barriers to employment for people with a learning disability are situated within the broader political and economic environment of the UK. This environment continues to be unsettled by political uncertainty surrounding the UK's planned withdrawal from the European Union. Furthermore, while some investment has been made to support employment opportunities for people with a learning disability, relatively

little has changed in the numbers of those in employment (Melling, 2015). The most recent statistics for people with IDD in paid work, as identified by social care outcomes in 2018, is 6%. This is an increase on the preceding 3 years but is a decrease from 6.6% in 2012 (DH, 2018).

There are few empirical research studies examining the role and interventions of occupational therapists supporting work related activity for people with an IDD. Yet whilst there is some ambiguity regarding the role of occupational therapists working with people with IDD (Lillywhite and Haines, 2010) there are also assertions that occupational therapy can be an important and effective part of employment support for people with IDD internationally (Siporin and Lysack, 2004; Kahlin and Haglund, 2009; Smith et al., 2010; Ineson, 2015; Coakley and Bryze, 2018).

#### **1.4. The research methodology and methods**

Chapters 3 and 4 together provide an in-depth exploration of the methodology and methods applied in this research. The research is a hermeneutic phenomenological study of the lived experience of people with an IDD who are in paid employment. The research applied inclusive research principles, maximising the involvement of the collaborators throughout the research process. Central to the aims of inclusive research is a commitment to taking people's stories and words seriously and affording them credibility (Walmsley and Johnson, 2003).

The hermeneutic phenomenological methodology was applied through the adoption of a phenomenological attitude to the data that was collected together with the individual with an IDD. In this thesis, the data comprises the collaborators' work stories (Chapter 5), which includes the narrative and visual components collated through semi-structured interviews and interviews with myself, the researcher, the collaborator and photographer. The photographer in these meetings also adopted a phenomenological attitude, focusing on an intersubjective understanding of the phenomena. The use of narrative and visuals in the data gathering stage of the research aimed to support the collaborators' engagement in the study, as there is a high prevalence of communication problems in people with IDD (Lund and Light, 2006). Visual materials were used to help with individuals' competence in communication,

increasing their ability to participate in interactions. In this thesis, this method is called a creative collaborative partnership. The work story, once agreed with the collaborator, formed the findings. The stories were then analysed collectively through the application of hermeneutic phenomenological reduction, allowing five narrative frames to emerge.

This hermeneutic reduction was applied to the individual work stories and the group of stories as a whole through the application of the hermeneutic circle, where the parts and the whole are reviewed (Moran, 2000). The narrative frames drawn from the reduction were shared with collaborators for resonance rather than validity. The critical realist assumptions applied in this research acknowledge that the first-person account is considered real and part of a shared reality within society (Dannermark et al., 2002) alongside an interpretivist epistemology. Critical realism is considered to support both phenomenological methodology (Finlay, 2006) and disability studies, due to its acknowledgement of complexity (Shakespeare, 2014). Furthermore, my reflexivity as a researcher is crucial in supporting the interpretivist approach and a reflexive diary was used throughout the research. In addition, my academic supervision has been of particular importance in reflecting on how my inherent bias as an occupational therapist affects my understanding of work and occupation. I have used Kielfhofner's model of human occupation (Taylor, 2017a) in this research, as it has underpinned my clinical reasoning throughout my career. Moreover, despite limitations that will be discussed as they arise, I believe it to be the most inclusive model. It has a strong focus on environmental / structural features that are compatible with Shakespeare's definition of disability (2014).

The dissemination of the research findings took place through an initial public exhibition (Ramsey, 2019 – Exhibition Catalogue). I constructed an assessment tool, My Work Plan (currently devised in draft), which aims to support the practical application of the findings in occupational therapy practice. Additional dissemination in partnership with the collaborators continues through conference presentations and writing articles for journals (Appendix 4).

## **1.5 Thesis overview**

This thesis is organised into eight chapters: an overview of the chapter content is provided below. The interpretivist position of the research is embedded throughout. This is made explicit through the reflexive accounts in text boxes and is also integrated within the discussion (Chapter 7) and conclusion (Chapter 8). Chapter 2 reviews the literature pertaining to the political, social, cultural and healthcare environment of work for people with IDD. There are three sections within the review commencing with the focus on work: the policy context; the role and function of work; and finally, what helps people with IDD find and retain work. The review examines the predictive factors and outcomes experienced by those with IDD in work, identifies the gaps in work related literature and links these gaps to the research aims.

Chapter 3 examines hermeneutic phenomenology and its appropriateness as the methodology for this research and sets out its capacity to illuminate the lived experience of work for people with IDD. This chapter explores the basis for this choice alongside other methodological considerations. The decision to apply an interpretive rather than descriptive phenomenological design is also discussed, in conjunction with the philosophical underpinnings, the ontological and epistemological position of the research and the critical realist assumptions. Narrative and visual methods are then discussed and their use in this project are justified as part of a creative collaborative partnership.

Chapter 4 provides a detailed outline of the method applied in this study, outlining the procedure for data gathering and analysis, the support of the advisory group, the creative collaboration with the photographer, ethical factors and grant funding. The use of the hermeneutic phenomenological crafting technique (Crowther et al., 2017) is detailed and its application in forming the narrative of the work story outlined. This is followed by details of the research collaborators' role and that of the photographer in the co-creation of the visual images supporting the communication of the collaborators' lived experience of work.

Chapter 5 outlines the first stage of findings contained within the work stories of the six collaborators: Jo, Ruth, Mark, Tabitha, Jennifer and Kenneth. These are detailed as work stories, composed of the individual narratives of the

collaborators' experiences of finding and retaining work, in addition to their co-created visuals. A further summary of the data gathering process, including demographic details of the collaborators and interviews with myself and the photographer, is provided. Due to the aim of this research being to enable the voice of the collaborators to be heard holistically and illuminate their experience of work, the work stories are included in full in this chapter. Furthermore, throughout the thesis the term 'work story' will be applied to describe the collective story, including both the narrative and the visual component.

In Chapter 6, Work[able] a quest for work, the second stage of analysis is outlined. A description of the application of the hermeneutic reduction and application of the hermeneutic circle is provided, prior to outlining the five narrative frames: 'the quest to do'; 'navigating bureaucratic seas'; 'finding a good fit'; 'the forging of identity'; and 'finding both friend and foe'. These are empirically located in the collaborators' job stories. The group meeting with the collaborators is described, in which the narrative frames were shared, and the planning of the public exhibition is discussed.

Chapter 7 discusses the findings, including the work stories and five narrative frames, in relation to the literature pertaining to working with IDD and occupational therapy. The chapter is composed of three sections. Section one is called 'understand me' and explores the experience of working with IDD and the nature of disability identity and the work role. Section two, called 'belonging versus stress and striving', contextualises the narrative quest within occupational therapy and the work-related literature, before looking at the learning from the collaborators' narratives, including finding a good fit in work or a poor fit with continued striving. The final section, 're-devising work and employment support', discusses the tension implicit in the findings that employment support is often protracted and unsupportive, and highlights the crucial role that social support and a social working environment have on a positive work outcome for people with IDD.

Chapter 8 concludes the thesis, presenting the study's unique contribution to knowledge and practice inherent in the collaborators' work stories and narrative frames. An occupational therapy assessment tool I devised (My Work Plan) is then presented in draft, alongside the broader implications of the findings and recommendations for people with IDD, their family and carers, occupational

therapists in practice, workers supporting people with IDD in work and for policy and service design. The chapter concludes with a review of the original contribution to knowledge of the creative collaborative partnership in supporting inclusive research methods and addresses the research limitations.

## **Chapter 2. Work for people with intellectual and developmental disabilities: a literature review**

### **2.1 Introduction**

In Chapter 1, the research aims and focus in relation to the employment of people with IDD were set within current priorities in IDD services, policy and clinical practice. This chapter will expand on this, reviewing literature pertaining to the political, social, cultural and healthcare environment. The following three sections will set out the need for this research in relation to people with IDD due to: the low number in paid employment; the importance of work on life outcomes and wellbeing; and the limited understanding of direct experience of work and inclusion in service and policy development.

The first area to be explored is the desire to work in the policy context. This will outline the current policy position and highlight its failure in increasing employment for people with IDD. There is then a discussion of perspectives on the reason for this failure and ideas for addressing it. The role and function of work is then examined in a review of the history of IDD, focussing on the significant relationship between work and the healthcare system in the twentieth century. Additionally, there will be an exploration of models underpinning this history. The final section will examine the predictive factors that support people to find and maintain work, as well as the outcomes experienced by people with IDD in work. A reflexive account exploring my response to the literature reviewed is also included in this chapter.

Appendix 5 gives a summary of the literature review search, which focussed on primary research that sought the experience of people with IDD in paid employment. Although there are numerous quality assessments in use for qualitative research (Booth et al., 2016) this research applied guidance from the Cochrane review, specifically Hannes' (2011) critical appraisal approach to qualitative research. Hannes' (2011) criteria include assessment of credibility, transferability, dependability and confirmability. Assessing credibility is defined as evaluating ‘whether or not the representation of data fits the views of the participants studied’ (Hannes, 2011, p4), while assessing transferability is defined as evaluating whether the findings can be transferred to other settings.

Dependability involves the evaluation of the logical, clearly documented and traceable nature of the methodology and method, including the researcher's position. Finally, confirmability refers to the 'extent to which findings are qualitatively confirmable through the analysis being grounded in the data and through examination of the audit trail' (Hannes, 2011, p4).

## 2.2 The focus on work: the policy context

The most commonly used governmental statistics for the employment rates of people with IDD in England is the Department of Health (DH, 2018). The data is captured in the adult social care outcome figures which state that in 2017–18, 6% of people with an IDD were documented by the local authority as being in paid employment (DH, 2018). These statistics reveal the reversal of a small downward trend in recent years back to the levels of employment in 2014–15 (6% in 2014–15, 5.8% in 2015–16 and 5.7% in 2016–17, DH, 2018).

Notwithstanding these figures, the desire to be in paid employment is a topic of importance for people with IDD.

Iriarte et al. (2014) conducted inclusive research in partnership with and directed by people with IDD. This sought to establish the key priorities for 168 people with IDD in relation to work and being a paid employee was one of the eight key priorities identified. Similarly, in a further report directed by people with IDD *We're not stupid*, Taylor et al. (2007) explored the daily life of people with IDD, finding that the theme of paid employment was raised in relation to the topic 'we want what everyone wants.' These studies positively embrace work as a goal for people with IDD. In doing so, they reflect an uncritical acceptance of the ideal of paid work on the part of many people that support people with ID, including academics, self-advocacy groups and advocacy organisations (Redley, 2009). This will be further addressed in the next section exploring the role and function of work.

At its core, all national and international policies hold to the premise that inclusion in the labour market through paid work enables people with IDD to experience a better life (Johnson et al., 2010). This focus is highlighted by Bates et al. (2017) and is due, in part, to high levels of poverty being experienced by people with IDD and their continued vulnerability in the current economic climate.

The World Health Organization's *World report on disability* (2011) placed work and employment as one of its six key priorities, similarly, outlining the vulnerability of people with a disability towards experiencing poverty and poorer health outcomes. The WHO report goes on to reference Article 27 of the United Nations *Convention on the rights of the person with disabilities* (UN, 2006), stipulating the right to work on an equal basis with others. The UN criticised the UK government for insufficient adherence to this convention in 2017, proposing that there had been a failure to monitor the impact of policy changes on disabled people in the UK. The UN highlighted that policy changes associated with austerity were increasing the levels of poverty for people with a disability (UN, 2017).

In UK law the *Disability Discrimination Act* (1995) set out the rights of people with disabilities, making it unlawful for people to discriminate based on a person's disability. This was later replaced by the *Equality Act* (2010). However, it was only in 2009 that aspirations relating to work for people with IDD were addressed within the green papers *Valuing people now* (DH, 2009a) and *Valuing employment now* (DH, 2009b). While work was a key focus in both these green papers, *Valuing employment now* (DH, 2009b) was seminal, in being the only policy document to have focused solely on work for people with IDD (Humber, 2014). The main goal of these documents was to place work as a central tenet of the support for people with IDD and to increase the number of people with severe or moderate IDD in work by 2025 (DH, 2009b). This aim, though admirable, was ambitious: there had been limited gains made in the employment of people with IDD in the 14 years since the *Disability Discrimination Act* (1995) came into force and there was a lack of improvement in employment figures for people with IDD in since this time. Furthermore, it has already been established that people with severe or moderate IDD are less likely to gain support towards employment from employment providers (Wilson, 2003; Humber, 2014; Nord et al., 2018).

The alignment of health and work in the lives of people with IDD is exemplified by the fact that *Valuing employment now* (2009b) was written by the DH. This association has continued in recent years with the green paper *Work, health and disability green paper: improving lives* (DH and DWP, 2017), which has developed recommendations for welfare, employment and health services for people with disabilities. This association will be expanded further in the next

section of the literature review, which will consider political and economic factors emerging from the 2007–08 global recession that have influenced the last decade of policy development.

Whilst law and national policy has identified work as a key priority for people with IDD, relevant research has reported that the number in paid employment in the UK has barely grown in the last 20 years (Dempsey and Ford, 2009; Melling et al., 2011; Humber, 2014; Nord, 2018). This lack of growth in the employment rates of people with IDD has equally been experienced internationally, leading to questions about the core policy premise of ‘work for all’ people with IDD (Saloviita and Pirttimaa, 2007; Dempsey and Ford, 2009; Lysaght et al., 2012a; Engeset et al., 2015; Lysaght et al., 2015; Nord et al., 2018). Indeed, Nord et al. (2018) state that in the USA ‘the nation ought not to tolerate another generation of people with IDD excluded from the workforce’ (p204).

The recognition of poor employment rates for people with IDD has led to claims of policy failure within the UK (Melling et al., 2011; Humber, 2014; Melling, 2015). However, Melling (2015) equally observes that it remains a relatively short time since these policies were put in place and that available statistical measures of people with IDD in employment may not be reliable. Nevertheless, the injustice of the continued low employment rates of people with disabilities has again been emphasised in *Work, health and disability green paper: improving lives* (DH and DWP, 2017). This injustice resonates with debates in the occupational science literature, specifically in relation to occupational injustice and occupational deprivation.

Wilcock’s 1998 definition of occupational deprivation referred to the influence of external factors that kept a person from acquiring, enjoying or using something. This definition was further developed by Whiteford (2000) in a focused inquiry into occupational deprivation as a phenomenon. Whiteford defined it as a state of preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside the immediate control of the individual. (Whiteford, 2000, p201). In the years since occupational deprivation was defined in these terms its application in research has been discussed alongside occupational injustice and occupational and human rights (Hocking, 2017). Subsequently, it has been viewed as a subset of social justice (Wilcock and Hocking, 2015) and as resonating with the social model of disability. The similarities include the

assertion of principles of equity and fairness for all people and the acknowledgment of external societal barriers that operate to limit people's inclusion in the things that matter to them (Hocking, 2017). Furthermore, going beyond the social model, occupational science makes the association between occupation (specifically, work) and health. Wilcock and Hocking (2004) note that occupational deprivation can be experienced when 'people have reduced options to do, be, and become because they are deprived of paid work' (p.165).

Melling (2015) suggested that only a significant cultural shift in perceptions and expectations of what people with IDD can achieve will lead to a change in the employment rate of people with IDD in the UK. However, she does not provide recommendations as to how this cultural shift might take place. Similarly, Lysaght et al. (2012) concluded in their broad ranging review of the theoretical concepts of disability, organisational management, employment and inclusion in Canada, that employers need to progress in relation to their attitude to people with IDD and to think of work in a new way. They stipulated numerous recommendations to address the challenges of supporting people with IDD into employment, including six on policy, four on job re-structuring and staff training, and three relating to schools and the alignment of training and expectations for the labour market. Although the transparency of their literature review can be questioned, given their criteria for the choice and focus of literature were not listed, the review highlights systemic problems surrounding employment for people with IDD and the challenges associated in addressing them. The suggestion that the nature of work for people with IDD requires reconsideration is in line with others (Wilson, 2003; Johnson et al., 2010). However, although broad ranging ideas similar to those detailed by Lysaght et al. (2012) are proposed, the complexity inherent in the changes and mechanisms for implementation are not addressed.

These complexities are also apparent at an international level, as identified in an exploratory study by Lysaght and colleagues (2015) where they review the international employment statistics of people with IDD. In their paper, they highlight the importance of an internationally agreed metric, as variance in terminology and definitions create a lack of credibility in the current statistics. They argue that an international group should be established to agree terminology and methods for the collation of these statistics to aid the understanding and comparison of data from around the world (Lysaght et al. 2015). While international agreement on such issues seems desirable, it could

be argued that the ICD-11 criteria for IDD or disorders of intellectual development (WHO, 2019) already provides clarity on classification. However, despite this and the guidance provided by ICD-10, establishing an IDD diagnosis remains variable and is often not specified within research studies. The proposal for an internationally standardised metric for outcome measures is echoed in a joint UK and Australian study (Dempsey and Ford, 2009). This explores the employment of people with IDD in both countries and the possibility of holding employment services more effectively to account. It concluded that there was a lack of reliable data in the UK and associated this with the outcome-focused approaches to evaluating employment services, in the context of continued high unemployment levels for people with IDD.

In their review of literature about community-based work from 2000–10, Lysaght et al. (2012a) explore inclusion and highlight the challenges that exist because of a lack of clarity in outcome measures. They found that of the 42 articles they reviewed, only five reflected the core features of inclusion, namely ‘belonging, reciprocity and need fulfilment’ (Lysaght et al. 2012a, p.1339). However, Humber (2014), observed that it was the UK Labour government who devised the constructs of inclusion and exclusion during their term of office (1997–2010) and that articles exploring these constructs as outcome measures prior to this period are understandably limited. In the literature explored in the later section of this review, it appears that quality of life was the primary outcome measure being examined (Kober and Eggleton, 2005; Verdugo et al., 2006; Jahoda et al., 2008; Beyer et al., 2010; Conroy et al., 2010; Flores et al., 2011). Nevertheless, social inclusion is the focus of Humber (2014) in his discussion paper exploring the marketisation of employment support for people with IDD in the UK. He states, drawing on interview-based research with people with IDD, that there needs to be a meaningful definition of inclusion, rather than an individual simply being present in the workplace and part of work-related processes. He goes on to state that the lack of specific measurable outcomes outlined in *Valuing employment now* (DH, 2009b) has led to a prime contractor model developing, where employment services focus only on those individuals who are likely to be successful in gaining work, whilst others remain in the system waiting for opportunities.

In summary, current policy is considered to be failing in its aim to increase the employment rates of people with IDD, both nationally and internationally

(Dempsey and Ford, 2009; Melling et al., 2011; Humber, 2014; Nord et al., 2018). Ideas to address this failing include the call to shift cultural perspectives, so that there is a recognition of the positive influence people with IDD can bring to a workplace (Melling, 2015). Further ideas are to: develop internationally agreed models, metrics and terminology to support policy (Dempsey and Ford, 2009; Lysaght et al., 2015); create improved and agreed outcome measures, particularly regarding inclusion for people with IDD (Lysaght et al., 2012b; Humber, 2016); and to make changes to employment systems (Nord et al., 2018). However, while the importance of supporting meaningful employment for people with IDD is clearly articulated in the content and the tone of the papers, none of the papers refer directly to the involvement of people with IDD in evaluating and devising policy and employment services. The importance of further research in this area is highlighted by the low number of people with IDD in paid employment and the challenges of addressing these issues.

### **2.3 The role and function of work**

De Botton (2009) states that what we do, our occupation or work, is central to our identity and social acceptance in British society, as indicated by it being the first question asked of a new acquaintance. For people with IDD, being in paid work symbolises and results in an even greater outcome societally and politically, namely 'equality or citizenship that invites participation in society' (Johnson et al., 2010, p.99). In short, the outcome is inclusion but this has not always been the case. O'Connor and Tizard (1956) noted that historically, for people with IDD, work was used as a way of defraying the costs of care and filling time. Equally, work has been said to have functioned both as a form of punishment for people with IDD and as therapy (Johnson et al., 2010). In this section of the literature review the differing roles of work will be explored in relation to recent historical, cultural and ideological influences on healthcare and occupational therapy. Situating work in this way is important in my collaborative research, due to my position as an occupational therapist.

The use of work to defray the costs of care, occupy time, punish and provide therapy are all previously articulated in self-reports by people with IDD. *Know me as I am – an anthology of prose, poetry and art by people with learning disability*,

edited by Atkinson and Williams (1990), appears to be the largest collection of self-reports, in which 200 people with IDD were invited to share their life stories involving institutionalised care in long stay hospitals. In an attempt to avoid fragmenting this experience, what follows is a number of quotations to illustrate the function of work in full. David (a contributor) articulates its role as a form of punishment, relating this to his experience of living in a hospital in the north of England:

Punishments (villa) 17 it were when they used big punishments. They were scrubbing floors and carrying sand, bags of sand, and if they dropped them there is somebody behind them to tell them to pick them up and keep carrying them. And when they scrubbed the floor, they had to scrub it again, keep doing it all the time, that's why they got tired! They used to be in pyjamas, and they used to have a dressing gown on.

(Atkinson and Williams, 1990, p.158)

Other narratives from people who contributed to this book refer to work functioning as therapy and as occupying time. Additionally, it is clear that in the institutions, the doctors led the working environment hierarchy, having both medical and institutional leadership, as this quotation from Ernest (a contributor) demonstrates:

Patients had to be careful how they behaved in their work and on the villa or wherever they were cos there was strict staff in those days and any offence, they used to be up before one of the senior doctors. (Atkinson and Williams, 1990 p.158)

At the turn of the 1900s, with the beginning of institutional care, occupational therapy began as a profession often located within institutional environments. Starting in the United States, it drew its professional boundaries from a number of disciplines and social movements, including psychiatry, arts and crafts, the women's movement, nursing and teaching. Initially, as a profession of women, there was a reliance on both the authority of men in medicine and women in charitable work (Quiroga, 1995). Coming from a 'middle class therapeutic world view' (Quiroga, 1995 p.31) it identified with views on 'productive work and citizenship' (Quiroga, 1995, p.275), with occupation at its core. This resonates with the role of employment in the early twenty-first century.

An occupational perspective on people and their health is central to the profession to this day, with people being viewed as occupational beings (Molineux, 2011; Fisher, 2013; Wilcock and Hocking, 2015; Taylor, 2017a). The doing of work sits within human occupation alongside leisure or activities of daily living, occurring in a physical, temporal, sociocultural context that defines human life (Taylor, 2017a). In a book by Quiroga (1995) that examines the first 30 years of the profession, occupational therapy walks alongside the history of people with IDD, as they came to be viewed. Developing within institutions, occupational therapists would have witnessed, and no doubt directly or indirectly supported, the institutionalisation of people with IDD. They would have observed how people came to be viewed through the medical model, labelled and defined as a homogenous group, in addition to being part of the implementation of work-based programmes with their variety of functions. In this respect the history of occupational therapy and the institutionalisation of people with IDD are interconnected. However, this interconnectedness is relatively unexamined within occupational therapy literature.

When work, as a concept, has been explored in the years since de-institutionalisation, numerous studies have found that, not only do people with an IDD perceive attending day services as work, but they see this as being both meaningful and desirable (McGlinchey et al., 2013; Engeset et al., 2015). In their Irish study, McGlinchey et al. (2013) created the term 'perceived work' after finding that 53 participants out of a total of 753 identified their attendance at day services as work. Moreover, they observed that some of the quality of life benefits associated with paid or sheltered employment were also evident in this cohort. However, there are questions about the significance of these findings as 67% of the cohort had moderate to severe IDD, indicating potential limitations in engagement with the research interview. Furthermore, 62.2% of respondents were between 50–64 years and the remaining 37.8% aged 40–49 years, indicating that they may have lived in institutions where work was an essential part of their care environment. As highlighted by Engeset et al., (2015) in their ethnographic research, 'work activities' were created and referred to by staff in the day service environment. It was not clear whether this was also the case in the day services covered in the research by McGlinchey et al. (2013). Nevertheless, within these two studies some of the research participants viewed activities within the day service as 'work' and valuable. However, their role in

these activities was reported to have low value and status by staff members involved in the research (McGlinchey et al., 2013; Engeset et al., 2015).

The fusion of work and care highlighted in the preceding section is exemplified by a quotation from a carer in an Australian research study by Bigby et al., (2011) which explored perceptions of retirement. This study had a focus group design involving people with IDD, their family and paid workers. A worker stating 'They like the extra money, but the therapeutic value is the ... instead of vegetating, they're occupied' (Bigby et al., 2011, p.171). The fusion is not a new phenomenon, as the history of work, occupational therapy and institutionalisation outlines, but merely an extension of that relationship. However, while it is understandable that these perspectives continue in care settings, it is interesting that this association continues to be supported systemically, through policy. In the UK, since the 1990s, personalisation has been championed and established. Personalised care and personal budgets, namely money for care that is managed by the individual (direct payments), was endorsed by *Valuing people now* as a way to support activities that bring people with IDD into employment (DH, 2009a). This approach has been criticised, on the basis that direct payments may not address the low rates paid to people with IDD in work, and that the level of complexity in managing them may be off-putting (Humber, 2014). However, direct payments clearly continue to cement the care and work fusion.

The conjoining of care and work is believed to have roots in capitalism and post industrialisation and to have been embedded during institutionalisation in long stay hospitals. Industrialisation fundamentally changed working and social relationships in Britain, leading to a labour market that was largely factory based, where those with functional limitations became economically dependent and therefore a problem for their families and for the government (Bambura, 2011). This circumstance is illustrated in an experience shared in the book *Know me as I am*, (Atkinson and Williams, 1990), which explored the experience of institutionalised care. Here, Grace (a contributor), talks about her experience of 'the colony', an institution in the north of England in the early 1900s:

*'I were at home with my mother and sister and brother. I must have been 15 or summat like that when (I came in). I left special school when I was 14 years old to work in t'mill. I did spinning and weaving. I only got 10 shillings a week but to me it were worth it'.*

*'I've no idea at all (why I came into the colony). I can never find out. Anyhow, I'm not bothered. It could be, as they say, I were 'black sheep of family'. They're all dead now, that's why I can't get to know anything'*  
(Atkinson and Williams, 1990, p.157).

Institutionalisation and the subsequent development of the welfare state led to the term 'disabled' being created in policy in the 1940s and defined and treated as a medical issue (Bambura, 2011; Oliver and Barnes, 2012). The challenge to the state definition of disability occurred through the politicised disability movement in the 1950s and 1960s. This movement heralded the arrival of the social model, which challenged the belief that the problem was with the individual and their impairments. The social model highlighted the multiple barriers, stigma and exclusion of disabled people, particularly in relation to work (Oliver and Barnes, 2012; Oliver, 2013). With the aspiration of de-institutionalisation, people with IDD moved into the community and were encouraged to take part in community activities as valued and respected individuals rather than second-class citizens, namely acquiring full citizenship (Flynn and Lemay, 1999).

While gains have been made in the rights of people with IDD, Oliver and Barnes (2012) argue that there is still a pervasive and dominant medical model of disability that affects the work agenda. Oliver (2013) states that the social model has 'barely made a dent in the employment system' internationally (p.1025). This position is echoed in the UK disabled people's manifesto *Reclaiming our futures* (Inclusion London, 2013), which calls for the removal of societal and economic barriers for disabled people in order for them to work. However, it equally asserts that economic productivity cannot be the only measure of people's worth.

In recent years, the combination of the economic climate and social welfare reform in the UK has led to largely binary portrayal of people with a disability in the media. Crow (2016), in her visual inquiry into the images of disability in 2012, highlighted this through the media's description of people with disability as being either 'scroungers or superhumans'. She compared the images of the 'immoral' benefit claimant with a 'heroic' Paralympian (Crow, 2016, p.171). Although it could be argued that binary approaches are the default position in relation to all areas of news coverage, Crow (2016) argues that these long standing 'either/or' perspectives on disability tell stories of people with impairments that are detached from their social situations and confine people to the status of 'other'.

In their position paper *The social model of disability: an outdated ideology?* Shakespeare and Watson (2002) examine in depth the paradigms that have historically driven dualistic perceptions of disability, and which continue to do so. The social model states that society is disabling (Oliver, 2013). Shakespeare and Watson (2002) argue that while it is clearly important, the social model has become a *sacred cow* (p5). They propose that its strength is becoming its weakness, as it is an ideology that cannot be challenged (Shakespeare and Watson, 2002). It could be argued that the history of normalisation and the perspective of the social model in the UK has led to people with IDD not discussing their specific impairments and how these might affect their experience of work. Certainly, as Wilson (2003) highlights in his position paper, which draws on three case studies of people with ID in employment, normalisation theory has significantly influenced policy and work ideology relating to people with IDD in the UK. Specifically, he suggests it has led to an expectation of people with IDD having 'real jobs', namely those that could be carried out by non-disabled workers. While I appreciate that this directive in policy may have been intended to avoid tokenism and the exploitation of people with IDD in work, it has perhaps had unintended consequences. Wilson (2003) concludes by arguing that a 'more careful appreciation of the nature and consequences of impairment in work situations is essential' (p.114).

The lack of appreciation of the impact of having an IDD in the workplace is in stark contrast to the literature surrounding mental health and employment, where the voice of the individual and their ongoing experiences of managing illness while in employment are well documented and examined (Kennedy-Jones, 2005; Boyce et al., 2007; Johnson et al., 2009; Secker et al., 2009; Urlic and Lentin, 2010; Williams, 2012; Cameron et al., 2012). In summary, it appears that the voice of people with IDD on the experience of having an IDD in work has been influenced by normalisation theory: there is no expectation to be treated differently in the work setting and therefore people have not been asked about their experience. Why, then, is the situation different in the area of mental health? Perhaps a contributing factor is that people with IDD, unlike those with mental health needs, are a demographically small proportion of the general population and an extremely small number of the working population. There may therefore be a reduced imperative to address this question.

Shakespeare and Watson (2002), in their criticism of the social model, go on to state that the issue and experiences of impairment, such as pain or limitations, are at risk of being ignored. They argue that people are disabled by social barriers *and* by their bodies. In brief, they outline a different social theory of disability with an embodied ontology and state that: ‘there is no qualitative difference between disabled and non-disabled people - we are all impaired. Impairment is not the core component of disability (as the medical model might suggest), it is the inherent nature of humanity’ (Shakespeare and Watson, 2002, p.27). This theory of disability is outlined by Shakespeare (2014) as always, an interaction between the individual and structural factors. He proposes an inclusive, non-dichotomous position that enables a holistic understanding of disability (Shakespeare, 2014). In this regard it may be the answer to the request by Lysaght et al. (2012b) for a new model of disability. However, Shakespeare and Watson’s (2002) model of an embodied ontology could equally be argued to lead to the individual needs of people with IDD being missed in the collective perspective that ‘we are all impaired’, whether disabled or non-disabled. In this regard, the complexity of applying a disability model that can serve both the collective or group politically, and the individual, is evident.

In this section, the role and function of work has been discussed, considering how work has been represented historically and in current policy in the lives of people with an IDD. It has highlighted the importance of acknowledging the complex association between the function of work, occupational therapy, institutionalisation and health care within my collaborative research. This association exists against a contested ideology on the nature of disability. My collaborative research illuminates the lived experience of people with IDD in employment in the context of their lives. In doing so it provides insight into the current role and function of work and the experience of ‘disability’, in order to inform the practice of workers with people with IDD, such as occupational therapists.

### **Reflexive account 1 – Literature review**

In devising my research question and particularly in conducting this literature review, I've been drawn to consider reflexively and reflectingly my own job story and its strong links, even in its relatively short life span of 20 years, with the history explored in this chapter.

My working life in the NHS started in a London mental health day service as an occupational therapy assistant linked to an institution in the process of closure. I recall walking through the near empty vast asylum building and talking with nurses about their experience of standing at a sink with one razor as male patients stood in a line waiting to be shaved one by one.

During my first term in occupational therapy training Mike Oliver, the key proponent of the social model, came to speak to us. His lecture stayed with me due to its resonance at the time and on numerous occasions since. He said that we identified him as a disabled man but that we too, as therapists, were disabled by the environment we worked in. Our job, he said, was to overcome these barriers to support the goals of the people we were working to enable. I recall going to the library straight after the lecture and sitting down to read his book on the social model of disability.

Since that time, I have extended this thinking within my practice and in supervision with staff and management. I have come to see the disabling environment as extending beyond the physical realm to the social environment, pertaining to people's prejudice and limited or fixed mind-sets, to closed bureaucratic systems of service eligibility, as well as to myself and my own limitations of self-awareness, competency and capacity. Furthermore, I've learnt to recognise what and who are enabling and to value and seek out this support to do my job, which aims to enable the people I support with a learning disability.

I believe my decision to specialise in working with people with a learning disability can be traced back to these moments. In viewing the history of occupational therapy and the parallel journey of the institutionalisation of people with an IDD and the way in which they have been defined and treated as a homogenous group, I have re-acknowledged my connection to this past, its models and practices. Reviewing the literature has reconnected me to the uncomfortable history of institutionalised care and the echoes in present day practice in the context of the transforming care agenda. It has led me to moments of disempowerment in considering the magnitude of change being needed at a systemic level in society and impact on policy, employers and individuals with IDD. Simultaneously, it has drawn me to marvel at the changes that have occurred, at the centrality of 'work for all' as one of the six priorities of the *World Report on Disability* (WHO, 2011) and its international policy aspiration. Equally, I've celebrated the increasing influence of the voice of self-advocacy on policy, in seeking a better life for people with IDD. As an employee of the NHS, I recognise the disconnect between policy aspiration and policy implementation. I acknowledge the fact that rarely, if ever, is there a plan for the 'how' when the 'what' is articulated, nor the finances available to support the required changes.

Acknowledging this history, I recognise the risk of being institutionalised myself within the NHS and my own thinking and the importance of the supervisory relationship to discussing the implications of this risk throughout the research process.

## **2.4 The factors that help people find and retain work**

The principal focus of the empirical research literature on work for people with IDD, which is examined below, is the exploration of predictive factors associated with successful employment and the evaluation of outcomes. The literature review takes the year 2000 as its starting point, rather than being limited to a short, contemporary timeframe, due to the small number of studies available. Furthermore, the sources of the research studies are from high-income countries within Europe and North America. I acknowledge that low to middle income countries are addressing fundamentally different complexities and are not fully reflected in the research base at this time. However, while the situation relating to work for people with IDD in this category of country was not discernible from the literature available, the fact that an estimated 80% of people with disabilities live in low and middle income countries (WHO, 2011) indicates the extent of the international research deficit. In a comparative study on adults with a disability in India and Cameroon, people were five times less likely to be in employment (accessing livelihood opportunities) by comparison with their non-disabled peers (Mactaggart et al., 2018).

The barriers to entering employment for people with IDD in the UK are many and varied but include social barriers, such as stigma and prejudice, barriers within organisations, such as inflexible practices, and personal barriers such as a lack of skills or reduced self-determination (College of Occupational Therapy, 2007). There is a body of literature that considers these barriers and how to overcome them, exploring the predictive factors that impact access to employment (Moran et al., 2001; Wehmeyer and Bolding, 2001; Moore et al., 2002; Rose et al., 2005; Simonsen and Neubert, 2012; Holwerda et al., 2013; McGlinchey et al., 2013; Wehman et al., 2014; Bush and Tasse, 2017; Southward and Kyzar, 2017; Sannicandro et al., 2018; Qian et al., 2018; Park and Bouck, 2018). In studies that examine outcomes, the definition of what makes ‘successful’ employment for people with IDD is largely related to policy drivers such as inclusion, financial betterment and improved quality of life (Kober and Eggleton, 2005; Verdugo et al., 2006; Jahoda et al., 2008; Beyer et al., 2010; Conroy et al., 2010; Flores et al., 2011; Akkerman, 2016; Kang et al., 2019). These findings will be explored alongside a small number of papers reporting research in partnership with people with IDD (Li, 2004; Timmons et al., 2011; Akkerman et al., 2014), and a review of

occupational therapy literature related to work and IDD (Siporin and Lysack, 2004; Kahlin and Haglund, 2009; Smith et al., 2010; Ineson, 2015; Coakley and Bryze, 2018). In conclusion, the gap in research and its implications for this thesis will be outlined.

#### **2.4.1 Predictive factors for the employment of people with IDD**

The research focusing on the predictive factors of successful employment for people with IDD will be reviewed in two parts and will be differentiated by age, due to the different characteristics of the cohorts. Initially, research will be considered that addresses factors for young people at the age of transition between children and adult services (16–25 years) and then the research relating to adults with an IDD of non-transition age will be discussed. This combined body of research predominantly focusses on the personal, educational and social situation of the individual with an IDD and the relationship of these factors to the likelihood of gaining employment. Meanwhile, it is argued that the employment environment, the role of workers who support people with IDD into employment and the social and cultural barriers all remain relatively unexamined in the literature.

In recent years, there has been an increased focus on employment opportunities for young people of transition age with IDD. These large-scale studies have predominantly been conducted in the US (Simonsen and Neubert, 2012; Wehman et al., 2014; Southward and Kyzar, 2017) and the Netherlands (Holwerda et al., 2013). The personal predictors highlighted in these studies that reveal a positive correlation with successfully gaining employment, include: the presence of high motivation, positive expectation of employment and self-determination in the individual. The social predictors noted were: positive family support, living alone or with family, experience of work while in school, engagement in work-related school programmes and completing school and post-secondary education. Despite a variance in the aims and methodologies of these studies similarities emerged in their findings, associated with living circumstances, self-determination and self-management of the individual (Simonsen and Neubert, 2012; Holwerda et al., 2013; Southward and Kyzar, 2017; Sannicandro et al., 2018; Qian et al., 2018; Park and Bouck, 2018).

A primary focus in recent studies has been the predictive impact of additional in-school or post-secondary education on gaining employment in the USA (Sannicandro et al., 2018; Qian et al., 2018; Park and Bouck, 2018). In their large scale study Sannicandro et al. (2018) used a quasi-experimental design, comparing employment, income and social security income (benefits) of people with an IDD who had received post-secondary education with those who had not. In their findings they concluded that students who had received further education had a statistically significant increased likelihood of employment, increased earnings and reduced dependency on benefits. However, the data was taken over a five-year period using a cohort of 11,280 individuals from a rehabilitation services database. The cohort had diverse levels of ability and was therefore highly heterogeneous, a weakness acknowledged by the authors. This is exemplified by the fact that post-secondary education was defined in the study as education that led to certification or a degree. In this respect, the findings that employment and income levels were higher for this population are perhaps not surprising. This has limited implications for people who would struggle to attain academic qualifications due to their level of impairment.

Similarly, Qian et al. (2018) reviewed the outcome of post-secondary programmes and transition planning in two technical colleges, while Park and Bouck (2018) assessed the impact of vocational training and transition planning in schools on employability for students with IDD. Qian et al. (2018) examined the impact of a mentoring programme on the outcomes for 228 students within technical colleges, again using a demographically diverse cohort. The findings that 73 of the students received above the minimum wage in earnings was positive. However, it was unclear if they included the 67 of the 228 participants who were defined as having a specific learning disability, indicating that there was a lack of generalisability of the findings across all levels of IDD. In Park and Bouck's (2018) quantitative analysis of US National Longitudinal data, descriptive statistics were analysed to establish the benefit of in-school services in predicting the employment of people with IDD. In their results they argued that the student's primary disability was the sole demographic associated with their work status, i.e., whether they had a mild, moderate or severe IDD. In-school training was described as vocational instruction, job readiness and placement support and these were indicative of the potential for students with mild IDD to gain employment. However, the quality and standardisation of training offered within

the school system was not clear, nor was the level of adaptation made to support students with the greatest needs, namely those with moderate or severe IDD.

The diverse nature of the demographic groups included under the term IDD, and their variable outcomes in relation to predictors of employability identified in the studies by Qian et al., (2018) and Park and Bouck's (2018) is reflected in associated literature. A key finding of Nord's (2016) research when he reviewed 39,277 people in vocational rehabilitation services in the USA was that 'people with IDD from different demographic groups had different outcomes' (p402).

Crucially, in his cohort, Nord found that individuals who had received 3 or more work-related services were 16 times more likely to gain employment.

Unfortunately, within this cohort, individuals with a cognitive impairment were the only population for whom this predictive outcome did not apply. This raises questions not only about the nature of support and training being provided to people with higher levels of need (as this was not detailed in the study) but also about whether current research is obscuring these issues through applying broad participation criteria.

Wehman et al. (2014) reviewed the effect of engagement in supported employment programmes on competitive employment outcomes. They found an association between being in employment and being a recipient of benefits and a high school graduate. However, this association should be considered alongside the fact that only those who graduated were put forward for supported employment programmes. This is relevant as the 20% increase in competitive employment was highlighted as an outcome for those who had been on supported employment programmes. Furthermore, it is not clear if the numbers in competitive employment were sustained, as the study did not review employment rates after the 90-day period when people were discharged from the supported employment programme. The importance of reviewing the success of competitive employment is pertinent given retention rates may vary considerably for people with IDD, as indicated below in the research undertaken by Holwerda et al. (2013).

In their US study, Simonsen and Neubert (2012) surveyed 338 young people with IDD 18 months after leaving school to establish their work situation. Of the participants surveyed, 57.1% were engaged in sheltered work or non-work-related activities, 14.2% were in integrated employment and 28.7% were in other

forms of community work-related models. In this paper, integrated employment was defined as standard community-based work, where the person received at least the minimum wage (4.5%). This was discussed alongside sheltered employment and other community work. Sheltered employment was defined as working alongside peers with a disability and receiving less than the minimum wage, while other community work would be, for example, where an 'enclave or crew' of people with IDD did cleaning work for 30 hrs a week in government buildings (Simonsen and Neubert, 2012, p.191). Similar findings regarding levels of integrated employment were found by Holwerda et al. (2013) who surveyed 735 young people with mild intellectual disabilities during their registration with the social security system in Holland. The follow up period of six months revealed that 67.5% of these individuals had not found work and 32.6% had found work. However, 17.6% had left their job, with only 15% working for six months. Survey uptake was high at 92.2%, though it could be argued that as participants were asked to complete the survey when registering for benefits, a level of coercive pressure may have been present.

These seven studies exemplify the level of complexity experienced by people with an IDD of transition age entering the working environment. This relates firstly to the numerous work settings and support available, including sheltered work, supported employment, other community work and integrated work. It is evident that certain criteria may limit access to some forms of support, e.g., supported employment in Wehman et al. (2014) being only offered to those who completed high school. Moreover, there are questions about employment rights in relation to the use of 'enclave or crews' of people working at minimum wage in contracted businesses (Simonsen and Neubert, 2012, p.191). Furthermore, only Holwerda et al. (2013) briefly monitored work retention after six months and their findings revealed that only 15% of the initial cohort of individuals was in employment at this stage. However, it is noted that this may not reflect the wider population of people with IDD in work: if they had become independent of benefit support they would cease to be registered. Nevertheless, it could be argued that high levels of self-determination and family support are significant due to the challenges of navigating the complex official support systems surrounding people with IDD. These complexities highlight the value of understanding more about the individual's lived experience of their journey to finding and retaining employment.

The predictive indicators highlighted in the studies of transition age individuals with IDD are echoed in adult studies for those over 25 years. A number of personal and social factors and work support options predict the increased potential to be in paid work. These include: the role of motivation (Rose et al., 2005), additional diagnoses alongside IDD (Bush and Tasse, 2017), levels of IDD (Nord et al., 2018), employment support (Moore et al., 2002) and increased levels of independence in the community (Moran et al., 2001; McGlinchey et al., 2013). Wehmeyer and Bolding (2001) expand on the importance of living and working with greater independence in the community as key in the development of self-determination and believe this should continue to be a central part of policy development.

There is an indication that low support needs are connected to employment potential. For example, those with mild intellectual disabilities are less likely to require support and more likely to live independently in the community (Moran et al., 2001; McGlinchey et al., 2013). However, the association between levels of IDD and the attainment of employment as indicated by a measurement of IQ is not fully supported. Martorell et al. (2008) found that IQ was not a significant variable in their quantitative research exploring the impact of different personal capacities on access to work. In their research, a comparison was made of two groups of people with mild and moderate intellectual disabilities, based on factors including IQ, self-determination, behavioural difficulties, psychiatric symptoms and social functioning. Of these factors all other variables, with the exception of IQ, were found to be negatively associated with access to paid work, highlighting the challenges to employment for people with complex co-morbidities. Similarly, for Nord et al. (2018) and Bush and Tasse (2017) additional clinical factors were important predictors to consider alongside IQ levels. The presence of an additional diagnosis of Autism (ASD), Down Syndrome (DS) and IDD were compared alongside choice making in the quantitative research by Bush and Tasse (2017). A review of survey data from people in receipt of public services across 27 states in the USA revealed that over a two-year period there were 19,880 people with ID, ASD or DS. The study controlled for levels of IDD and found that people with DS had the highest rates of pay in community jobs. The overall employment rates remained low for people with IDD and individuals with Autism had the lowest rates of employment. The research also identified that choice making (assessed by 6 questions in the survey about control over daily

activities) was positively associated with employment status. However, it was possible that the survey, although completed in a face to face interview, might have included responses provided by a care giver, such as a paid carer or family member. This may impact on the validity of the findings about choices, as over 35% of the cohort were categorised as having a profound IDD.

The study by Nord et al. (2018) also identified the impact of co-morbidities on the potential for employment, finding that individuals with an IDD who had communication and mobility issues, and those under guardianship, had a lower potential of gaining employment. However, unlike Martorell et al. (2008), Nord et al. (2018) did establish that an increased level of impairment related to a person's IDD was negatively correlated with working potential. Within the literature relating to predictors of employment in IDD, Nord et al.'s study (2018) was one of only a few that took account of environmental and structural factors, indicating (as with the educational programmes in transition age adults) the need to consider features beyond the individual and their network. Nord et al. (2018) reviewed a year of National Core Indicators from 26 states in the USA and sought to establish, alongside the effect of the level of disability experienced by the individual, the impact that having a service plan employment goal had on a person's work outcome, either in a community or a facility-based setting. Within their findings they indicated that people with an employment goal had a statistically higher potential for community work, leading them to call for a national conversation to address a system change within employment structures.

In reviewing this literature, it is clear that certain predictive factors positively correlate a person with IDD and the successful gaining of employment. However, it is equally evident that these associations have not been proved to be causal. Furthermore, the predictive features associated with the private and public employment environment and the characteristics of paid workers providing employee support remain relatively unexamined by comparison with the personal and social features of the individual with IDD. Subsequently, many of the strategies continue to put the onus on the person, their social situation and their personal network rather than on system change or on the skills of an adviser to establish the person's individual capabilities and help them navigate the social and cultural barriers (Johnson et al., 2010). Of the studies exploring the broader issues surrounding work for people with IDD, only one was found that examined the outcomes associated with the training needs of the employment coach or

consultant. Significantly, Butterworth et al. (2012) revealed, when comparing a group of employment consultants who received training with a control group who didn't, that there was an increase in work opportunities for the people they supported, which included more weekly hours worked, an increase in the hourly rate of pay and more work placements. Similarly, few studies explore the tools utilised to support people with IDD in the development of work-related activities. In their meta-evaluation of seven literature reviews relating to supported employment for people with IDD, Rusch and Dattilo (2012) highlight the lack of awareness of the tools utilised, arguing for consistent tools to promote the effectiveness of strategies employed in the workplace. These strategies include the use of self-management, the use of co-workers as opposed to job coaches in training and an improvement in the techniques for cueing staff into tasks required (i.e. pictorial prompts).

Ellenkamp et al. (2015) raise the concern that few studies focus on employers and how they work with people with IDD. In their systematic review of 26 articles that focused on the factors involved in people with IDD gaining or maintaining employment, they examined what features of a working environment best support people with IDD. They outlined five themes: positive employer decisions in supporting the person, the content of the job and the presence of job coaches, positive integration and positive work culture. Additionally, they noted that when employers had experience of working with people with IDD, they had a more positive view than those who did not have such experience. There is a lack of literature examining the working environment as experienced by people with IDD. When this is included, it is viewed as a 'homogenous independent variable' whose features are not examined or explored (Jahoda et al., 2008, p.15).

In summary, the predictive features associated with people with IDD of any age gaining employment have been examined largely in relation to personal factors. Conversely, the role of workers who support people with IDD into employment, the tools they use, the role of the employer and the role of the work environment are all features that are relatively unexamined.

#### **2.4.2. Outcomes of being in employment for people with IDD**

Research that has sought to establish the outcomes of being in employment for people with IDD has examined a number of key features linked to policy drivers. These features have included improvements in the quality of life, inclusion in the workplace and society and to a lesser extent, due to the limited focus of the studies, financial betterment. Research exploring the outcomes of being employed for people with IDD has primarily focussed on quality of life. However, this concept has been poorly defined. As a result, quality of life has tended to include analysis of the levels of inclusion experienced by the worker with IDD both in and outside the workplace. Both quality of life and inclusion will be discussed in this section and issues relating to how they are measured will be addressed.

Broadly, the literature shows that being in employment leads to improved quality of life outcomes for the person with an IDD (Kober and Eggleton, 2005; Verdugo et al., 2006; Jahoda et al., 2008; Beyer et al., 2010; Conroy et al., 2010; Flores et al., 2011; Akkerman et al., 2016). However, the comparators and definitions of quality of life outcomes applied in the studies are varied and their measurements indicate variable reliability. In two systematic reviews exploring the outcomes of work for people with IDD in supported and integrated employment settings, a variety of features supportive of improved quality of life were extrapolated. Jahoda et al. (2008) examined the quality of life for people with IDD in their review of thirteen case-controlled studies on the socio-economic impact of being in sheltered employment. They concluded that despite weaknesses in some of the studies, quality of life, individual wellbeing and autonomy were positive outcomes for people with IDD. However, they noted that a lack of social acceptance in the workplace was also indicated. Akkerman et al. (2016) considered factors linked to inclusion in their review of thirteen papers addressing job satisfaction. They extrapolated that satisfaction is higher if there is a greater sense of belonging, an absence of stigma and good social support from colleagues and supervisors in the workplace. Neither of these systematic reviews considered articles that used comparative data or addressed outcomes associated with financial wellbeing, although Akkerman et al. (2016) did recognise this limitation.

Flores et al. (2011) reported broader environmental and social features that support positive outcomes in quality of life. They state, in their exploration of quality of working life for 507 workers with IDD in supported and sheltered work in Spain, that an improved quality of life was associated with low job demand or stressors and good social support from co-workers and supervisors. Equally, Forrester-Jones et al. (2004) explored the impact of co-workers and argued that supported employment led to increased social networks. In their study of 18 people with IDD monitored before and after gaining employment, they found an increase of up to 10% in their network. Although promising, this was not found to be statistically significant. Moreover, the authors made the point that network size alone is not an indicator of an increased level of support or reciprocity of relationship.

Where comparator groups and extended studies were used in establishing quality of life outcomes for people with IDD, the findings were variable. Beyer et al. (2010) showed improved quality of life and satisfaction in people with IDD who were in supported employment. However, when these outcomes were compared with their non-IDD work colleagues, the participants with IDD had quality of life outcomes that were significantly lower. Similarly, Siporin and Lysack (2004) found that families and job coaches had differing (positive) perspectives on the quality of life of the employee with IDD compared to the employees with IDD themselves, which were negative.

Studies exploring the quality of life for people with IDD in different work settings have indicated both positive and negative associations between quality of life outcomes and different working environments. Beyer et al. (2010) revealed reduced quality of life and satisfaction outcomes for people in supported employment as opposed to those in day services. Conversely, Kober and Eggleton (2005) found a higher level of quality of life for those in open employment versus those in sheltered employment, arguing that there was an association between open employment and improved quality of life. Critically, in all these comparison studies, quality of life was only assessed as a one-off event, and therefore did not provide comparison against a baseline. It could be argued, therefore, that the individual's quality of life measure might have been the same prior to engaging in the work-related activity. Additionally, the validity of the quality of life improvement tool for people with IDD is questionable. The research by Conroy et al. (2010) explored improvements in the quality of life for

27 people taking part in microenterprise opportunities and highlighted a positive correlation between engagement with the opportunity and improved quality of life. However, the measure of quality of life used was dependent on a then and now measure of happiness gained in one assessment, which was reliant on the individual's memory of how they felt before and after. This has questionable validity for individuals who have cognitive impairments, as these can impact on their ability to manage complex information.

In summary, the quality of working life appears to have been the favoured outcome measure at the beginning of the century. Subsequently, inclusion appears to have replaced it (Humber, 2014). As it stands, the quality of working life is multi-dimensional in nature (Flores et al., 2011) and appears within the literature to be a 'catch all' for factors associated with work as an activity, including personal, environmental and cultural features. Despite the issues posed by variable definitions of quality of life within the literature, the mixed outcomes found in the research involving comparator groups indicate the need for greater consideration of the individual's wider environment. Significantly, nowhere within the literature is quality of life found to be defined by people with IDD themselves. Therefore, a greater understanding is required of the contextualised experience of work for people with IDD and the relationship to their construct of wellbeing, financial betterment and/or social inclusion.

Quality of life and its association with an improved financial outcome for the person with IDD was not addressed in real terms in the literature, even though high levels of poverty for people with IDD are widely reported as an international driver for policy (WHO, 2011). More broadly, there is a paucity of research that explicitly examines pay as an outcome for people with IDD. Only one paper was located that directly addressed this question as a sole issue in the USA. Kang et al., 2019, reviewed the earnings of over 26,813 individuals with IDD accessing vocational rehabilitation services, through applying a quantile regression analysis and ordinary least square. The authors identified that in these settings women earned less than men and individuals with less disabling impairments earned more (up to 30%) than those with severe disabilities. Yet it would appear the vocational working environment is mirroring the wider labour market, as during the programme both in relation to levels of equal pay and the fact that individuals had the opportunity to receive college and university training, thereby increasing their earning potential. It is unclear whether significant adaptations were being

made to support those individuals with increased disabilities, or whether higher earning work options would not be achievable or available to them.

The findings by Kang et al. (2019) echo studies that have touched on the topic of pay as part of the broader inquiry into work for people with IDD. In their US research exploring career advancement for low paid workers with IDD, Lindstrom et al. (2014) contend that participants in stable employment earn an annual wage significantly lower than the poverty line. Of the other articles referenced in this review, pay levels were not highlighted in terms above the minimum wage. This includes the work of Conroy et al., (2010), who highlighted that there were lower rates of pay for people involved in the microenterprise as opposed to when they were in sheltered employment schemes. Simonsen and Neubert (2012) observed that all 338 participants of their research study continued to be in receipt of disability benefits 18 months after leaving school. Jahoda et al., (2008), in their systematic review, refer to the fact that while there is a rhetoric that supports career development and choice for people with IDD, the reality for the majority appears to be low pay in jobs involving menial tasks with minimal social opportunities. While low levels of pay and precarious employment is known to affect people other than those with IDD (Taylor, 2017b), the lack of financial benefit in real terms and the insecurity and precariousness of work disproportionately affects people with IDD (Bates et al., 2017). In reality, the policy promises of improvements in employment participation and subsequent financial betterment seem to be absent for people with IDD (Johnson et al., 2010).

#### **2.4.3 Research in collaboration with people with IDD**

Few articles were found that directly engaged people with IDD regarding their perception and experience of work and what helped them, although some studies gave quotations that provided insight into people's experience in the workplace. Three studies that sought collaborations with people with IDD in the area of employment are outlined below. Alongside these is a reflection on the issues raised within the broader literature that draw directly on the reported words of people with IDD in the work setting.

Timmons et al. (2011) conducted participatory action research in the US. This involved interviewing people with IDD, their families and support providers to establish the factors that influenced their employment decisions. In their research they highlighted both social influencing factors, including family in the early years, the importance of school and community rehabilitation support, and personal factors, including gaining earnings, productivity, achieving the admiration of others, having quality social relationships and being a member of the community. However, while a co-researcher with an IDD was employed and took part in the interview process alongside the authors, there was no indication of their involvement in the data analysis or the development of recommendations. Moreover, although the authors individually interviewed sixteen participants with an IDD, they conducted a total of 28 interviews with family members and employment support staff. This subsequent information gathering is not clearly reported in relation to how the themes arose or developed, although quotations from participants as well as family and staff are equally represented.

Akkerman et al.'s (2014) exploratory study on job satisfaction using Photovoice, which aimed to gain the perspective of nine employees in unpaid sheltered and integrated employment in the Netherlands, revealed a partial application of this form of action research. The nine participants who took part did not appear to be involved in the data analysis, which applied a thematic coding based on grounded theory. Similarly, although there is a reference to the researchers asking about changes the participants would like to see in their workplace, this was not expanded, and no recommendations were articulated relating to policy changes sought by the community. Nonetheless the themes mentioned, including working conditions, job demands, social relations at work, opportunities for using competencies, opportunities for growth, support received, perceived autonomy and meaningfulness, indicate a depth and richness of data that appear to be absent from many other studies.

The third study, by Li (2004), explores employment experience through in-depth interviews with 18 individuals with a mild IDD in Hong Kong. All had experience of work and 15 of the 18 were in work. Li (2004) also highlighted rich data relating to the participants' experience of being in employment. Motivating factors for being in work included meeting family expectations, avoiding boredom, learning new skills and developing social networks. In the discussion, six

participants reported positive experiences of being employed and they all reported negative experiences, linked to poor relationships with co-workers or managers and getting admonished or disciplined in the workplace. However, in this very short article no methodological clarity was provided, with reference being made only to the method of interviewing and indirect reference being made to the use of grounded theory techniques. Seven of the 18 participants highlighted ways to promote their work opportunities relating to skill development and to changes in the systems and support around them.

In the studies by Timmons et al. (2011), Akkerman et al. (2014) and Li (2004), themes were raised that had been poorly addressed in the literature discussed earlier in this review. Three of the collaboratively orientated studies highlighted both positive and negative experiences taking place in the working environment and a desire to have increased opportunities in the workplace and to promote work skills (Akkerman et al., 2014; Li, 2004). The personal factor that was important to people with IDD at work was principally gaining earnings (Timmons et al., 2011), which the other literature gave very limited attention to.

The three articles considered in this section of the literature review might be criticised in relation to the varied levels of participant involvement in different aspects of the research design, analysis and dissemination. However, the experience and voice of people with IDD has greater prominence in these papers. The reason that their voice is perhaps not more evident in these three collaborative studies is due, in part, to the application of thematic analysis, namely, capturing diverse and poignant qualitative data under a broad theme. This is exemplified in these three collaborative studies, where direct quotations from the individual participants are included in the full body of the text and the nuance and meaning of their experience is communicated more vividly. An example of this is taken from Akkerman et al., (2014) who identified the theme of 'experienced job demands' and provided a quotation from a man who delivered medication to patients as part of his job. This man described an experience of verbal abuse, stating, 'I have one patient, he thought it funny 'hey dwarf' or something like that, I did not find that funny' (Akkerman, 2014, p.548). The challenges connected with the use of thematic analysis and its potential to disassociate and fragment the participant's experience was recognised as a risk within my collaborative research. To overcome this, separate aims were applied, firstly in the construction of the individual's narrative and visual work stories and

secondly in my application of the hermeneutic reduction (see Chapters 3 and 4 for details).

Within the wider literature that addressed work in IDD, some of the challenges faced by people in the workplace were highlighted. Wehmeyer and Bolding (2001) indicated that many sheltered working environments had limited scope for choice or autonomy. Restrictions within employment settings were equally found to have a negative effect on employment outcomes for people with IDD, including high rates of job loss (Moran et al., 2001). Moreover, Iriarte et al. (2014) found that the Irish population of people with IDD they consulted were dissatisfied with their income and low paid work. Banks et al. (2010) looked at the outcome of job breakdown on people with IDD, finding that while anxiety and depression scales were not negatively associated with job loss, people with IDD found the loss of work traumatic. This trauma appeared to have a negative impact on their self-image, with them calling themselves 'lazy' and 'useless'. Bigby et al.'s (2011) exploration of the experience of individuals with IDD and their carers in relation to retirement also highlighted negative language and negative perceptions. They concluded their findings by indicating that individuals who chose to retire did not have the financial remuneration, respect or support from their network when entering this phase of their life.

#### **2.4.4 Work-related occupational therapy research with people with IDD**

This review of the literature about the predictors of gaining employment and employment outcomes highlights not only a paucity of research involving direct experiences of people with IDD in this area, but also the challenges and complexity surrounding access to and retention of work for people with IDD. As stated previously, occupational therapists view it as part of their role to support people and agencies to overcome the complex barriers to work for those with intrinsic and extrinsic disabilities (Lillywhite and Haines, 2010). Although there is a limited quantity of research by occupational therapists directly addressing work-related issues for people with IDD (only five articles have been located), it largely supports the description of the occupational therapist's role as outlined above by Lillywhite and Haines (2010). By contrast with the preceding literature and perhaps in recognition of their role in addressing complexity, four of these

five articles focus on research with people with IDD and, specifically, the difficulties associated with a more severe IDD (Siporin and Lysack, 2004; Kahlin and Haglund, 2009; Ineson, 2015) or complex co-morbidities, namely mental health and forensic history (Smith et al., 2010). However, in the fifth of the five articles Coakley and Bryze (2018) do not provide sufficient details of the two participants in their research to establish their level of need.

Smith et al. (2010) describe the creation of an accredited work-based learning programme for people with IDD in a forensic service, working in partnership with a hospital, a further education college and a workplace. This course aimed to improve social skills, work skills and literacy and numeracy. While this paper described the positive qualitative outcomes for those patients involved in the pilot, the effectiveness of the pilot in preparing people with forensic histories to access employment on discharge were not within its scope and were a limitation of the research. Furthermore, Ineson (2015) was not successful in making an occupational therapy intervention to secure paid employment for the participant, who had a severe IDD, in this single case study research. In summarising her intervention, Ineson highlighted the lack of responsiveness from the three employment agencies she approached, the limited aspirations and condescension evident from the person's keyworker and home manager, as well as the tenacity required in 'marketing' the person she was supporting to employers. This highlighted the 'chasm' that exists between the aspirations of policy and the reality of putting these into practice (Ineson, 2015, p.63) and illustrates the complexity surrounding policy failure in the UK, as outlined in the previous section.

Kahlin and Haglund (2009) assert, like Ineson (2015) and Smith et al. (2010), the value of occupational therapy assessment and intervention in supporting people with IDD into work. Kahlin and Haglund (2009) partnered with a supported work provider in Sweden to assess the strengths and needs of people with IDD using The Worker Role Interview assessment tool. They concluded that of the 30 people they assessed who had moderate and mild IDD, significant psychosocial strengths positively affected their work role. However, although the assessment tool included the environment, adding in social and physical features, it remains an impairment-based tool that focuses predominantly on the individual's capabilities. Consequently, the application of a single assessment tool may be viewed as a limitation. This is in contrast to the range of assessment tools used

in the qualitative case study research completed by Coakley and Bryze (2018). In their research they assessed the value of occupational therapy intervention with two people with IDD in supported employment services in the USA. The assessments they provided included The Assessment of Motor and Process Skills (AMPS), the Occupational Self-Assessment (OSA) and Work Environmental Impact Scale (WEIS). Additionally, they outlined support for their practice by adopting the Occupational Therapy Intervention Process Model (OTIPM). In detailing the outcomes of their research, they highlighted an improvement in the two participants' AMPS scores on re-assessment and a positive response from the job coaches relating to the support from OT. However, the reliability and validity of the AMPS could be questioned. It was applied in a non-standardised format in order to support the person in relation to their IDD only one week following the intervention and it was not, therefore, clear if the improvements were sustained beyond this time. Moreover, details of the assessment findings and interventions provided by the OTs, including task and environmental adaptation, predominantly focused on the individual's capacity, including their need to adopt and adapt to environmental cues.

In their research, which employed a case study design, Siporin and Lysack (2004) explored the quality of life for three women with IDD in sheltered employment in the US. This is one of the few studies that included direct observation of people with IDD in their workplace. In a similar vein to previous studies, there is a weakness in the design that might be considered to undermine the self-reports and observations of the women with IDD in the study. Nine people were interviewed in total for the study, which included a family member and staff member for each participant. However, there was a lack of clarity about the source of the information analysed, i.e. it was not always clear if it was the person with an IDD, their family or staff member providing the contribution. Furthermore, it was unclear if the participants were involved in the data analysis process or construction of recommendations. However, central to the inclusion of the study in this literature review are the rich descriptive findings surrounding the participants' work lives, revealing a discrepancy between the perceptions of family members, the employers and the participants' own views. The women themselves reported limited choices, with two stating they didn't want to stay in their jobs. Inclusion and relationships were found to be their key priorities, with the participants reporting that they were pleased with the quality of the job they

did, their friendships with other people with IDD that they worked with and the social activity they engaged in with others outside work. However, inclusion for them was solely with other people who had an IDD in the community, rather than with their non-disabled colleagues. In their conclusion, Siporin and Lysack (2004) stressed the importance of occupational therapists becoming increasingly knowledgeable about the issues surrounding work-related activity and of them becoming advocates for policy change. This supports broader demands within occupational therapy research to prioritise occupational therapy intervention in employment (Priest and Bones, 2012; Machingura and Lloyd, 2016).

Central to the calls for research into employment to be prioritised is the need to seek the views of people with IDD. Siporin and Lysack (2004) note that the voice of people with IDD has rarely been heard when employment services are designed. In their systematic review Ellenkamp et al. (2015) reported the striking absence within the literature of both employers and employees with an IDD. Similarly, Lysaght et al. (2012a) highlighted that the subjective experience of social inclusion is not addressed in published studies and the perception of the person with IDD is overlooked. Furthermore, Akkerman et al. (2016) recommend the creation of a self-report measure for people with IDD to provide a qualitative account of their perception of work.

In this section, the literature on gaining employment and its outcomes has been discussed, highlighting the research gaps in the field. The current research base has focused on individual and social factors that support someone with IDD into employment, with employment support and the working environment remaining relatively unexamined. Similarly, the literature exploring outcomes for people with IDD in employment has centred on quality of life and, in recent years, inclusion. However, people with IDD have not been involved defining these terms and outcomes and the impact of pay on their lives have barely been addressed. In the few research studies that involved greater collaboration with people with IDD, experience is communicated through direct quotations. This illuminates a complex experience of work and its outcomes that is not fully explored in the wider literature. Finally, the limited nature of the research base associated with work, IDD and occupational therapy demonstrates the need for further research in this area, with people with IDD at the centre. In the light of these deficits in knowledge, there is a specific need for research to illuminate the lived

experience of people with IDD in paid work in their work settings and broader lives.

## 2.5 Summary

This literature review has outlined the political, social, cultural and healthcare research related to work for people with IDD, highlighting the research gaps and reasoning behind the focus of my collaborative research. In summary, the section ‘the focus on work: the policy context’, outlined the current failure of national and international policy in relation to increasing the number of people in employment with an IDD. It summarised the numerous ideas outlined to address these failings in terms of cultural perspectives, changes in metrics, terminology and outcome measures. Critically, it noted that none of the papers reviewed involved people with IDD in the evaluation or devising of policy or employment services. In summary, in light of the current policy failings, it is imperative that research is carried out that can learn from the 5.7% (DH, 2018) of people with IDD in paid employment.

The second section of this chapter, ‘the role and function of work’, examined the recent history of work for people with an IDD and the significant and complex relationship between work and the healthcare system past and present. It highlighted the relationship between the institutionalisation of people with IDD and the history and role of occupational therapy, noting that this is a relatively unexamined. Finally, it outlined the role and function of work and how it exists in conjunction with a contested ideology relating to the nature of disability.

In the final section, ‘The factors that help people find and retain work’, the research base associated with work and people with IDD was reviewed. There was an examination of research studies that addressed the factors involved in supporting someone into employment and the outcomes of being in work. In the literature on factors influencing the gaining of employment, a focus on individual features was identified. In the literature that addressed outcomes associated with quality of life and inclusion, there were weaknesses in the methods and a lack of involvement of people with IDD. This section also highlighted unexamined features in the research base relating to the nature of employment support, the role of the working environment and employers, the impact of having paid work

for people with IDD and the current limited knowledge about the lived experience of people with IDD in work. In response to this research gap my collaborative research addresses the question of what is the experience of people with IDD in paid work? It seeks to address the dual aims of illuminating the lived experience of six working people with IDD and gaining knowledge to inform other people with IDD, families, employers and workers supporting people with IDD in employment. The next chapter outlines the choices made about delivering these aims through the application of an appropriate methodology.

## **Chapter 3: Methodology**

### **3.1 Introduction**

In Chapter 2, the history of work for people with an IDD was contextualised within the social, healthcare and policy environment alongside empirical research exploring this issue. The chapter concludes with identifying the importance of illuminating and learning from the lived experience of the small number of people with an IDD who are in paid employment.

This chapter focuses on the decision to apply a hermeneutic phenomenological methodology to address the research aims, to hear the voice of people with IDD in paid work and to gain insights from them for other people with IDD interested in work, their families, employers and workers in employment services. Initially, the chapter will explore the qualitative methodological considerations and the decision to use inclusive research principles. It will expand on the rationale for applying hermeneutic as opposed to descriptive phenomenology, underpinned by critical realist assumptions, and the adoption of an interpretative epistemological position.

The hermeneutic phenomenological approach will then be discussed, including the subjective and intersubjective position, hermeneutic reduction and the role of reflexivity in the research. The use of visual and narrative methods that form the creative collaborative partnership will also be outlined. A reflective account of the exploration of the methodology also forms part of the Chapter (Reflexive account 2. Methodological considerations).

### **3.2 Methodological considerations**

#### **3.2.1 Inclusive research**

Walmsley and Johnson (2003) contend that research and methodological mechanisms have historically supported the subjugation of people with IDD. They assert that people with a disability have been under the control of others, which has led to people speaking for and about them in research. Smith-Chandler and Swart (2014) go further in their paper exploring the methodological

implications of narrative inquiry for people with disabilities, asserting that people with disabilities have been negatively conceptualised, marginalised, excluded and stereotyped. With this in mind, they observe that parity and equality in research relies on how disability is conceptualised and theorised. They challenge the homogenisation of people with a disability and cite that previous research has perpetuated disablement. Consequently, inclusive research principles are recommended to redress the central premise of the power relationship between those being researched and the researcher (Nind, 2014, p.73).

Walmsley and Johnson set out principles for inclusive research that include:

- Those involved in the research have a commitment to social change arising from it. There may be a commonly shared definition of what this constitutes among the people involved in it at the commencement of the research process or this may evolve as the work continues
- There is a commitment to taking people's words seriously, to believing them as credible respondents with their own understanding, without a need for triangulation or other checks
- The research is undertaken with the aims of empowering those involved in it. This may involve empowerment in terms of consciousness raising and preparedness for action resulting from the findings of the research and designed to achieve social change. It may also involve empowerment in terms of learning new skills through doing the research itself
- Research is holistic in nature, concerned not to fragment the individual, but rather to focus on freeing their voices and enabling a consideration of lived experience, taking into account the broader context of their lives (Walmsley and Johnson, 2003, p.41)

The authors go on to caution that it is not sufficient to access the voices and views of the disadvantaged, as they themselves should be taking control of the action, whether it relates to social policy or research. They observe that there is a risk specifically in relation to data analysis: if interpretation undermines a contribution the empowerment of the collaborator or co-researcher is diminished

(Walmsley and Johnson, 2003).

The application or doing of inclusive research was explored in a collaborative research study by Nind and Vinha (2012). Their findings highlighted four principles that emerged from discussion of working in partnership, including learning from and listening to each other, enabling new researchers by clarifying things with them, making communication accessible and being honest (Nind and Vinha, 2012). With regard to the methodology applied to inclusive research, a wide range of approaches and methods have been used including, but not limited to, emancipatory, participatory, partnership and user led (Nind, 2014). Nind and Vinha (2012) argue that, as this diversity of approaches indicates, ‘there is no right way of doing it’ (p108) and that defining a specific approach to conducting inclusive research may inadvertently lead to it becoming rarefied and separate to wider research.

My collaborative research has sought to hold closely to the principles of inclusive research outlined by Walmsley and Johnson (2003) and to apply the flexibility of approach on how to do research inclusively as summarised by Nind and Vinha (2012). In applying this approach both the terminology used for the individuals involved in this research and their role was considered and the term research collaborators employed as opposed to research participants. This decision was taken firstly to reflect the partnership and collaborative nature of involvement by the collaborators in each phase of the study and exemplified in the creative collaborative partnership (See Chapter 4). It highlights that the research collaborators were instigators of ideas, authors, co-analysts and disseminators of the research. Furthermore, the term research collaborators also sought to reflect in linguistic terms the power balance within my collaborative research that drew on joint decision making and joint ownership of the research findings.

Nevertheless, I equally recognise my collaborative research’s limitations in not being fully inclusive. I acknowledge the suggestion that inclusive research is incompatible with the requirements surrounding doctoral studies (Bjornsdottir and Svensdottir, 2008). Additionally, I acknowledge, as do Bjornsdottir and Svensdottir (2008), that a doctoral project ‘will most likely receive little attention from policy makers and professionals’ (Bjornsdottir and Svensdottir 2008, p.265). Consequently, it will be difficult to see, without significant access to policy and change makers, ‘social change arising from it’ (Walmsley and Johnson, 2003).

Nonetheless, this has not diminished my commitment, working in conjunction with the research collaborators, to pursue social change and influence the practice of occupational therapists working with people with IDD in relation to employment.

### **3.2.2 Qualitative methodological considerations**

The process of engaging in qualitative research is presented by Finlay (2006) as akin to ‘going exploring’ (p.3), in that it involves embracing uncharted territory and choosing between a large number of options. In the preliminary phase of this research consideration was given to these options, in discussion with supervisors, during a period of attending the university’s postgraduate studies programme and carrying out personal reading. There was then a process of narrowing down the options until the selection of phenomenology and hermeneutic phenomenology was achieved. An overview of this process is summarised below, with a discussion of the principal benefits and criticisms of each methodology in relation to this project. It concludes with an exposition of the chosen methodology of hermeneutic phenomenology.

During the initial phase of the research I gave consideration firstly to grounded theory (GT) and ethnography. These methodologies were excluded as they were viewed as incompatible with achieving the research aims even though they were recognised as having significant strengths. In GT, the benefits afforded by the structured method leading to systematic generation of theory (Stanley, 2006) was, I recognised, attractive in its potential to provide a hypothesis and theory related to engagement in work for people with IDD. Similarly, ethnography, in its study of culture through observing its members and listening to them in context (Holloway and Galvin, 2017) was perceived as potentially advantageous in offering me the opportunity as researcher to spend time with the collaborator doing their job in their work setting. I recognised this situated observation could have been particularly valuable, as there would be less reliance on the ability of the collaborator to verbally communicate their job role and experience. Nevertheless, the central focus of the ethnographic study would be to devise a portrait of the work culture. This, though important, was considered to be a departure from my research aim, which was to gain the individual’s voice

(perceptions and opinions) in exploration of their individual experience of work as a phenomenon. Similarly, within my collaborative research the GT focus on hypothesis and theory generation was viewed as a limitation as this was not congruent with the primacy of the research collaborators in directing the study.

Following consideration of GT and ethnography the potential of narrative inquiry was reviewed as I recognised a resonance between the method of establishing the occupational narrative and the research aims. Furthermore, I was aware that biographical methodologies are suggested to provide the greatest opportunity for self-representation for the research collaborators, in their focus on the individual and their story (Atkinson and Walmsley, 1999). However, I observed that there appeared to be uncertainty in the theoretical basis of narrative inquiry, the application of analysis within the approach and in relation to the researcher's position. These features, I believe, resulted in limited transparency in applying appropriate safeguards in the research. However narrative research was identified as a positive, encompassing term, incorporating many approaches including phenomenology (Holloway and Galvin, 2017). The strengths outlined regarding self-representation and gaining insight into the individual's story, I anticipated to benefit this research and this will be discussed further in section 3.6.

I also gave consideration to action research and a branch of action research, photovoice. Action research is defined as research that seeks to address a specific aim of a community or service collectively, with results focused on agents of change for that community (Koch and Kralik, 2006). Although accepting that participatory action research now sits as part of a 'family of overlapping approaches' (Nind, 2014, p10), that inform inclusive research it was discounted due to the origins, recruitment and ethical considerations of my research. This will be described in consideration of photovoice below.

Greater attention was given to photovoice as I wished to explore methodologies that offered adapted forms of engagement for participants supporting inclusive research principles. As a methodology, photovoice is a form of participatory action research. It has been welcomed within the research literature in recent years as an empowering method for facilitating the increased involvement of people with an IDD in research (Jurkowski, 2010; Walton et al., 2012; Schleien et al., 2013; Akkerman et al., 2014; Povee et al., 2014; Cluley, 2017; Overmars-

Marx, 2017). Photovoice addresses three goals, including enabling communities to communicate their concerns and strengths, promoting critical dialogue and knowledge of these issues within group discussion and ensuring this knowledge reaches policy makers (Wang, 1999). Central to its application in IDD is: the establishment of a group or community of people with IDD; their collective identification of a theme to be researched; the selection of photographs that reflect the theme either by the individual or group; the identification of themes that occur across all photographs; and finally, the targeting of policy makers beyond the group with the findings (Booth and Booth, 2003). However, as with participatory action research, I did not consider photovoice to be compatible with the aims of my research. My collaborative research is not based on an issue identified by a community of people with an IDD, which following critical dialogue delivered direct and multi-level outcomes in action and advocacy as recommended in photovoice methodology (Catalani and Minkler, 2010). As research this project originated from my clinical practice and forms part of my doctoral studies. Furthermore, I recruited research collaborators individually, therefore participants were not part of a pre-existing group. Additionally, in order to maximise the engagement of any potential research collaborator, full anonymity was offered within the research process relating to engagement with any group, exhibition or dissemination activity.

While photovoice has not been adopted as a methodology, I have given consideration to its use of image making and the learning contribution it can bring to this research. It can be empowering, accessible and engaging for people with IDD, due in part to the application of the visual image making process (Povee et al., 2014). Furthermore, it has been more successfully applied when it has been tailored to meet the needs of the person with IDD (Cluley, 2017) and, potentially, adapted to be guided photovoice (Overmars-Marx, 2017). This is where the researcher accompanies the participant when taking the photographs to support the image making (Overmars-Marx, 2017). In summary, both Cluley (2017) and Overmars-Marx (2017) stress the importance of catering to the needs of each individual participant due to their variety of needs. This was important learning for my collaborative research, supporting the call to make reasonable adjustments and provide further support in the making of images to enhance the engagement of the research collaborators.

Finally, in the exploration of methodological considerations, phenomenology was

considered a natural fit, both in terms of the centrality of the lived experience of a specific phenomenon and its focus on the individual's everyday life (Holloway and Galvin, 2017). These essential components, consistent with both descriptive and interpretative phenomenology (Holloway and Galvin, 2017), are recognised as matching the aim of the research to illuminate and learn from the lived experience of having an IDD and engaging in paid work. There was a desire to do research inclusively and offer flexibility in the methodology in order to embrace the creativity implicit in the creative collaborative partnership. There was also a wish to give experience a central place in the methodology. This therefore led to the decision to adopt a hermeneutic phenomenological perspective. Discussion surrounding this decision will be expanded on in section 3.3 below, with particular reference to phenomenology's philosophical foundations.

### **3.3 Phenomenology**

Phenomenology as a philosophy was characterised by Moran (2000) as being a practice of doing philosophy, rather than a set of dogmas that exist within a system, aiming to get to the truth of phenomena. It is noted to have no agreed method, no agreed theoretical perspective regarding knowledge, consciousness and the world (Moran, 2000). It is not surprising, therefore, that when applied as a research approach, it is perceived as being unlike other approaches in that it 'does not categorise or explain behaviour nor does it generate theory. It seeks solely to do justice to everyday experience, to evoke what it is to be human' (Finlay, 2011, p.3). As this quotation from Finlay (2011) indicates, there is an element of exploration and discovery in establishing a phenomenological project which, it could be argued, mirrors the process contained in conducting the research itself. This section will commence with an expansion of the points relating to methodological considerations, particularly concerning the decision to apply a hermeneutic as opposed to descriptive phenomenological approach. This will be followed by a discussion of hermeneutic phenomenology and its application to this research, including the ontological and epistemological considerations.

Phenomenology, when defined in research, is identified as an exploration of meanings and structures of experience that include the study of phenomena (Holloway and Galvin, 2017). As a philosophical field, phenomenology is both singular and pluralist, stemming from a number of philosophers including, but not limited to, Husserl, Heidegger, Merleau-Ponty and Sartre (Smith et al., 2009). Husserl is considered to have inaugurated phenomenology as a way of doing philosophy at the turn of the 20<sup>th</sup> century, in his second volume of *Logical Investigations* (Husserl, 1970). In this text, he saw the need for a wide-ranging theory of knowledge. He set out his desire for a more inclusive phenomenology of experiences, challenging the positivist view of science and its claims on knowledge and referring to the 'intuitively seizable and analysable in the pure generality of their essence' (Husserl, 1970, p.249). The most significant and important internal critique of Husserl's phenomenology came from Martin Heidegger, who rejected three of its central features. Significantly, Heidegger stated that phenomenology must not be content with descriptions of consciousness but must attend to 'Being-in-the-world', as humans are always and already in the world (Heidegger, 1962, p.169). Drawing on theological hermeneutics, Heidegger asserted that every description includes interpretation, which is a form of description. Finally, he stated that phenomenology was the approach to highlight the 'question of being', therefore ontology was only possible through phenomenology. However, he did not question the essence embodied in the phenomenological approach, namely the process of allowing things to reveal themselves through the subjective experience (Heidegger, 1962).

Finlay (2011) observes that all phenomenology is descriptive in some sense, although most researchers and scholars distinguish between descriptive and hermeneutic (interpretive) phenomenology. As a methodology, descriptive phenomenology is largely understood to hold to Husserl's original project examining the collective 'essence' of phenomena, while interpretive phenomenology aligns with Heidegger and contextual variants of the lived experience of phenomena (Finlay, 2011). Husserl (1970) challenged the positivist view of science and its entitled claims on the origin of knowledge, referring to the 'lifeworld', which he defined as the everyday life that we all are part of and take for granted. In order to examine everyday experiences truly, he asserted the need to adopt a 'phenomenological attitude', which involved

stepping out of our ‘natural attitude’ of observation to a reflexive position on those objects and experiences (Smith et al., 2009). This shift in viewpoint he termed ‘bracketing’ and believed that this led the person into a position of ‘transcendental subjectivity’ or ‘reduction’, which allowed phenomenological insight to occur (Husserl, 1970). In the process of reduction and immersion in the text the researcher is encouraged, as in the guidance by Moustakas (1994), to dwell with the data and extract themes, which reveal the hidden nature of the phenomena itself. Unlike Husserl, Heidegger believed that it was not possible to be outside the world or bracket oneself off from the world. In his seminal work *Being in Time*, Heidegger (1962) defines and builds on his term ‘*Dasein*’, which is literally translated as ‘there-being’ and is concerned with the quality of human existence concretely situated in the world, namely ‘worldliness’. *Dasein* for Heidegger (1962) is ‘always already’ in people’s pre-existing worlds of culture, objects and language and cannot be separated from it. This overlapping relationship with the world is conceptualised in the term ‘intersubjectivity’ (Heidegger, 1962).

Although the differences between descriptive and hermeneutic phenomenology are clearly articulated by philosophy scholars, many of the features of both approaches present as shared and overlapping (Holloway and Galvin, 2017). These include a focus on the ‘lived experience’ of participants, definitive examples of phenomena and the unique individual everyday experience (Holloway and Galvin, 2017). In fact, it has been argued they could be seen as different ends of a continuum, with researchers valuing one end or the other more highly (Finlay, 2011). These approaches differ in their detail, relating to their focus on and approach to working with the phenomena (Holloway and Galvin, 2017). Given the collaborative nature of this research greater value has been placed on hermeneutic phenomenology, whilst acknowledging the areas that overlap across the two approaches. The intent of my research question is to illuminate the lived experience of people with an IDD in the context of their life world of work, as a phenomenon. It seeks, through a hermeneutic reduction, to connect with lived experience and to avoid generalisation. Therefore, a methodology that sought the universal essence of phenomena (or activity) (Lopez and Willis, 2004), without full consideration of the individual’s life, would not have supported the research aims. Furthermore, the ‘bracketing’ stance of the researcher outlined in descriptive phenomenology, namely, to be separate

from the world they are studying by being fully engaged in the phenomena in a new way (Finlay, 2011), is questioned in my collaborative research. Interestingly, Husserl's students questioned the achievability of bracketing at the time of its proposal (Smith et al., 2009). Bracketing was identified as being incompatible with this research, as it stands apart from the lives of people with IDD and is therefore not congruent with inclusive research principles. Consequently, it potentially undermines the ethical safeguards of the research.

Moving away from a traditionally descriptive phenomenological research approach may be associated with some risks. Van Manen (2017) cautions against phenomenology being confused with psychology, stating that therapists and psychologists might be interested in how people see or interpret their experiences. However, this, he argues, is not phenomenology; instead, he stresses that phenomenology is a study of how things give or reveal themselves. This research acknowledges these risks and recognises the importance of establishing the phenomena to be explored, the ontological and epistemology position and the role of the hermeneutic phenomenological attitude and reflexivity. Therefore, these features will be discussed in the section below in a consideration of how to apply the hermeneutic phenomenological approach.

## Reflexive account 2. Methodological considerations

*I am seriously in a fog, having spent the day with the phenomenological philosophers and feeling like I might as well have cut myself loose upon the sea for the sheer sense of terror that it's all raised. Far from feeling like I'm finding ground, I instead feel like I'm drifting away entirely from phenomena and I can't see the methodology. It feels like soup.*

I remember feeling a great sense of interest and excitement when I first began to read the phenomenological philosophers. Then as the above quotation taken from my reflexive diary communicates, I got quite lost and disorientated. This became even more the case as I explored other methodologies and what they could teach me about the use of the visual as I grappled with the idea of what I've called a creative collaborative partnership.

In returning to the philosophers, once I'd identified the hermeneutic phenomenological approach, I was both challenged and moved by the biographical details of their lives, particularly in relation to their interaction with the Nazi era, as outlined by Moran (2000). Although I'm highly reluctant to draw parallels with the grotesque metanarrative that was Hitler's Germany, faint echoes resonate for me with the past and present treatment of people with IDD. Issues related to the abuse of power, homogenisation, institutionalisation, abuse and belittlement in terms of their humanity.

I recognise that history, both a long time past and more recently, has led to my conviction of the importance of the centrality of the person with an IDD in my clinical practice and research. In making this journey through the methodology, I appreciate that it means I run the risk of being almost evangelical in my commitment to maximising inclusion with the collaborators and avoiding the risk of negatively conceptualising people with IDD, wishing to support them to communicate the whole contextualised story (Walmsley and Johnson, 2003). In this respect, my

focus has strongly aimed to do ‘justice to everyday experience, to evoke what it is to be human’ for people with an IDD (Finlay, 2011, p.3). However, I’ve realised that this too runs the risk of being a fixed biased position like any other. Although it’s impossible to avoid all bias, it’s been reassuring to recognise the importance of methodology and its centrality and role in providing a framework of associated safeguards.

### 3.4 The research position

Critical realist assumptions have been adopted within this research as they acknowledge a pre-existing external reality, mediated by and through the person and their experience, which is contextually situated (Bhasker, 1979). The adoption of critical realist assumptions and their foundational function in underpinning this research and methodology will be discussed from an epistemological and ontological perspective. The research position will also include reference to relevant phenomenological and occupational perspectives.

In recent years, critical realism has been increasingly embraced within health and social care research and its capacity to account for the complexity experienced in clinical practice valued and espoused (Angus, 2011; Craig and Bigby, 2015; William et al., 2016). This value is asserted firstly in relation to a symmetry between its philosophical principles and health science (William, et al., 2016). Additionally, it is reported to improve and increase the conceptualisation of complex health and social care issues, leading to more effective solutions (Angus, 2011) that take into account the multifaceted nature of the public sector environments (Craig and Bigby, 2015). Similarly, Shakespeare (2014) asserts that critical realism is the appropriate approach in understanding disability and the social world, as it allows for complexity. He goes on to reflect on the importance of a critical realist approach because it distinguishes between the ontological and epistemological. In the discussion of disability, he states, ‘critical realists believe that there are objects independent of knowledge: labels describe, rather than constitute, disease’ (Shakespeare, 2014, p.73). Furthermore, he observes that a critical realist perspective provides a foundation on which to devise an understanding of disability, in part due to its expansive capacity to

combine traditional approaches, social constructivism and the social model of disability.

The importance of critical realism to my collaborative research is additionally in its symmetry with an interpretive epistemology, where reality operates in three domains and the first-person account is considered real and part of a shared reality within society (Dannermark et al., 2002). The three domains in critical realism are defined as the ‘real’, ‘the actual domain’ and the ‘empirical domain’. The ‘real’ is where mechanisms and structures exist that have the ability to produce an event (whether they do or do not). When an event takes place, whether it has been acknowledged or not, this takes place in the ‘*actual domain*’. Finally, when such an event is experienced it becomes an empirical fact and comes under the ‘empirical’ domain (Dannermark et al., 2002).

Within phenomenology, researchers are observed to adopt a largely realist or critical realist position as they seek to illuminate how phenomena and their essential structures are experienced in an individual specific reality (Finlay, 2006). Giorgi’s (1994) paradigm, grounded in critical realism (Finlay, 2012), proposes that rather than making statements about reality, the way phenomena presents itself is described. In his phenomenological paradigm he asserts that reality is independent of consciousness, but that knowledge can only come through consciousness of it. He states:

The researcher’s phenomenological task, then, is not to specify in advance what reality is about but to describe the nature of reality as taken up and posited by the research participants. This frees the researcher to discover reality claims that may be outside of his or her ‘*a priori*’ specifications. (Giorgi, 1994, p 203)

Consequently, the researcher engages with the participant and their reality as they engage in the three domains outlined within the critical realist perspective. Furthermore, within phenomenology, the researcher is situated in the research context and known to be part of the world being studied (Finlay 2012). This will be expanded upon in the subsequent section (Hermeneutic phenomenology: the research application).

The philosophical base in phenomenology is important in this research due to its resonance with the theory base of occupational therapy and the focus of this

research. Central to the professional belief of the occupational therapist is the premise that people are ‘occupational beings’ (Clark, 1997, p.86). Similarly, Arendt (1958) asserted that the human condition could be understood through acts of doing, outlined as ‘work’, ‘labour’ and ‘action’, which when considered together were termed *Vita Activa* (Arendt, 1958). Although identifying herself as a social theorist as opposed to a phenomenologist, her work has been characterised as a breed of phenomenology concerned with the public space, which is a ‘world of appearances’ (Arendt, 1958). Arendt’s phenomenology addresses human living in the world with a particular interest in the world that exists between people (Arendt, 1958). Her most important work, *The Human Condition* (Arendt, 1958), presented a phenomenological account of human action in the public sphere, focusing on the plurality of people. Arendt defines labour as the enclosed and repetitive world of necessity, linking it to the physical life of people ‘the human condition of labor is life itself’ (Arendt, 1958, p.7). Work, conversely, is presented as the ‘artificial’ world of objects that humans have created on earth and actions, which are links to our potential as specific individuals and in our connection with mankind, a source of hope and danger (Arendt, 1958). Unsurprisingly, the importance of *The Human Condition* has been acknowledged within occupational therapy, particularly in recognition of its symmetry with occupational science theory (Jansson and Wagman, 2017).

Jansson and Wagman (2017) assert that Arendt’s seminal work offers occupational science a more profound perspective on occupation. Of interest in the case of this collaborative research is the connection they identify between occupational deprivation, namely being deprived of the opportunity to engage in occupation and Arendt’s concept of ‘being deprived of the capacity to act’ (Arendt, 1958, p.188). Arendt (1958, p246) states that action is ‘the one miracle-working faculty of man’ and is essential for human beings, operating in the public sphere where it takes place in and through interactions with people, with the power to influence and bring about change. Furthermore, Jansson and Wagman, (2017) highlight that not having access to the action modality can lead to exclusion from the public sphere, an assertion that resonates and expands on discussions surrounding the inclusion of people with IDD in the working world.

Within occupational therapy, it is understood that occupation or ‘doing’ takes place in an environment (both social and physical), with objects, in time and through engagement of mind and body (Taylor, 2017a). This non-dualistic

perspective on mind and body and the acknowledgement of the temporal and cultural contextualising of activity equally resonates with phenomenological philosophy. Heidegger's (1962) *Dasein*, or 'always already', situates the 'lived experience' in people's pre-existing worlds of culture, objects and language and makes the proposition that it cannot be separated from it (Heidegger, 1962). Similarly, Merleau-Ponty's perception of the body-world constitution, namely that 'the body is the vehicle of being in the world' (Merleau-Ponty, 1945, cited by Finlay, 2011), resonates with occupational therapy theory as outlined in Keilhofner's Model of Human Occupation (Taylor, 2017a). Merleau-Ponty presented a new focus on the body, not as an object in the world, but rather as the way that humans interact and communicate with the world (Smith et al., 2009). Similarly, phenomenology is non-dualist in its perspective, proposing a unification of the mind and body (Moran, 2000). Furthermore, Jean-Paul Sartre's development of existential phenomenology, expounded in *Being and Nothingness*, focused on the 'phenomenon of being' (Sartre, 1995). In this, he observed the importance of social and personal relationships, pointing out that our own experience is dependent in part on the absence or presence of others (Smith et al., 2009). Although not adopting an existential position, this thesis and occupational therapy acknowledge the importance of the social environment in supporting or restricting human doing (Taylor, 2017a).

While there is a synergy between phenomenology philosophy and occupational therapy, this should not be overstated, as there is a difference between philosophical resonance and clinical practice. However, acknowledging theoretical influences through applying the reflexive position is in line with the key tenets of hermeneutic phenomenology and critical realism. This supports rigour and transparency in the application of the methodology (van Manen, 2002).

### **3.5 Hermeneutic phenomenology: the research application**

(Hermeneutic)...phenomenology also pursues the intertwining of science with art, the imparting of a poetic sensibility to the scientific enterprise. Science in this sense blends with the stylistic realms of the humanities. It is this artful rendering of science which hermeneutic phenomenologists are drawn towards. (Finlay, 2011, p.109)

Finlay (2011) observes that phenomenological research offers a bridge across the expansive divide between practice and research for therapists, as it draws the theory-based research world and clinical world together. However, as mentioned, phenomenology as a research tool does not prescribe a method (Smith et al., 2009). As van Manen states, ‘there is no step by step model that will guarantee phenomenological insight and understanding.’ (2017, p.777). Nevertheless, there are four characteristics described as supporting its application in hermeneutic phenomenology: a commitment to the use of interpretation; a focus on building beyond science towards the humanities; the researcher’s reflecting on their involvement reflexively; and attention being paid to expressive writing, with the potential use of myth or metaphor (Finlay, 2011). These four characteristics will be examined in terms of their application within my collaborative research. Firstly, the role of interpretation and its epistemological implications will be addressed, followed by a discussion of the phenomenological attitude adopted and then a consideration of the reflexive position of the researcher. Finally, an exploration of the artistic and expressive dimensions in collating and communicating the findings of the research will be examined.

### **3.5.1 A commitment to the use of interpretation**

The explicit application of the interpretative position has been of central importance to this research. It is asserted, epistemologically, that the longstanding influence of the philosophy of phenomenology is the abiding way it has protected the ‘subjective view of experience as a necessary part of any full understanding of the nature of knowledge’ (Moran, 2000, p.21). In hermeneutic phenomenological research, the phenomena is illuminated in the contextualised ‘lifeworld’. It seeks to go beyond description to explore the meaning ascribed to activity in daily life. It supports and centralises the subjective experience of the research collaborator, alongside acknowledging the researcher as having a meaningful and valuable role in the inquiry process (Lopez and Willis, 2004). The epistemological position associated with the interpretivist stance within hermeneutic phenomenology states that situatedness is a determinant of understanding (Finlay, 2006). Furthermore, it acknowledges that the researcher is part of the research world being explored, whose interpretations are intertwined with the findings. Consequently, a researcher/collaborator

intersubjectivity is adopted (Finlay, 2011), which is described as a process of ‘mutual identification where self-understanding and other-understanding is intertwined’ (Finlay, 2005, p.290). This research has acknowledged and sought intersubjectivity within the creative collaborative partnership, appreciating its compatibility with doing research inclusively as defined by Nind and Vinha (2012) and its recognition of both separate and shared experience. Similarly, Gadamer’s perspective that the strength of a shared moment or ‘event’ of understanding brings a level of enlightenment (Moran, 2000) is equally seen as being congruent in part with my research position. The event, understood in dialogue, is defined as a ‘fusion of horizons’ and is suggestive of a resolution in dialogue (Gadamer, 1975), the act whereby people connect with the world (Moran, 2000). In this research, interpretation developed from meetings between me, the collaborator and, at times, the photographer, in shared space. In the process of being embodied in an intersubjective space empathy was facilitated and the beginnings of a co-created dialogue occurred (Vessey, 2009).

A challenge to the adoption of a hermeneutic ontological position comes from how things reveal themselves. Moran (2000) has criticised Gadamer and Heidegger for linguistic idealism in their assertion that things reveal themselves only through language, namely that ‘being’ was understood through language. Furthermore, it has been argued that Heidegger’s prioritisation of language stands in opposition to *Dasein* and the importance of context, which includes culture and objects in addition to language (Moran, 2000). However, this thesis, while not supporting linguistic idealism, does acknowledge that as people with an IDD are likely to have difficulties with written and verbal communication, the ability to engage with and understand their lived experience purely in linguistic terms is restricted. Similarly, Gadamer’s (1975) ‘fusion of horizons’, namely the connecting in time through dialogue, was identified as confined by the sole use of language. However, within my collaborative research it was found, and is presented, as occurring during communication that is not dependent on language alone. Consequently, these considerations have been weighed up when devising the method for this project. The aim was to maximise collaborator engagement in the research process but also, crucially, to illuminate and enrich the communication of their lived experience and their engagement with work as a phenomenon.

A further feature implicit in the use of an interpretive and hermeneutic approach is that of the researcher's analysis. Polkinghorne (2007) examined the risks in relation to participants' stories in his exploration of the narrative, arguing that if a researcher has a section on the interpretation of the stories, this needs to be justified. He states that not all narrative research studies propose an interpretation, as the stories themselves are often presented as profound insights into the lived experience. The call for a lack of interference with or analysis of the story is central to life story work with many people from marginalised groups, including those with IDD, and this will be explored further in the next section.

Polkinghorne observes that if a researcher does comment on a text, it should be a 'commentary that uncovers and clarifies the meaning of the text' (2007, p.483).

The hermeneutic philosophical position, specifically Schleiermacher's perspective, suggests that interpretation of the text could lead to a better understanding of the individual than they might have of themselves. Smith et al. (2009) caution that this runs the risk of research analysis being presented as having greater truth than the words and language of the person themselves. Gadamer highlights the complex relationship between the interpreter and the interpreted, stressing the need to distinguish between the meaning of the text and the meaning of the author of the text. He states that there is a process of continual projecting that occurs when you interact with the text, namely, it is through the interaction with the text that your preoccupations emerge and they cannot be identified without that interaction (Smith et al., 2009).

In this collaborative research the adoption of an interpreter and interpreted position, or interpretation in its conventional sense, has been rejected, as it would undermine the research collaborators and their identity as valued respondents with their own understanding (Walmsley and Johnson, 2003). However, I equally acknowledge the paradox that interpretation is unavoidable in phenomenology as 'it is concerned with meanings that tend to be implicit and/or hidden' (Finlay, 2012, p.23). In this respect, the position adopted in this research, drawing on Gadamer and described by van Manen (1997), states that interpretation suited to phenomenology is pointing to something, as opposed to interpretation that points out a meaning and imposes a framework. Supporting this interpretative position is the application of the creative collaborative partnership detailed in Chapter 4 and Nind and Vinha's (2012) principles for doing research inclusively (learning from and listening to the collaborators,

clarifying things, being honest and making adjustments to maximise communication and involvement). Furthermore, reflexivity and reflection through the use of a reflexive diary and within supervision were of central importance and are discussed below.

### **3.5.2 Reflexivity: reflecting on the researcher's involvement**

Within this research, both the photographer and I applied the hermeneutic phenomenological attitude. This attitude does not propose to 'bracket' or set aside the researcher's involvement in the study, but rather consists of openness to the phenomena being expressed (van Manen, 1997). In this position I, as researcher, was prepared to wait to be surprised and moved by the research; specifically, I was open to a shift in understanding and I was prepared for my perspectives and preoccupations to be altered (Finlay, 2011). In relation to the application of the hermeneutic phenomenological attitude, van Manen (1997) asserted that the hermeneutic reduction involves applying a reflexive examination and thinking through of the variety of preunderstandings that affect the reflexive gaze. He asserted that this process of examining is not targeted at the researcher gaining a perfect vantage point, as this would not be achievable, but rather that it ensures the meanings ascribed to the lived experience of the collaborators are explored, as opposed to being superimposed with a construct of meanings (van Manen, 1997).

In applying the hermeneutic reduction, I embraced an appreciation of Heidegger's (1962) description of the hermeneutic structure of the question, namely the 'fore-conception' in the question, reflexively as a researcher. I acknowledged my focus, as an occupational therapist, on the occupational narratives of collaborators. I recognised the risk of seeking the answers I wanted to hear and used my reflexive diary to challenge this and go back to the narratives afresh. Similarly, I applied Heidegger's (1962) construct of the hermeneutic circle within the hermeneutic reduction. Heidegger (1962) contended that discourse is circular, but not a closed circle or frustrated like a rationalist debate but rather involving a relatedness that has a backwards and forwards motion (Heidegger, 1962). The hermeneutic circle is concerned with the dynamic interplay in the relationship between the part and the whole. In seeking

understanding of the whole, the parts require examination and vice versa (Smith et al., 2009). Furthermore, its application to analysis (in the case of this research alongside the phenomenological reduction) supports a holistic focus for research in protecting against the fragmentation of the collaborator's story. The hermeneutic circle has been criticised by reductionists (according to Smith et al., 2009) for being circular, namely not coming to a conclusion as a linear process might. Similarly, Finlay (2011) highlights the challenge for researchers in knowing when to include self-reflection, theory and experience. A mechanism that is responsive to these issues is the reflexive position that I adopted in applying this research.

Hermeneutic phenomenologists argue that it is impossible not to bring yourself into the research. When adopting the phenomenological attitude, there is an attempt to disentangle the understandings and perceptions from the phenomena; to support this interplay, reflexivity is often applied (Finlay, 2011). Finlay (2003) defined hermeneutic reflexivity as the process of reflecting on the phenomena and the researcher's interpretation of the experience and phenomena to move beyond partiality and previous understanding. Caution is expressed that the researcher does not become preoccupied with their own experience and emotions and privilege their own position over that of the research participant (Finlay, 2012). The practice of the reflexive position therefore not only restricts the risk of researcher-prejudiced research, but also acts as a safeguard against exploitation and abuse of collaborators in research (Walmsley and Johnson, 2003).

The degree to which the researcher brings reflexivity into the research varies between acknowledgement and sustained reflexivity throughout the research (Finlay, 2011). In this research reflexivity was applied through use of a written reflexive component in most chapters, drawn in part from a reflexive diary kept throughout the research process and through explicit use of the first person in outlining the author's position. My collaborative research also acknowledges the risk of hyper-reflexivity from the researcher (Finlay, 2011) and has sought to avoid this through engaging in a contemplative openness in debate and discussion in supervision (Spence, 2017). The important role of academic supervision to this research will be discussed further in the next chapter.

### **3.5.3 Beyond science: towards the humanities**

The final of the four characteristics that form part of applying hermeneutic phenomenology is the attention paid to creative and expressive writing that uses myth or metaphor (Finlay, 2011). This is situated in a hermeneutic phenomenological focus on moving beyond science towards the humanities. It is defined as an artistic feature in the writing up of phenomenological research, which aims to unsettle professional or psychological sensibilities (van Manen, 2017). This process and the subsequent writing seeks to slow down the reader and researcher so that they might sit with the lived experience and phenomenon (Finlay, 2011). This research has been attentive to creative and expressive use of writing during the phenomenological reduction and in discussion with the research collaborators. Furthermore, it identifies a symmetry with occupational therapy in drawing on the humanities in conjunction with the sciences.

Occupational therapy was historically congruent with and influenced by the arts and craft movement in its inception as a profession (Quiroga, 1995). Moreover, the research enhances this association, in supporting the research aims through the use of visual images alongside the collaborators' narratives to establish the enriched lived experience of people with IDD in their work. The use of the narrative and visual methods will be examined in the next section.

## **3.6 Communicating the lived experience: narrative and visual methods**

Narrative and then visual methods will be critically discussed below, alongside the development of the creative collaborative partnership. Consideration will be given to how they were applied within this research as tools to support doing research inclusively. Recognising that people with IDD have something to say about their experience of the world is still a relatively recent phenomenon and communication of their 'life story' has been pivotal in this change. Life story and a chance to hear the voice of someone with an IDD was said to have begun with Deacon (1974) and his book 'Joey, an unforgettable story of human courage'. This interest in narrative has gained an increasingly high profile in social research over the last three decades (Andrews et al., 2013) and has also been seen in health research (Ison et al., 2014). The focus on individual narratives has

grown as society has, according to Goodson (2006), moved away from the grand narratives of previous centuries, such as Marxism or Christianity. Atkinson and Walmsley (1999) state that life story work in IDD is the most effective means of self-representation. It is in acknowledgement and recognition of this that it has been applied in this research.

Crowther et al.'s work (2017) was used as a guide to crafting stories in hermeneutic phenomenological research, as it supported self-representation and aided the desire to reveal the voice of the collaborator, taking their words seriously and crediting respondents with their own understanding. This device involves the process of creating narratives from interview transcripts (Caelli, 2001). It holds to a process of drawing details of the phenomena directly from interviews with only the use of link words to enable the story to flow. However, constructing narratives within research may risk undermining the very aim of self-representation. Polkinghorne (2007) observes the limitations of language in capturing the complexity of experience and the complexity of texts being co-created with the interviewer. There is also a concern that life story work, in particular, can constitute an invasion of an individual with IDD's private life, which often has already been taken over by many state figures (Denzin, 2014). In my collaborative research, I acknowledge that this is a risk and the safeguards that have been employed included my reflexive position as researcher, clarity in the scope of the project at the time of consent and ongoing consent at key points of agreement, i.e., exhibiting and when the collaborative approaches were applied.

Nind (2014) highlights an additional factor relating to first person narratives when they are applied as a method in inclusive research, in her discussion of the criticisms and defence of inclusive research. When debating the assertion that inclusive research leads to more authentic or improved knowledge, Nind (2014) observes that there is a risk of reifying insider knowledge of people with a minority status and of considering it a more authentic form of knowledge. This research recognises the risk of overstating or overgeneralising the insider experience of the six collaborators in this research, particularly through applying critical realist assumptions that support the belief in reality of their individual lived experience. The research also acknowledges the particular risk of generalising findings, as people with an IDD are a heterogeneous population. However, through applying inclusive research principles it is possible to be consistent with Nind's assertion that 'some inclusive researchers already work from the premise

that people may not know themselves best, but they do know themselves differently' (Nind, 2014, p.69). Nevertheless, while there is a risk of the insider experience being reified or rarefied, there is equally a significant history of the experience being absent or devalued, and this needs to be addressed.

In the same way that narrative research has grown in its application and use across disciplines in recent years, the use of visual methods has equally been widely adopted, reflecting a more collaborative, participatory form of scholarship (Pink, 2013). Consequently, it is not seen as being in conflict with narrative storytelling, but rather indicates that a collaborator's story can be told with images (Holloway and Galvin, 2017). Moreover, the use of visuals also aided the story development with the collaborators, the interpretivist position of the research and dissemination activity.

In research contexts images may inspire conversations, conversations might invoke images; conversation and performances visualise and draw absent printed or digital images into their narratives through verbal descriptions and references to them. (Pink, 2013, p.1)

Crow (2016) highlights the importance of drawing on images that are created by people with disabilities regarding their experience of life and urges people with impairments to create their own representation that does not divide them from their context but communicates their broader life, challenging cultural assumptions.

Although rejected as a methodology in this research, consideration was given to the use of image making as applied in photovoice, namely, providing a camera to the individual to make images. Photovoice offers the participant the opportunity to take photographs that capture the realities of their life and to reflect on their experience, feelings and ideas (Mitchel, 2011). In this research, while the option of the person taking their own photos did happen for one research collaborator, Jo and was discussed with others, it was not selected as a sole method of image making primarily as it was felt to limit the potential of image making in communicating the lived experience. This is exemplified in the limitations of photovoice to include the person in the image or the person in acts of doing in their workplace. Similarly, photovoice would have relied on the static image rather than the option of video (as applied by one research collaborator, Tabitha in this research), although the application of photovoice might change with the

increased use of smart phones. In this respect, although a benefit of photovoice would have been for the collaborator to take images over an extended time frame, not just when the researcher and photographer were present, the variety of image making opportunities and the extended time working with the research collaborators on their lived experience was believed to best support the research aims. Similarly, consideration was given to alternative visual image making options such as drawing, painting or sculpture. These options were not pursued due to the foreseen complexity in data gathering and dissemination. This complexity included the potential time involved in image making by the artist and also the relatability of the artwork to communicate what the research collaborator wished to emphasise in their work stories both to them and also to a wider audience during dissemination. In this respect concerns existed that the artwork may inadvertently hinder rather than support access to the collaborators work stories. In contrast, photography was recognised as being immediately relatable to as a medium, accessible in both the making and reviewing of the image and less time intensive in creation. However, the importance of image making for two of the research collaborators themselves who wished to include their own drawings in their stories was embraced and viewed as compatible with the research aims (Chapter 5 – Research collaborators Ruth and Kenneth).

The photographer's role was primarily to support the co-creation of the visual element of the collaborators' work stories. Alongside the myself as researcher, the photographer was principally asked to adopt a phenomenological attitude in approaching the collaborators' lived experience and work as phenomena. Namely, the photographer was requested to adopt an openness to the phenomena and an acceptance and empathy in line with humanist values in their collaboration with the collaborators (Finlay, 2011, p.7). This position of openness within the creative collaboration supported the collaborator to communicate what was important in their lived experience. The interviews conducted with the photographer, me and the research collaborator focused not on gaining more information about work but rather on eliciting a different kind of information in representation of the collaborator's work story (Harper, 2002).

Within the creative collaborative partnership, the photographer, in the same way as the myself as researcher, aimed to ensure trustworthiness in the ethical base of the research and to safeguard and mitigate the risk of invasion of the individual's private life (Denzin, 2014). Further safeguards in this collaborative approach

included my presence in all creative meetings. It was recognised that an intersubjective experience was occurring between all three parties with the potential for a ‘fusion of horizons’ to take place (Gadamer, 1975). Thus, the photographer applied a reflexive position in the data gathering process through discussion with me following the interviews. This was recorded as part of my reflexive diary and the assumptions and bias of both myself and the photographer were challenged, supporting a refocusing of the creative interview if it moved away from the lived experience of work and work as phenomena.

Denzin (1991) observes that there are questions around ownership of the story and images once they are created (Denzin, 1991). Pink (2013) highlights the importance of ensuring that joint ownership and joint control of the use of images is part of an ongoing discussion in collaborative research. Therefore, a ‘re-negotiation of consent’ (Pink, 2013, p.63) is indicated at every decision and it is recommended that dissemination is discussed as early as possible in the research process. In my collaborative research, it was agreed that the collaborator owned their own visual and narrative story and agreed that it could be used in my thesis and research dissemination, including the exhibition. Discussion did occur with the photographer who had taken the images relating to their role in the image creation. It was acknowledged in the exhibition (for example) that she had taken the images, but crucially the images were not hers and it was the prerogative of the research collaborators to agree or refuse permission for the photographer to use the images beyond the completion of the research. A summary of dissemination activity is provided in Appendix 4.

### **3.7 Summary**

This chapter commenced by establishing the research position with regard to inclusive research, prior to outlining the methodological considerations given to qualitative research methods and the choice of hermeneutic phenomenology. First phenomenology, then hermeneutic phenomenology were critically discussed alongside the theoretical influences from phenomenological philosophy and their resonance with the occupational therapy literature and the research position.

The phenomenological research position and research application were then set

out and there was a description of the critical realist assumptions underpinning the research and the interpretive epistemology. Within this, the importance of my reflexive position as researcher was discussed and its synergy with both inclusive research principles and hermeneutic phenomenology detailed. Finally, the use of narrative and visual methods to support inclusive research and the communication of the lived experience were critically discussed in relation to the application of the creative collaborative partnership.

The next chapter will detail the research method underpinned by the application of the hermeneutic phenomenological methodology. This will be outlined within four distinct research phases, including research development, data collection, data analysis and research dissemination. Additionally, a description of the creative collaborative partnership will be outlined.

# **Chapter 4. Method**

## **4.1 Introduction**

This chapter addresses how the hermeneutic phenomenological and inclusive research approach, as outlined in Chapter 3, has been applied within the research method. It additionally describes the application of the creative collaborative partnership in the hermeneutic phenomenological context.

This chapter begins with the research aims and the research process overview shown below in Table 4.1. Details will then follow of the four research phases: research development, recruitment data collection, data analysis and data dissemination. Reflective accounts regarding the application of the method are also included within the body of this chapter.

### **4.1.1 Research aims**

- To illuminate the lived experience of having an IDD and engaging in paid work as a phenomenon
- To gain new knowledge that will inform the practices supporting people with IDD in relation to employment

These aims, developed from the research question ‘How do people with an intellectual and developmental disability experience work?’ were achieved initially through the creation of work stories made through a creative collaborative partnership. This partnership, supported within the hermeneutic phenomenological methodology, was applied alongside a phenomenological attitude and the reflexive position of the photographer and myself. The subsequent analysis applied through the hermeneutic reduction led to the formation of the five narrative frames.

**Table 4.1 – Research process overview (original in colour)**

Phase 1 – Research Development	Phase 2 & 3– Data Collection and Analysis	Phase 4– Dissemination
<p><b>Research question</b> formulation</p> <ul style="list-style-type: none"> <li>• Literature review</li> <li>• Supervision</li> </ul> <p><b>Advisory Group Support</b></p> <ul style="list-style-type: none"> <li>• Ethics</li> <li>• Collaborator information sheet</li> <li>• Interview questions</li> <li>• Interview pilot with job story map</li> </ul> <p><b>Methodology and method</b> development – decision hermeneutic phenomenology</p> <p><b>Ethics</b> application &amp; agreement</p> <p><b>Grant</b> application and funding agreed</p>	<p><b>Recruit research collaborators</b> through supported employment provider</p> <ul style="list-style-type: none"> <li>• <b>Collaborator invite</b></li> <li>• <b>Collaborator fact sheet</b></li> <li>• <b>Consent form</b></li> </ul> <p><b>Group meeting - 1 Introduction to whole group –</b> offered but abandoned due to logistics</p> <p><b>Recruit photographer</b></p> <p><b>1. Initial interview</b> Use semi-structured interview and job story</p> <p><b>2. Second interview</b> Job story reviewed with questions</p> <p><b>1. Analysis - Transcribe interviews and construct job story (Crowther et al., 2017)</b></p> <p><b>3. First creative meeting</b> <b>photographer and researcher</b></p> <ul style="list-style-type: none"> <li>• Share job story with collaborators</li> <li>• Collaborator changes made</li> <li>• Agree direction of artists work start photos if relevant.</li> </ul> <p><b>2. Analysis – Amend narrative of job story as collaborator has indicated.</b></p> <p><b>Reflexive discussion with photographer</b></p> <p><b>4. Second and third creative meeting with photographer if necessary</b></p> <ul style="list-style-type: none"> <li>• Take photographs</li> <li>• Review photographs</li> </ul> <p><b>Reflexive discussion with photographer</b></p> <p><b>5. Agree final job story images and narrative</b></p>	<p><b>3. Analysis - Apply hermeneutic reduction of individual job story and group of stories. Hermeneutic circle leading to a synthesis of illuminations.</b></p> <p><b>4. Group meeting</b> Optional</p> <ul style="list-style-type: none"> <li>• Meeting with collaborators to discuss narrative frames</li> <li>• Plan exhibition</li> </ul> <p><b>Easy-read document summary of findings</b></p> <p><b>Public exhibition</b></p> <p><b>Co-presenting at conferences</b></p> <p><b>Write up – journal contribution etc.</b></p>

**Reflexive diary & Supervision throughout**

## **4.2 Phase 1: research development and recruitment**

### **4.2.1 Advisory group involvement**

The ‘fore-conception’ (Heidegger, 1962) of the research question, as described in Chapter 1, was solidified during the literature review and through academic supervision into the specific question as given above. I then approached a local self-advocacy group of people with IDD to help develop the research aims, recruitment methods and structure and to support the interview process. An initial presentation to the group was made, which involved describing the focus of the research and the role of the advisory group. Following this presentation, permission was gained from the group for me to attend their meetings on a quarterly basis to support the development of the early research phase. It was clarified that the work with the advisory group would continue until recruitment had taken place. Once research collaborators were recruited (detailed in the next phase), the collaborators would be central in the research process.

The group’s engagement in the development of the research was voluntary. They viewed their involvement as fitting with their aim as a self-advocacy group to promote the needs of people with IDD. The group was composed of eight individuals, half of whom were in paid employment with the other half having had experience of paid work. A written record was made of feedback gained and recommendations agreed with the group prior to the close of each meeting.

Their involvement included:

- Discussion of the relevance of the research question and the development of the research aims
- Ethical considerations in recruiting and involving people with IDD in the research
- Review of participant information for intelligibility and clarity, including the letter of invitation, the collaborator fact sheet and the consent form (Appendices 3–5)
- Review of the semi-structured interview questions and job story map
- Support for pilot interviews: three members of the group took part in pilot interviews using the job story map

#### **4.2.2 Recruitment of photographer**

In Chapter 3 details of the role and function of the visual image within my collaborative research has been outlined in supporting the communication of the lived experience of work for the research collaborators. Furthermore, the decision to recruit a photographer, as opposed to another form of image maker was summarised.

The criteria applied for the recruitment of the photographer included firstly that they identified with being an artist (who predominantly used the medium of photography) as opposed to a commercial photographer and secondly that they had experience of working collaboratively on art projects with different people groups. The choice to recruit an artist was made due to the expectation that an artist would look beyond the literal or representative and apply an open and creatively enquiring approach to the person and the research. Additionally, it was anticipated that an artist would be familiar with discussing their interpretative stance - an important consideration when applying hermeneutic phenomenology.

The photographer who took part in my collaborative research was recruited by word of mouth through a friend. They had worked on visual arts projects with marginalised groups previously and revealed a sensitivity, interest and openness within their work and personal attitude. They also demonstrated during initial communication a thoughtful interest in my collaborative research and the research collaborators as individuals. This was considered to be of particular importance by me in view of the ethical considerations of working in partnership with people with an IDD.

#### **4.2.3 Ethical considerations**

Ethics approval was gained in January 2017 (Appendix 6) and consideration given to six areas of concern, with corresponding actions put in place to reduce exposure to these risks. These risks included: collaborator coercion or suggestibility; disclosure of abuse or neglect; a collaborator becoming upset in an interview; abuse through exposure to different people associated with the research; the collaborators' employment being threatened by a negative

portrayal of the employer; and the exposure to risks if images were seen as the photographer's work and shared more widely. Robust risk management strategies are detailed below and were put in place to address each of these risks and underpin the research practice.

#### **4.2.4 Collaborators' recruitment**

In total, six collaborators aged 18 and above, 3 male and 3 female, in paid employment, were recruited through an employment support provider (ESP). This ESP was commissioned by the council to provide employment support services for people with LD and was advertised as such. It also supported people with developmental disabilities as part of its contract remit from the council. The collaborators needed to be able to give verbal consent to engage in the research. Individuals under 18 years old and in unpaid work were not invited to take part in the project. Exclusion from the project did not result in any individual being denied access to services.

As I was aware of the broad criteria of the ESP, the information I provided about my research spoke of having a learning disability as opposed to IDD in order to encourage engagement from people who identified with this terminology. Additionally, in discussion with the work consultants, I asked them to approach people with the highest level of need on their case load. This enabled me to commence the research without concerns that they did not meet the eligibility criteria defined by WHO (2019), namely, a person with a disorder of ID occurring during the developmental period (prior to age 18 years) and characterised by a significantly below average adaptive functioning and ID. While the first five research collaborators were comfortable with the term 'learning disability' being on the research fact sheet, even if they didn't fully ascribe to it as a label, the complexity of terminology was raised when I recruited the final research collaborator Kenneth. He did not identify with the term learning disability but was keen to be involved in the research. I found making the decision about whether to include him in the research extremely difficult (Reflexive account 3 – recruitment criteria). A resolution was found through discussion with my supervisor, who supported me to review my criteria for involvement in the research and to ensure it was not compromised. Subsequently, the terminology adopted in the thesis broadened to people with Intellectual and developmental

disabilities, reflecting all the collaborators involved.

### **Reflexive account 3. Recruitment criteria**

It was a difficult conversation with Kenneth today around the learning disability terminology. Kenneth does not have a learning disability but what is clear is that he has significant learning difficulties that impact his ability to work, which raises many questions about the criteria for learning disability and reflects the questions raised about terminology within the literature. In fact, it makes me wonder how often we rely on the structures surrounding someone to notify us of their support needs, i.e., day services and supported living indicate a level of learning disability in a way that ESP support doesn't.

I'm feeling seriously a bit stretched with this. Even though my criteria have not been compromised, it's just that my focus has and that all feels a bit difficult. I think it would be good to look at this with the group, especially in relation to the terminology used in the exhibition.

I resolved it in my meeting with Kenneth, as we talked about the fact he had the power to define himself as long as he didn't mind being linked to a project with people who had a variety of 'labels'. He was happy with this and I really didn't want him to be further excluded from another thing as exclusion and lack of belonging is such a big topic for him. I'm also aware that I am applying a level of pragmatism about this in the way I am with Jennifer, who no longer has paid work but had expressed an interest in being part of the research when she did.

#### **4.2.5 Consent considerations**

Due to their intellectual and developmental impairment and the potential of collaborators to have reduced communication skills, easy-to-read information was provided in written form, in addition to increased time and support in the recruitment and data gathering process. The collaborators were offered the opportunity of having a 'person of support', i.e., a carer or family member, attend a session/s as required. All asked for their work consultant to be there for the first meeting but did not seek to have a person of support at any other meetings. They all had the option to take part in the exhibition and actively assist with

dissemination of findings as they wished. All collaborators chose to take part in the exhibition and two have taken part in other dissemination activity, such as sharing the images in a further exhibition and co-presenting.

Consent for engagement in the project was gained using an easy-to-read letter of invitation (Appendix 1), research fact sheet (Appendix 2), consent form (Appendix 3) and the support of the work consultants in the ESP. The process of gaining consent was underpinned by the Mental Capacity Act (DOCA, 2007), namely that all the relevant information relating to the research including potential positive and negative implications were given to the collaborator and reassurance was gained that the person understood the different options and possible consequences of involvement. The collaborators knew that they had the right to refuse involvement without giving a reason to me, as researcher. The collaborators then demonstrated (see below) an ability to weigh up the options and use the information to make and communicate a decision regarding their involvement in the research (DOCA, 2007).

The practical process of gaining consent to engage in the research was as follows:

- A letter of invitation was provided to the manager of the ESP, who circulated it to people who met the criteria through their work consultant.
- The work consultant established if there was an interest in participating in the study through discussion with the collaborator; they were highly skilled at working with people with IDD and were clear in communicating the voluntary nature of involvement in the project.
- If an individual supported by the ESP communicated an interest in taking part in the study, a meeting was set up with me to go through the fact sheet and ensure that they were aware of the implications of involvement; the work consultant was present at this meeting.
- At this meeting, I asked the potential collaborator to repeat back to me the positive and negative implications of participation in the research and to demonstrate they were able to weigh up this information during a discussion.
- When the person communicated a desire to participate in the study, the

work consultant showed the individual the consent form and talked through it\*.

- The individual was asked again by the work consultant if they wished to take part in the study and the consent form was completed at this point if the answer was yes\*.
- The consent form was then posted to me or handed to me at another meeting.
- In each meeting, I re-stated the voluntary nature of involvement in the study and was prepared to stop the interview if an individual appeared under duress or unsettled. This action was required on one occasion when a collaborator, who later chose not to be part of the study, became upset.

\*It is recognised that it is not standard practice for support to be provided to an individual during the consent process as it can be seen as coercive.

However, it is consistent for individuals with an IDD to be supported with many aspects of their daily life, including shopping, managing administration or finances and with securing a job. I was concerned that without reasonable adjustments being made to the consent process, individuals with IDD would struggle to respond to the invitation to be involved in research. This supports the premise proposed by Cameron and Hart (2007) that people viewed as vulnerable should be given the opportunity to be involved in research and have their needs investigated.

Consultation also took place with an advisory group who provided advice on the research process, as detailed above. The feedback from this engagement with the advisory group were incorporated into changes to the aspects of the project highlighted.

The documentation used for the recruitment of collaborators was also informed by the INVOLVE public information packs, which included ‘jargon busting’ and ‘what is it all about’ sections. I also drew on the format of Mencap’s consent forms for people with learning disabilities who share stories with them as an organisation. These were sought as examples of good practice in relation to easy-to-read information.

#### **4.2.6 Collaborators' payment**

Collaborators were not paid an hourly rate for their involvement in the study due to the fact that a payment might have had significant implications on their tax status and any benefits they were receiving. A gift of a £50 shopping voucher was given to each collaborator from the grant monies secured. The receipt of this gift was discussed with each collaborator's work consultant with regard to the potential tax implications.

I visited the research collaborator at a convenient venue for them for organised meetings. Expenses were reimbursed if the collaborator needed to travel to these meetings. Refreshments were also provided at these times and were also paid for from the grant monies secured.

A copy of the collaborator's work story, including the narratives and photographs created with and by the collaborator, were provided free of charge to each collaborator at the end of the project.

#### **4.2.7 Research funding**

Once ethical approval was gained, a research development grant of £10,000 was applied for and successfully gained from UKOTRF, hosted by the College of Occupational Therapy (Appendix 7). This grant supported the funding of the resources and expenses incurred, including the photographer's time, travel reimbursements, material resources and exhibition costs, in addition to collaborator's travel and refreshments, and my university fees for the 2017–18 academic year.

#### **4.2.8 Academic supervision**

PhD supervisory support is considered of upmost importance within what is a non-uniform degree (Peelo, 2010). Described in part as a conversation 'between individuals and their worlds' (Peelo, 2010, p.6) the interaction includes both a suggested capital bought by each individual and what is created during the

interaction. It is considered to be vital, when applying inclusive research principles, that the student recognises their own values and attitudes throughout the research process (Walmsley and Johnson, 2003) and this is equally important when practicing reflexivity in phenomenological research (Finlay, 2011).

Within hermeneutic phenomenology specifically it is recommended that the student-supervisor relationship is supported by a ‘contemplative openness’ (Spence, 2017, p.836). Applying openness is recommended, alongside the use of a reflexive diary and reflection more broadly, in order to discuss preunderstandings in the research process and to expand understanding (Spence, 2017). These principles supported the supervision of this collaborative research, providing a safe and trusted place to debate, discuss and reflect on my own values and presupposed attitudes. Furthermore, it also supported my movement towards what Murphy and Wibberley (2017) define as the development of an academic identity and maturity.

### 4.3 Phase 2: data gathering

Collaborators shared their work story, including what they did in relation to work or education before their job, the process of getting their job and working and their hopes and ambitions for the future. The collaborators all committed to a minimum of five meetings during data gathering. Initially, two optional group meetings were proposed but the planned initial group was replaced with an initial meeting due to the extended recruitment period and geographical differences (details of this change are provided in Chapter 5). Therefore, an additional meeting with the collaborator and the work consultant was included at the beginning of the project to discuss issues that would have been covered in the group meeting. The data gathering included:

- An **initial meeting** that was conducted to review the research aims, research fact sheet and protocol and to provide an opportunity for questions. The collaborator was invited to attend with a person of support if they wished. At this time, the practical considerations were discussed in relation to the time, place and expectations of each meeting.

- An **initial semi-structured interview** (Appendix 8) took place with me to talk about the work story (all collaborators refused the option of having a person of support available at this and further meetings). Answers to the questions were plotted visually and in simple written form. Features of person-centred planning were used to chart the narrative arc and for me to create a person-centred ‘job story map’ (Illustration 3). This was used for supporting communication regarding the construction of the narrative of the lived experience during the interview. I travelled to meet with the collaborator, at their convenience, in a private space in a public location. Audio recordings were made of the first and second interview and then transcribed. Extracts from my reflexive diary relating to the use of the job story map are detailed below (Reflexive account 4. The job story map).

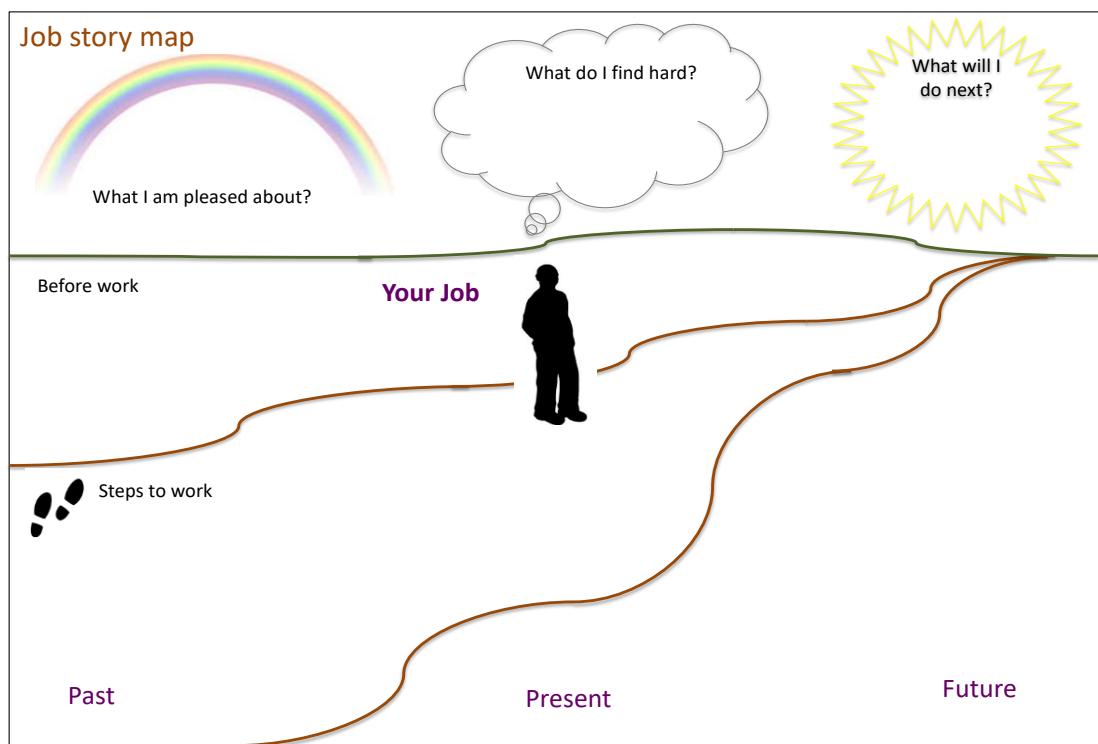


Illustration 3. Job story map (original in colour)

#### **Reflexive account 4. The job story map**

The thing that really struck me putting together my first job plan after the first meeting with Jo, was that as soon as I didn't include his own words, the power of what he was saying was totally lost. It was immediately sanitized and bland in my language. It made me think of the power of direct quotations or poetry that bypasses our filters in order to make a connection.

If I'm honest I think it (the job story map) functioned really well for me in terms of seeing where the gaps were in a person's story after the first meeting, but didn't really help the collaborator to view their story (as far as they have said), as it was still in a written format, so required me to read it out. However, I didn't use the job story map with the last collaborator, Kenneth, as he was so articulate, I thought that it wouldn't be supportive. However, in the second interview and in its transcribing, I could hear him explicitly say that I was confusing him, in reflecting back to the first interview in order to contextualize a follow up question. I now feel that I made an assumption and the job story map would have helped.

- A **second semi-structured interview** took place where the job story map was reviewed with the collaborator, to ask further questions if information was missing and to determine whether they wanted to add or remove anything. Themes and metaphors were reflected on in this session and clarity sought from the collaborator about what was important to them.
- An initial **creative meeting** between the collaborator, the photographer and me took place. At this meeting, the hermeneutic constructed work narrative (see the section on data analysis below for details) was reviewed with the photographer present. Changes to the narrative were agreed with the collaborator and the areas of key importance in their lived experience of work were discussed. The collaboration then continued with the photographer discussing and gaining agreement regarding the focus of the photographs. The collaborator chose whether to be the subject of the

photographs or not. The creative meetings were not recorded but I captured thoughts and feelings in my reflexive diary.

- Between one and three further **creative meetings** then took place. The photographer continued to co-work with both the collaborator and me, taking and reviewing photos (as relevant). The collaborator was then encouraged to choose images that best communicated the information they wanted to contribute to the narrative of their work story.
- **Agreement of photos.** A final individual meeting took place between the collaborator, the photographer and me to agree the information the collaborator wanted to share both in written and visual form. Agreement was also clarified with the collaborator as to whether they wished to be part of the exhibition.
- A **group meeting** took place prior to the exhibition with all collaborators to review the narrative frames (see section 6.4) for resonance, discuss and agree the title of the exhibition, titles for the work exhibited, levels of disclosure of names and publicity surrounding the exhibition and how they wished to be identified as a group in relation to their IDD.

#### 4.4 Phase 3: data analysis

As outlined in Chapter 3, a hermeneutic phenomenological methodology was applied alongside the creative collaborative partnership method in creating the stories of lived experience of work communicated by the collaborators. This approach was utilised as the words and visuals identified by the collaborator were a significant and legitimate means to present the individual's voice and perspective (Riessman, 2008). The methods of data gathering and analysis are summarised in Table 4.1 and details of each stage are provided below.

- The **initial interview was transcribed and anonymised** with consideration given to narrative components holding the story (Appendix 9), and the **job story map was partially populated** and gaps in the narrative identified for further exploration (Appendix 10) and presented to the collaborator in the second interview. The job story map, a tool used to support the interview process, included direct quotes from interview 1 and was collaboratively discussed with the collaborator, i.e., they were asked if

they still held to the initial observations in interview 2. Clarity was also sought and more detailed questions asked regarding areas covered in the first interview.

- The second interview was then transcribed, with the **two transcripts** **crafted together** into one story, following the narrative arc of before work, the job itself and the future (Finlay, 2011). This followed the guidance laid out by Crowther et al. (2017) on constructing narrative in hermeneutic phenomenology and agreed with Polkinghorne (2007), when he indicated that stories themselves are profound insights into lived experience. Crowther et al. (2017) highlighted that the interpretative process should ask questions of the crafted story and transcripts, including asking if the story reveals the experience, if it engages the reader, if it continues to retain the meaning for the collaborator and, fundamentally, if it works as a story. Crowther et al. (2017) described the practicalities of drawing out a narrative from interview transcripts. These practicalities included: retaining sentences that hold meaning; removing data that is extraneous, i.e., discussion about pets or social activity since the last meeting; keeping the content that holds the story; supporting the flow of the story by adding in words to link sentences; moving sentences to allow the organisation of the narrative; and reading out loud to listen to how the narrative sounds. It was constructed using the direct spoken words relating to the phenomena of work with link words added to make the story flow. All words added by myself as researcher were printed in a different colour in the narrative and were therefore clearly visible to the collaborator when shared at the subsequent meeting (Appendix 11).
- The **co-constructed narrative** was made and read back to the collaborator by me in the third interview. At this point, **amendments and corrections** were made and changes added. Either the collaborator or I made the alterations, depending on the collaborator's level of literacy in facilitating the changes.

I observed at the point of sharing this narrative how individuals' stories began to shift when anonymised (see Reflexive account 5, below). Although all the collaborators recognised why the stories were being anonymised, I was aware that this altered how it read and flowed. The

use of pseudonyms was considered but discounted, as they did not address the way in which direct references to people and places anchored stories in the world, e.g. in referring to Oxfam as an employer.

#### Reflexive account 5. Constructing the narrative

Names being changed, using terms like work consultant rather than a person's name, Employment Support Provider or employers rather than individual names of providers, which lose some of the subtlety of the story and formalizes something which otherwise flows and is personalised.

- In the first **creative meeting** with the photographer, collaborator and me, the collaborator was asked about the parts of their story that they felt were of **greatest importance in communicating their lived experience of work**. The photographer allowed this to start the process of exploring the work in a visual form with the collaborator. The aim of the photographer's work was to encourage the collaborator to consider what they wished to express about their work in a way that was meaningful to them and to discuss images that communicated this. The process of image creation took a number of forms, including: the photographer supporting the collaborator in taking their own images; the photographer taking images of the person in their workplace where an employer consent form was completed (Appendix 12); the photographer setting up and taking images based on the guidance of the collaborator away from the meeting; and the photographer constructing a film with an individual. Following the image and film construction, the visuals were reviewed and discussed with the collaborator and amendments made or new images requested. This discussion took place in an intersubjective space and facilitated the beginnings of a co-created dialogue (Vessey, 2009).
- In the final meeting focusing on the **work story**, the collaborator provided the photographer and me with final **agreement** of the visual and narrative contribution.
- The second stage of analysis took place through the application of the

**hermeneutic phenomenological reduction.** In this process, I immersed myself in the lived experience described in the work stories (van Manen, 2017). Specific attention was paid at this time to the artistic dimension of hermeneutic phenomenology, in exploration of the emergent essences and meanings (Finlay, 2011). Elements of the lived experience of the phenomena of work for people with IDD were illuminated and considered through the application of the hermeneutic circle. This occurred through immersion in the individual story and its components and then involved consideration of all the stories (Moran, 2000). The narratives were then examined for relevant metaphors, scripts and themes (Finlay, 2011) and guidance from van Manen (2016) about ‘existentials’ were applied. These are described as theme types to guide reflections on the data, including: lived space - spatiality; lived body - corporeality; lived time - temporality and lived human relation - relationality. The narrative frames emerged, therefore, through the hermeneutic reduction and consideration of the existentials and relevant metaphors, forming the second stage of findings.

- As outlined in Chapter 3, the **reflexive** and **reflective** were an essential part of the research process, involving use of a reflexive diary and academic supervision. Excerpts from the reflexive diary are incorporated throughout the thesis to support openness and rigour in the research process, explicitly outlining the interpretivist position. Reflexivity was equally applied in discussions with the photographer as part of the creative collaborative partnership method. This took place following creative meetings and was documented within the reflexive diary.
- As part of the collaborative approach, **meanings illuminated through the application of the hermeneutic phenomenological reduction** were shared with the collaborators and discussed in relation to their resonance with the person’s lived experience. This discussion had the greatest prominence in the group meeting with all collaborators present and this is summarised in Chapter 6 (section 6.4).

## **4.5 Phase 4: data dissemination**

Discussion of dissemination, including risks and benefits, was carried out in the group meeting with collaborators. All the research collaborators were asked if they would be willing to take part in dissemination activity and they all agreed that they would be interested and that, beyond the exhibition, they would be consulted on a case by case basis. Priority was given to taking part in dissemination activities that had the potential to influence public opinion, policymaking, policy development and professional practice in the area of employment.

- An **exhibition** was set up with all collaborators to showcase their job stories publicly in a city library, to share the visual images, video and an exhibition catalogue containing the full narrative stories (Ramsey, 2018).
- The collaborators were also invited, if they wished, to take part in other research findings **dissemination activity**, both in verbal and written form (Appendix 4). Efforts were made to ensure that at least one research collaborator was involved directly or indirectly (i.e. through an audio contribution to a presentation) in every dissemination activity that has taken place.

## **4.6 Summary**

This chapter has focused on the methods used in this research, including the detailed application of the creative collaborative partnership method, which supported doing this research inclusively. Within the four phases, details have been provided of how the method was underpinned by the hermeneutic phenomenological methodology. In summary, during phase one the research was developed with the support of a self-advocacy group who provided guidance on the research ethics, the development of easy-to-read paperwork and application of the semi-structured interview. Additionally, ethical approval for the project was sought and gained and grant funding secured.

Within phases two and three, the recruitment and data collection processes were described. The process of recruitment, which occurred in partnership with the

employment support provider, and the data collection process with the collaborators were both summarised. This was followed by details relating to data analysis, which resulted in the construction of the first stage findings in the form of the co-created work stories, using the narrative device outlined by Crowther et al. (2017). The application of the hermeneutic reduction was then outlined, detailing the second stage of analysis and the formation of the narrative frames.

This chapter also included a summary of the approach to dissemination activity and three accounts from my reflexive diary relating to the data gathering phase. The focus of the following chapter is the presentation of the first stage of findings, in the form of the combined visual and narrative work stories of the six research collaborators, Jo, Ruth, Mark, Tabitha, Jennifer and Kenneth.

# **Chapter 5. The work stories**

## **5.1 Introduction**

Through hearing individuals' voices, we are reminded to honour and witness their experience – to truly listen. (Finlay, 2011, p238)

The research findings (Chapters 5 and 6) address the two research aims: illuminating the lived experience of having an IDD and engaging in paid work as a phenomenon; and explicating new knowledge for people with an IDD and those that support them in relation to employment. The details of the data gathering method were outlined in Chapter 4, including how the stories were co-created with the research collaborator, me and the photographer as part of the creative collaborative partnership.

This chapter will initially provide an overview of the data gathering process and the first stages of analysis (see Table 5.1 and section 5.2), including the expanded construct of work which occurred during the data gathering phase. The work stories of the six collaborators in the research, Jo, Ruth, Mark, Tabitha, Jennifer and Kenneth, are then presented (section 5.3). These six hermeneutic stories form the core findings of my collaborative research alongside the five narrative frames detailed in Chapter 6. Using the methodological device detailed by Crowther et al (2017) to craft hermeneutic stories, it aligns with their assertion that crafted stories 'provide glimpses of phenomena that other forms of data analysis and presentation may leave hidden' (p826).

The names used for the collaborators are not their real names but have been changed to ensure confidentiality. Any personal identifying features such as the names of workplaces or people of support have also been removed or changed. The two collaborators who are identifiable in their photographs have been made anonymous in all other details to reduce the risk of being recognised and expressly chose to share their image, including in the public exhibition. Reflexive accounts linked to the data gathering process are included in text boxes within the chapter: reflexive account 6 considers the creative collaborative partnership and reflexive account 7, the intersubjective experience.

## **5.2 The data gathering process**

At the initial phase of data gathering, six people expressed an interest in being collaborators in the study, but data gathering was commenced with four people. The other two people's circumstances changed prior to facilitating a meeting, although no details were provided. One person withdrew from the project at the second interview; data provided by him was deleted and not used in the research. On withdrawal, his support staff stated that he was not well and participation in the research appeared to exacerbate his mental health difficulties. Therefore, the initial data collection occurred with three collaborators, Jo, Ruth and Mark. Recruitment was revisited with the ESP who reissued the invitation to be involved in the research to the work consultants and three further research collaborators were recruited, Tabitha, Jennifer and Kenneth.

As highlighted in Chapter 4, an initial change in the data gathering process emerged after meeting with the manager of the ESP to discuss the letter of invitation for collaborators. It was clear, both in discussion with the work consultants and in consideration of the data collection process, that an initial group meeting would not be viable. This was due in part to the diary implications for each research collaborator but also because the recruitment process spanned a full year. Therefore, a replacement initial meeting was carried out with each research collaborator and their respective work consultant to review the research fact sheet and arrange the first interview date.

The data gathering process as detailed in Chapter 4, included initially conducting a semi-structured interview (Appendix 8) between myself and the research collaborator and populating a job story map. Following the transcription of the first interview, the content was anonymised and collaborator narrative associated with the work story highlighted (Appendix 9). Additionally, areas that required exploration in the second interview were noted and the job story map was populated with key statements from the initial interview and outstanding gaps in the narrative of the work story (Appendix 11). The job story map was then revisited in the second interview as a focus of the discussion. Directly after transcription of the second semi-structured interview the two anonymised transcripts were then crafted into a hermeneutic story following guidance of Crowther et al, (2017). This included:

- Anonymising personal identifiable data within the transcripts

- Removing extraneous information from the transcripts (i.e.: discussion of a recent social event since last meeting)
- Retaining the data which relates to the ‘story’ of the experience
- Retaining the data that holds meaning
- Supporting the narrative flow through adding words or links to bring sections together.
- Re-ordering the data to support the flow of the narrative
- Hearing how it sounds by reading it out loud as a narrative

Crowther et al (2017) also recommend removal of repetitive phrases, improving grammar and going back to the narrative to add words to improve the overall narrative. However, I chose not to fully adhere to these recommendations as I felt they interfered with the narrative as it had been shared by the research collaborators and risked impacting their ‘voice’. Nevertheless, some narratives required greater inclusion of, for example, the questions being asked in order to contextualise the responses by the research collaborators. This was particularly the case in Jo’s work story as his verbal responses were shorter than other research collaborators (Appendix 9).

The narrative aspect of the work story was then crafted together as one narrative with my additional words being highlighted in a different colour (Appendix 11) and read by or with the collaborators. At this point changes were then requested by the research collaborators and amendments made (See Table 5.1 for details). The final crafted narrative was then read out loud to the photographer alongside the collaborator in the first creative meeting and ideas relating to visual images were discussed. It became evident during the initial interviews and in crafting the hermeneutic stories in conjunction with the research collaborators that the experience of paid work itself formed only a part of the story they wished to share. In this respect, without exception, all research collaborators shared details about their experience of trying to find work, applying for work, losing work and engaging in voluntary work. In many of the narratives detailed below these experiences form the majority of their work stories. In this respect, the construct of work within my collaborative research grew to hold all these parts of the collaborators stories which were experienced as work. Therefore, paid work in this context became the central point from which all other work-related activity appeared to pivot and the construct of work was therefore expanded.

The focus of the first creative meeting was on what the collaborator felt was important for to highlight from within their crafted narratives. Subsequent creative meetings were conducted to take or construct the photographs and agree final images, or as in Tabitha's case, a final film. A summary of the full data gathering process and collaborator's demographic information is detailed in Table 5.1. As part of the data gathering process, two research collaborators wished to make their own artwork or include their artwork, obliquely, as part of their story. This included Kenneth wishing to include a self-portrait in the exhibition (Illustration 21), which was included in the exhibition catalogue, and Ruth sharing an image of her drawing, to communicate her feelings about the reduced value given to doing art (Illustration 9).

#### **Reflexive account 6. Creative collaborative partnership**

This afternoon, the photographer and I spent a long time talking about where art fitted in research. Is it about an image to illustrate or enrich a study or is it more than that? What is art as opposed to the image making, we all do? What about when you are getting paid? I could hear her concern about the images being purely illustrative, as it felt like this diminished art's potential and her part in the collaboration, making her more like an observer or journalist. However, I equally emphasised that we were making the collaborators with LD central and for the artist to lead the visual work would not be appropriate as it was a collaboration. In this regard, the artist was sharing, enquiring, partnering and witnessing what was shared. These considerations we recognised were important to consider consciously in each meeting in order to support the centrality of the collaborator and research aims.

**Table 5.1. Data gathering process and collaborator demographics**

Collaborator	Job	Age and Situation	Meetings	Edits to the story	Visual image and titles
1. Jo (male)	Cleaner and café worker  (School holidays and weekend work)	Age 29  Living with his sibling	1 meeting with work consultant and researcher  2 meetings for interview - researcher  4 meetings with photographer and researcher, 3 at his workplace (Jo took pictures in his workplace with photographer's camera) and one with Jo's grandmother present	Minor edits – timings and content of job	Title – 'A day in my working life' (Illustration 4)  Jo was asked to identify aspects of the story that were important to him and though repeated attempts were made to facilitate this, the researcher was unable to establish his preference  Jo brought in pictures of his family in their work, which included working outdoors; a family connection in his work was discussed in the meetings
2. Ruth (female)	Administrative assistant, public sector, through sub-contractor (P/T)	Age 27  Living with her family	1 meeting with work consultant and researcher  2 meetings for interview – researcher  4 meetings with photographer and researcher	Minor edits – dates and grammatical changes at accuracy check	Title – 'Work plan confidential' (Illustrations 5- 10)  Ruth's workplace was the only one that wasn't accessed during the study due to its sensitive data which she stipulated as a reason not to visit.  Ruth highlighted four statements from her story, which are included in her own writing on the visual images within her job story
3. Mark (male)	Assistant caretaker, groundsman, railway volunteer (P/T and weekend work)	Age 31  Living alone	1 meeting with work consultant, and researcher with subsequent research interview  1 further interview with researcher 4 meetings with photographer and researcher including 1 in each work setting	Minor edits – dates and grammatical changes at accuracy check	Title – 'Working man' (Illustrations 11-15)  Mark was clear from the outset that he wanted portraits taken in each work setting, including objects that he was working with

<b>Table 5.1 – Data gathering process and collaborator demographics (continued)</b>					
<b>Collaborator</b>	<b>Job</b>	<b>Age and Situation</b>	<b>Meetings</b>	<b>Edits to the story</b>	<b>Visual image and reflections</b>
4.Tabitha (female)	School catering assistant (P/T)	Age 31  Living with her family	1 meeting with work consultant and researcher  2 meetings for interview – researcher  2 meetings with photographer and researcher	Tabitha wished to remove a section of the text that referred negatively to a previous work setting alongside minor changes	Title for film – 'Never think doing a job is easy' (Illustrations 16-18)  All communication about organising appointments with Tabitha went through her mother as Tabitha struggles with organisation and time management  Tabitha requested that photographs be taken of her in her work setting where she was present, but indirectly. During the visit to her work setting, Tabitha did not stop in her duties but worked through her routine and a video was shot of this process and made into a short film.
5. Jennifer (female)	Volunteer cleaner, voluntary shop worker (P/T)	Age 44  Living with her husband	1 meeting with work consultant and researcher  2 meetings for interview – researcher  2 meetings with photographer and researcher	Minor edits – dates and grammatical changes at accuracy check	Title – 'Waiting to bloom' (Illustration 19)  Jennifer had shown interest in the project at the time of being in employment, therefore it was considered ethically appropriate to include her in the study.  Furthermore, the researcher felt that the weekly voluntary cleaning job (which she has been doing for 4 years) should be re-examined as paid work.
6.Kenneth (male)	Cleaner (P/T)	Age 40  Living alone	1 meeting with work consultant and researcher  2 meetings for interview – researcher  2 meetings with photographer and researcher	Minor edit – dates and grammatical changes in accuracy check in addition to reducing his happiness % and changing 'that' to THAT'	Photograph title – 'Working with an analytical eye'  Painted 'Kenneth self – portrait'. Kenneth wanted to include this as part of his story, so it was a self-initiated action on his part (Illustration 20 and 21)

### Reflexive account 7. The intersubjective experience

**Example 1.** Last week, the photographer met Ruth for the first time (with me) for a truly inspiring meeting. It's hard to pinpoint exactly why it felt so positive, apart from the fact that Ruth brought so much to the process... It brought out exactly what I had not quite anticipated, which was that it established that work is not everything for her, it doesn't define her, but it is really helpful in so many ways when it's a good fit. It highlighted that 'yes', we are occupational beings and that work sits as a framework to support life rather than necessarily being a goal in itself.

Also, I thought the photographer was so thoughtful. She came at it with an expectation for collaboration, not as a professional held by the models of practice and professionalism, which was my risk. She was open and talked as an equal about things that she recognised echoed her own journey.

**Example 2.** The second creative session was so much tougher than the first, as Jo really struggled to engage in it and his warm, smiling silence left us to sit with the quiet in his workplace in a way that felt tough. That process in and of itself was telling. The routine nature of his work, going over the routine over and over again, walking the litter picking route over and over, then he would be back to the toilets to check and walk about again. It's little wonder that he enjoyed his time in the café, its potential to see people and do something different. However, I'm aware I'm projecting my interpretation of the tasks that feel boring and lonely to me. It's not surprising that we were drawn to where pleasure is. His family, bowling, travel made affordable by his work. Set next to this it feels really difficult. Yet is he bored? I don't know. I don't know how much he is asked to do things that are monotonous and dull but with simple acceptance he does it.

I think the photographer and I faced panic in this visit, concerned that we were over interpreting while Jo brought his quiet self. Open to talk, slowly open to reveal himself as we waited.

### **5.3 Jo's story: a cleaner and café worker at a family country park**

*I was signing on at the job centre for three or four years. It was not too bad going there, my nan went with me so if there were any awkward questions, they could ask her. I didn't ask why they didn't find me work, especially at the time because we were going through that recession. During this time, I was doing bits and pieces, spending time at home or going out. Bored some of the time. I didn't have a job I really wanted to do apart from mainly probably gardening. My grandad used to be a gardener so sometimes I used to go out with him.*

*Before the job centre, I did work with my dad, my uncle and brother in a boat company that make covers and sails and different bits and pieces for boats. I did tidy up, sweeping every day for nearly a year, just helping not for money. But they had to let me go. There was another one as well that I did before, I worked at a college as a junior groundsman. This was more gardening, cutting grass. It was paid, and it was pretty much the same, nearly a year. I did like it at the college; they let me go too, same reason.*

*Two years ago, I came to the employment support provider who tried to find other things, but it was like getting there and back. So, the work consultant had a word with her work colleagues and had a chat and they sort of made up the job for me. I know it was done by a few other people in the summer before, I think that's when they started it off. The most helpful support to finding work was probably the 'Access to Work', getting there, the taxi money. The most helpful people were the employment support provider as they helped me find this job.*

*Having a learning disability made it hard to find a job because of travel and maybe reading and writing. At the job centre I did have an advisor that specialized with people with learning disability, yeah so that helps. Telling people, I'd either say I've got a learning disability or I'm not very good with my reading and writing.*

*My job is a cleaning job between four and five hours a day during school holidays and I work at weekends in the café from 12-3pm. With cleaning I usually start between 10 or 9.30am until 3pm and sign in at reception and then start. I go to my cupboard where everything is kept and go and get this little box with everything in. It's the same routine. I can have a break if I want one. Sometimes I go to the café and sometimes I bring a drink with me.*

*I check the toilets are clean; check the basins are clean, check the toilet rolls and towel rolls as well. Spray air freshener, occasionally clean mirrors and then check the bins. There are four toilets I do and sometimes they get some portaloos in. Oh, and yeah there's a disabled toilet as well. Usually they call me when I'm out because I've got the phone with me and if I'm out they'll call and one of the toilets is a state or a blocked toilet. I was a bit wary of the blocked toilet the first time I did it but once I'd done it once it was ok. I do the litter pick and then back to the toilets again. I cover the whole site but not through the farm. The most important part of my job is making sure the toilets are clean. My uniform is a t-shirt; you have to wear your own jeans. Café work as well, I love that. It's cleaning tables, taking food out and bringing back, unloading and loading up the dishwasher.*

*Nothing is difficult apart from there is one thing that we have a dispenser toilet roll holder thing. Sometimes I have trouble opening it. It's actually putting the toilet roll in, it's all right putting it in, but it has to get through a slit bit and down that's a bit tricky. I do manage it and if I do struggle, I ask at reception. But apart from that... There was someone with me at the start till I got used to the job, then after the first couple of weeks I was alright. Reading the label on the sprays at the beginning was hard but I've got used to it and realise what the different ones were. Just learned it really.*

*I'm easy going so.*

*Sometimes I get a little tired.*

*But it's sometimes mentally.*

*Sometimes, when it's weather like this (sunny) I'd like to be not working.*

*They're nice people at work. Sometimes I see my boss walking round the grounds and sometimes if I'm walking past, I'd say hello. We've never really had a proper conversation. If I need something I'd maybe go to reception and there is another person that I know as well, that my family know quite well, so I'd go and see her as well. When you go around you will bump into other staff. Yeah, I wouldn't mind seeing people I say hi to out of work. I think they usually do a social at Christmas, but I didn't go to the one last year. That would have been my first one. I think I was busy at the time.*

*I'm most proud of all of it really. That I've done a good job. When it looks clean and sparkles. What I like best is going to work, talking to everyone and being out in the fresh air. Money is important; I'm going on holiday in October to France. I don't know how much I get paid, my aunty looks after that side of things. I get a certain amount of money.*

*Out of all the jobs I've had I enjoy this job most, you go around talking to more people, at college you were just getting on with it. In the future maybe, I'd like a bit more work. I haven't really got any other plans, not at the moment, not for the next couple of years anyway.*

*To someone else who was like me at the job centre looking for work I'd say stick at it; something might turn up like it did for me.*

#### Illustration 4. A day in my working life (originals in colour)



## 5.4 Ruth's story: an administrator in the public sector

*I first went to the employment support provider in 2011 but they weren't very helpful. Then they put me to help out in the enterprises, but I had a stalker problem at the time, someone was trying to have relations with me. He was about 40 and I was about 21 at the time and it's like 'no'. I said, 'Please do something about this' and I ended up losing that and yet the person still walks free. But they were like, 'Oh he's had a problem with other girls' and I'm like 'How about you let it be known that it's not right?'*

*Then I was doing a year's work experience in a café, but I had another person trying to be over friendly with me, but that was my fault. This was through my mum and I went there quite often. It was nice working there, but it was a bit of a problem with this other person because they were like very persistent and they wouldn't change his days.*

*I wasn't a 100% sure what job I wanted to do but then they put me on the work programme for two years which was a lot of false promises, they said they'd get me a job but that never materialised.*

*I do like drawing, painting. Yeah, I have too many hobbies. People just don't want to pay for art. They want to get something for nothing. Like they were trying to get me to do a magazine cover, but they were like 'We're not going to pay you' and I was like 'No'.*

*It was an awful long time to get to where I wanted to be. It's like they suggested all sorts of things. It does hurt; it does make you feel like shit. And them saying different things and sometimes treating you like an idiot and like you don't know what you're doing. Everyone is doing better than you and you feel awful, it's like I want to do things too. I want to go on holidays. I want to visit people.*

*I know for a fact that when they tried to put me in a pigeon hole it was like, I can't do care work whatsoever, you won't see me in an old people's home or home for people with impairments, to be honest, I would not have*

*the empathy for it. Yeah, sometimes I'd sign on to agencies and they'd say 'Oh! we've got this cleaning job', but I don't want to do cleaning, or when they say, 'Do you want to do hair dressing?' 'No.' My mum got a bit annoyed with them for that. She can be a bit overprotective.*

*I did apply for stuff in the meantime. A mix of things, I ideally wanted an admin job at the time and put my CV through to a lot of places. My first interview was in December 2013, it was like an NHS job. They said I interviewed well but they said I didn't work well as a team but the other members in my team were quite passive. So yeah. But after that failed my advisor for work (at the job centre) suggested I sign on to get a referral on to someone and then I started going to the employment support provider and then I met my advisor there and that then led me to their office. So, I was like a Tuesday afternoon volunteer for six months. I did a few work experience bits and bobs here and there. I did a trial at the library, so I was applying for library jobs in the meantime like I thought that would boost my chances.*

*When I was working in the employment support provider office in January 2015, my advisor at the time said, 'Oh you'd be really good at training with us' and put me forward. I sat in the session in July 2015 and another session in September 2015 and then got an interview at the end of September 2015 and I got accepted almost instantaneously. It's basically going around the country, speaking how people with disabilities, or as I like to call them learning impairments, can be more secure in society like jobs and what not. It's only one session a month if that. I'm less involved at the moment because I have my other job.*

*Well I took a very part time job in March 2015, interviewed in December 2015 for an administrative assistance, like part time work at the office. At the beginning May 2016 someone phoned me and said 'Oh we need you to work 2 days a week'. It was like 'get in there'. One of the people working with me at the time said, 'Oh let's look for jobs for you' and a job popped up for a place and I was like, sent them an email they didn't say to send your CV straight away. Send in a side of A4 about yourself and*

*strengths. And I sent that in, and they were like, ‘We want to interview you’, I was like ‘Result’. But I said I can’t go for an interview that week because I can’t do an interview so suddenly, I was having some family stress at the time because my brother’s partner was having quite a strenuous operation. So, I sent in my CV and in the middle of my last year, I went for an interview. We had a talk first then we did a few tasks, like typing tasks, then a few days later it was like ‘Oh, you’ve got a job’ and they were very flexible which is what I wanted to start with. It took a while to get started because we had to get the clearance forms. I’m working with sensitive data, and they need to know I’m trusted with sensitive data. And that’s how I started it.*

*I’m an administrator. I get in about 12pm, after walking from home to wherever. I get my computer out of my locker because we’ve got work laptops that we can’t take home. I sign in, check my emails, sign into the electronic system, go upstairs, take out incoming post, take that upstairs. If I’ve got any files to merge or locate, they get located and merged first. Then I go upstairs, take the files that are in the in tray, put the files back down with me and then put them in the out trays. I’m also doing file maintenance at the same time, so as like labelling, putting orange slips in all the files, fixing broken files, putting things in the right place more often than not.*

*I like to try and keep smart. I put my own little touches here and there. We’re quite smartly dressed in our side of the building. But there’s people on the other side of the building are not smart dressed and it’s like ‘Oh come on’. I think it’s important to be smart, unless it’s certain jobs where it’s not flexible to wear smart dress.*

*I only work three hours a day so technically I don’t get a break and yeah, I just like to try and concentrate on getting as much work done as I can. What’s most important is knowing that I’ve made a difference and helped the company. Because they are saying it’s a lot neater now, when I started it was an absolute tip. Files were all over the place, stuff was not*

*labelled correctly, tent files and paperwork everywhere, paperwork should have been archived years ago even though we've had changes.*

*It's a temporary contract, which is a little bit worrying, I do apply for jobs in the meantime just in case. But I'm pretty confident this time they are going to extend it because they've just introduced a new ranking system and I'm at a decent position that I'm quite pleased about. There's like 185 and I'm like 25 in that. I didn't expect to be that good. It ranks all our employees throughout of the county; it's like a league table. It's not stressful but it encourages me. (In June 2017 I was made permanent).*

*Heavy lifting's a bit of a pain at times but it's manageable at least. There are a lot of files to take with me. I just get stressed if people can't find their files properly. Or sometimes it takes forever for certain things to arrive, like files; I'm still waiting on blummin crystal tabs even though we ordered them like goodness knows. Yeah as soon as I get the files, I will sort them out, I will put them in the right place, as soon as file comes that needs to go to archive. I will fix down the box put a sticky note in and tell them to go.*

*I'm not really that talkative. I'll say hello to people in the office, sometimes they'll offer me stuff. But I'm not really that much of a talkative person. My boss is friendly to me; it seems like a good environment and if I'm up, I'm up away from office politics.*

*I feel like I'm making a difference. That is the most important thing of all. The best bit about work is I have some sort of schedule, schedule is good, knowing people are proud of you, things like that. Money is quite important to get nice things- but some people go over the top and it's like, if you save more then you wouldn't be whining about needing money all the time. I might have gone a bit nuts last week when I went into town. But it's not like hundreds of pounds it's like £60, which isn't bad in the grand scheme of things. My mum gave me a good analogy, it's like how much you get paid now, you've worked this much hours to get this sort of thing.*

*The learning impairment doesn't affect my job, not really, if anything it helps. Makes it a bit of a pain to find work, because people don't understand it correctly. If anything, it shows who's a lot more organised. You're analytical, you look over things and this is because of my learning impairment. I'm happy in my job about 90%. My family are pleased for me.*

*I prefer the name learning impairment. I just find it impairs life, I find it a more polite term, more positive. Disability sounds a bit demeaning at times. I think it's more the public at times and friends, like, I don't know what to do with this person she's weird. I haven't really mentioned it to other people. It's not really something that you bring up in conversation because I look relatively normal, so I don't make a big deal about my impairments. Sometimes my family don't 100% understand. It's like I'm a bit sensitive to loud noises, which isn't best. My dad popped a big air bubble the other day and he said, 'Oh you don't like loud noises do you?' and I'm like, 'You should have known that'.*

*I don't want to go around carrying cards saying, 'I have this that and this please be careful', you can look a bit of an idiot. I think that if it's really going to affect you in life, to be honest. 'She's a moron, don't speak to her she's weird.' Mainly it's what I think people think but some people just give me stares. I think sometimes I look threatening. I don't like to say, 'I'm special, treat me different', I don't want to do that. I want to be treated like everybody else.*

*In the future I'd like to be permanent, more hours, maybe more organisational jobs, building my skills, I want to learn minuting. I'm not sure where I'll be in a few years to be honest, depends, things can change, social circumstances can change. Things like that really, I can't give an answer. I just want to be comfortable, money and life things. Sometimes life things can be quite difficult.*

*If I had a partner or something, I'd love to live with them, a cat, a few animals. I don't know if I'd actually move away. Knowing where my friends*

*are, moving away might be an option, leaving, which is sad but at the same time it is something to think about.*

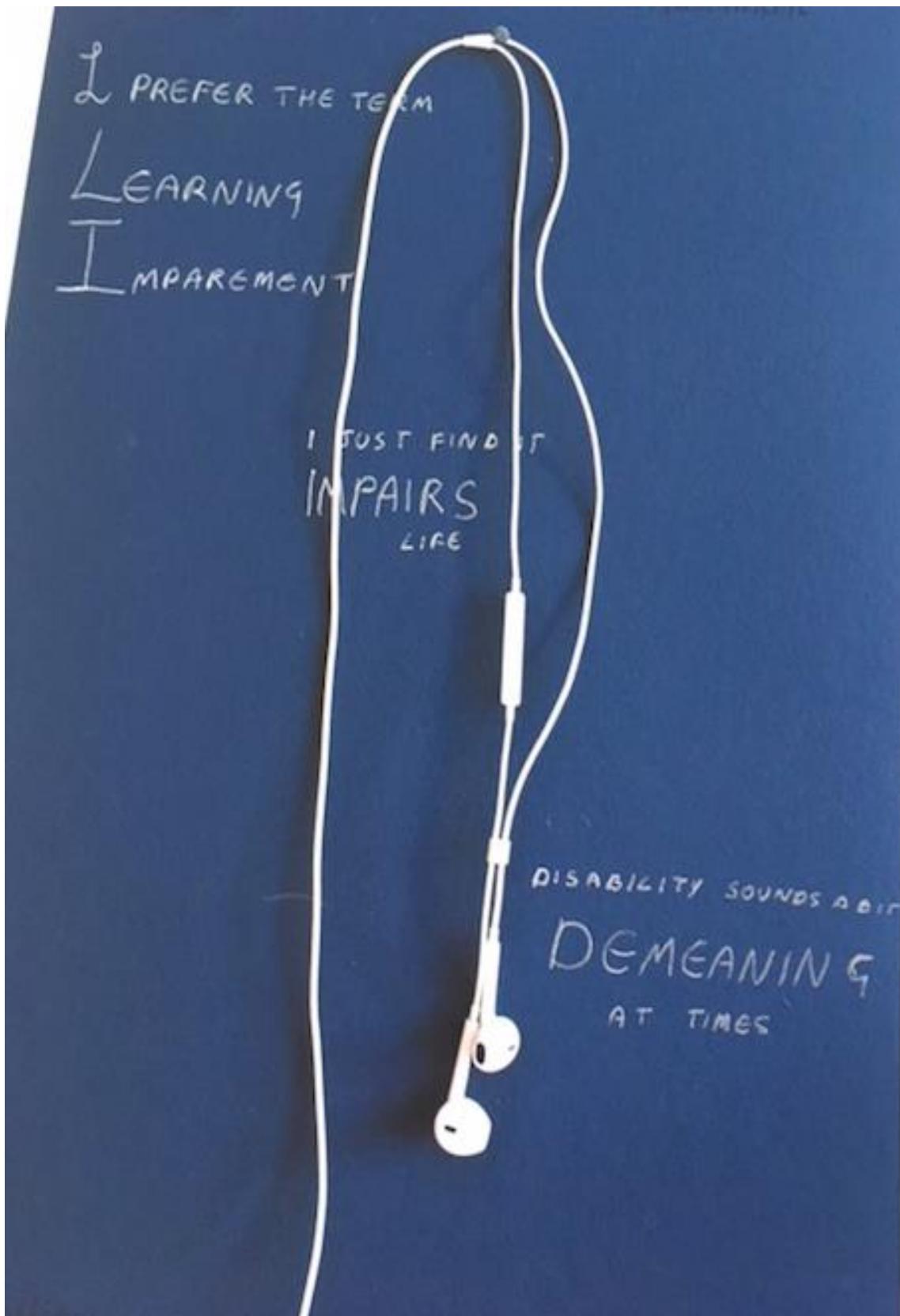
*To someone else who was like me trying to get work I'd say, 'Trust your instincts and be persistent, you're going to get there eventually and it's going to be great!'*

### **Illustration 5. Work plan confidential (originals in colour)**

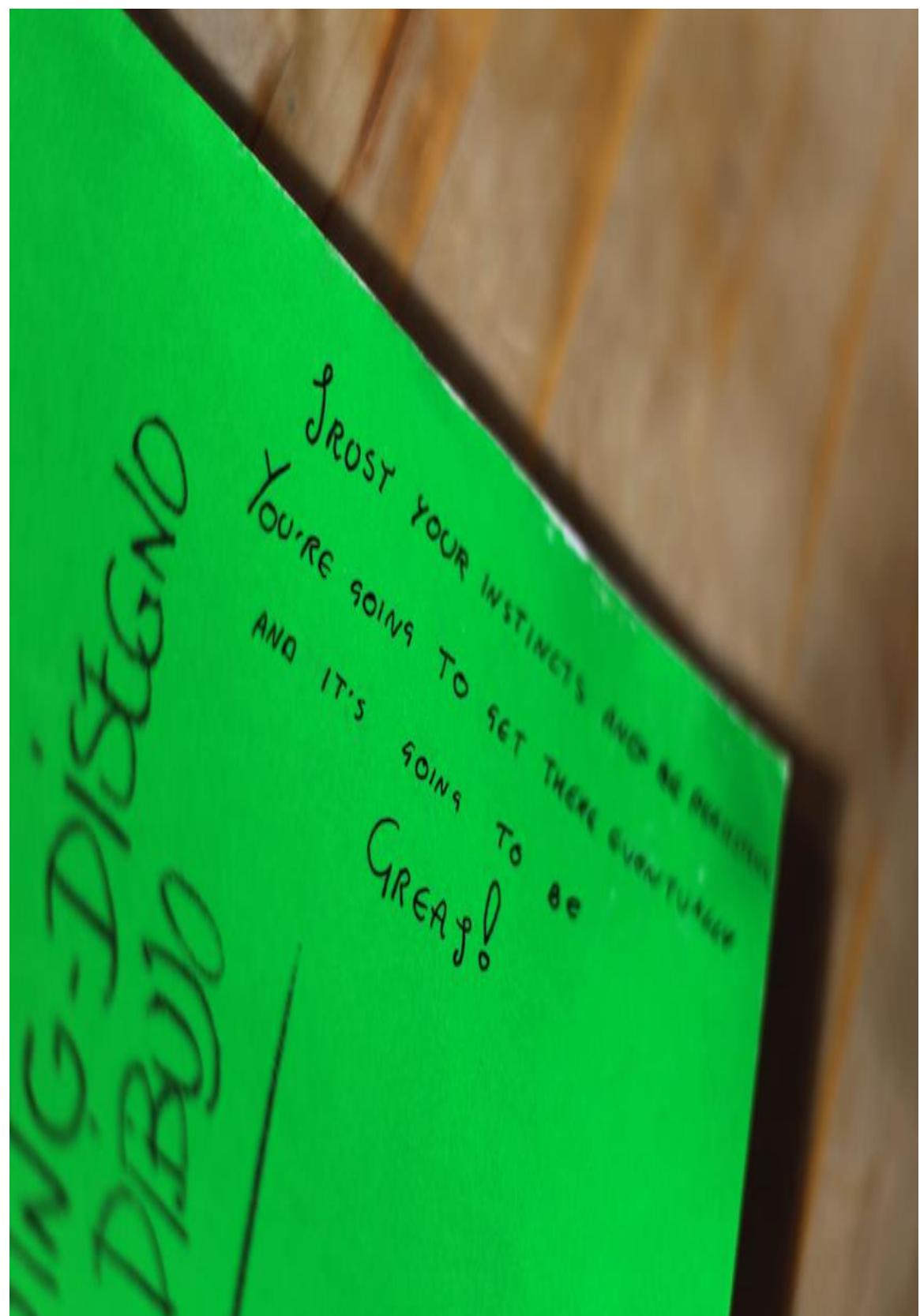


PRIVATE AND CONFIDENTIAL

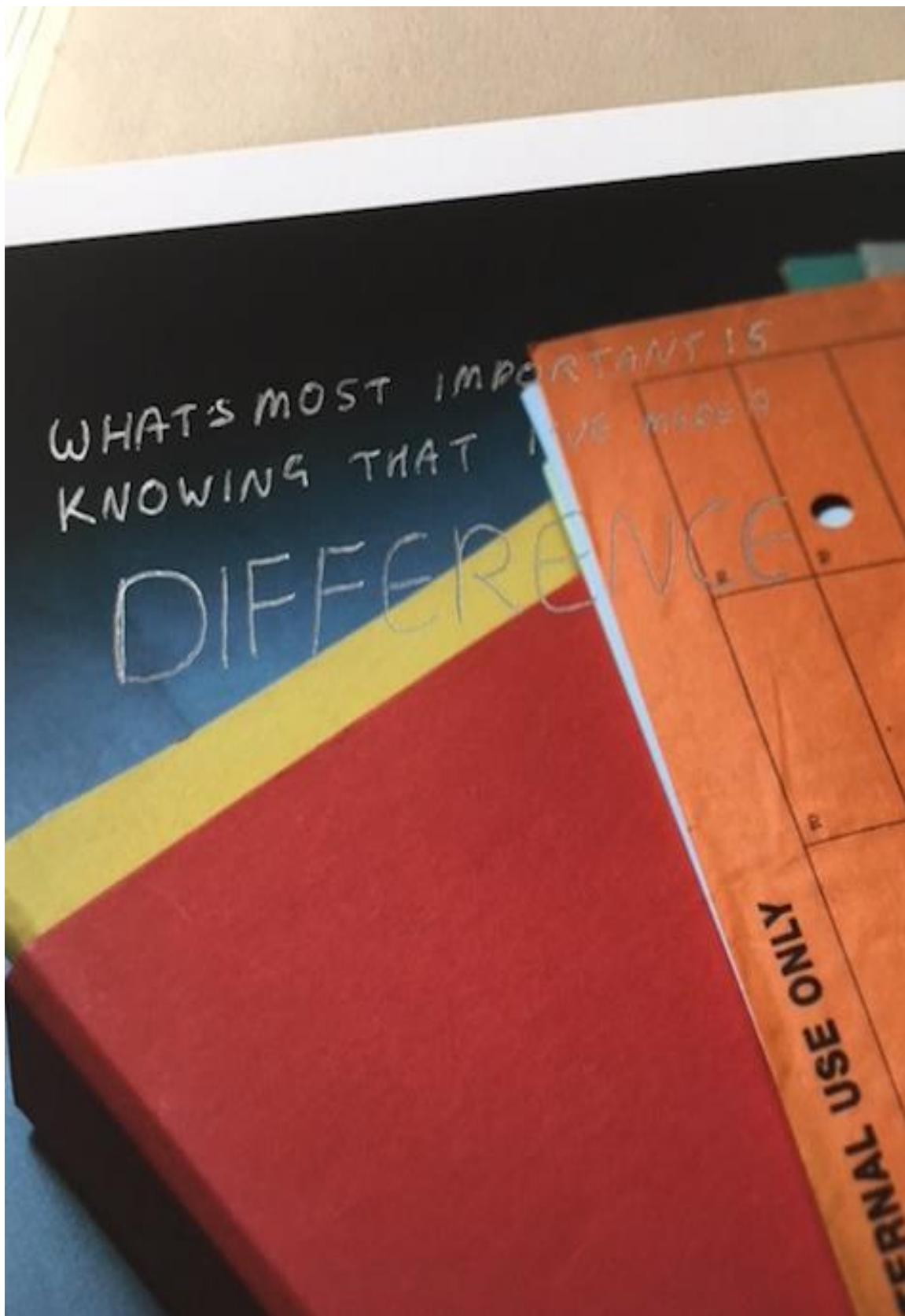
## Illustration 6. Work plan confidential



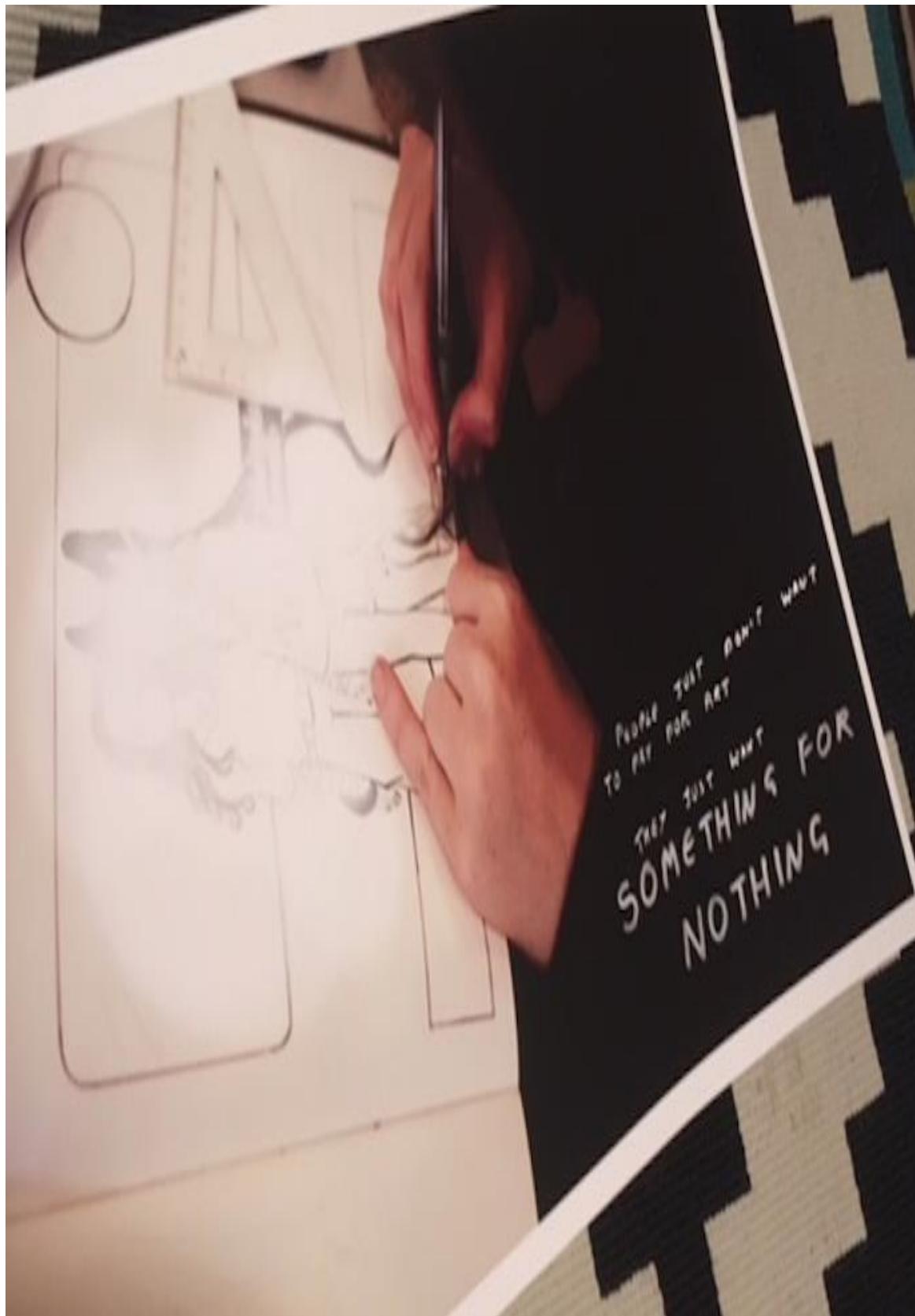
## Illustration 7. Work plan confidential



### Illustration 8. Work plan confidential



### Illustration 9. Work plan confidential



## **5.5 Mark's Story: an assistant caretaker, groundsman and volunteer**

*Before I got this job, I was volunteering at a place called the Centre, from 2008-2013. It was a place for people who have got Learning Difficulties and learning disabilities and I was helping out in a horticulture section in a gardening job. So, I used to grow organic vegetables and I'd also do lawn mowing and strimming to keep the grounds nice. They used to have a shop and sold vegetables.*

*After the Centre had closed, I wasn't doing much work. I found another job that I used to do at a community garden and worked there from 2009 and until 2012. That was also helping in a community garden. They used to also grow organic fruit and vegetables there. It was every Tuesday and I enjoyed it.*

*I think that it was around 2009 that I heard of the employment support provider, I think it was the work consultant who talked to me about the employment support provider and what they do. The work consultant used to be a member of staff at the Centre and he referred me to them. It was both our idea to look for paid work. I was signing on during this time.*

*I also volunteered in an older person's home. That was a little bit of gardening plus also helping one of the people who was in charge of maintenance work.*

*Basically, I had a system of small maintenance jobs and sometimes we'd (myself and the caretaker) have to visit the local builders' yard to buy a few things or parts. I did this for about three years every Thursday.*

*I kept on applying for jobs in that time. I know I've applied for a large number of jobs. I was always looking for paid work. It was frustrating when I had applied for a job and they didn't reply or told me they couldn't offer me the job. So, I just kept on looking. At times I did feel a little bit fed up. But well, I just kept on looking.*

*I did used to see people from the job centre for a few years, but they were not really helpful in finding paid work. When the work consultant became my advisor, I then started looking for paid work. It must have been about a year before the work consultant told me about my current work at the warehouse. I had always been most interested in doing gardening jobs and working in garden centres before.*

*The company I work for is to do with taking orders for companies that deal with mail order. So, they get goods coming in and then it gets stored in the warehouse and then gets put into packages and then gets sent out by lorry. Some goods go to shops and some go directly to the customer.*

*I'm an assistant caretaker and I work 10 o'clock to 5 o'clock Tuesday and Thursday. I started the job in January, and I wear a company polo shirt, work trousers, and also wear steel toecap boots and high visibility jacket. When I started, I did have my colleague who's the main caretaker help show me what to do for about a month or so.*

*I get two 15 min breaks and half an hour for lunch. I normally sit in the canteen and relax. The canteen just has vending machines, tables and make your own tea and coffee. I bring my own food, a sandwich, crisps and a drink.*

*I work with a large number of people in the warehouse, about 20 or 30. I do chat to the other staff if I have a problem with anything. They're friendly. I do see my boss walking around and if there's anything I need to see him about I'll talk to him in his office. I'm not sure if people meet outside work or have socials.*

*So when I get in, first I put my person protective equipment on and then first thing I do is turn on the machine that crushes the cardboard and then I start to load up the cardboard into the machine, then once all the cardboard bins have been emptied I then I start to go round all the workshops emptying the litter bins and then taking all the waste outside to larger bins. I take the*

*cardboard outside and eventually that get taken away for recycling. That normally takes one or two hours to do. Then normally after I've had my break, I then do some floor cleaning around all the different aisles around the warehouse. What I use is the full cleaning machine, which mops the floor and vacuums up the dirty water. It is quite noisy. The most important part of my job is to make sure I get everything nice and tidy.*

*I feel proud I'm helping to keep the warehouse clean and sometimes do people a favour. Well sometimes helping to throw out extra waste for people. The best bit about my job is it keeps me busy, because I'm working really hard and I like loading the cardboard into the machine and using the floor cleaner.*

*I know I've done a good job cause people do say I've done it really well. My family thinks it's good I've got a job there. I have a mum who lives locally and older sister in America. I am happy in my job. It's different from my voluntary work because I know that at the end of the month, I'm getting paid to do the work. The money mostly goes on shopping and paying bills.*

*I don't mind the term learning disability. With my learning disability I sometimes do forget to take care, watch out when the forklift truck is approaching. Sometimes I forget to take a look before I go out onto a main aisle and sometimes, I do need to remember health and safety. Sometimes, because I've got a learning disability, I struggle to find the right words and sometimes I get a bit nervous.*

*I think having a learning disability made it hard to get a job, yeah. Because sometimes when I would apply for a job and upload my CV, I'd get an email from the employer saying they couldn't offer me the job on that occasion. I do find it hard to talk to people at times.*

*I also have a job at the rugby club. I started doing the rugby club last year on a Saturday. I help to set up before the match starts, to set up the pitch, putting posts around the pitch and then putting pads and flags on some of the posts, and once this is all set up during the match we keep the score,*

*and when the final whistle blows we then put all the posts and all the equipment back into a container.*

*They pay me every month. Most matches are every week during the season. I turn up an hour before the match and then once we've put the equipment away, I normally stay for an hour before going home. The best bit of this job is walking around helping everyone. Helping set the pitch up.*

*I also volunteer at the railway on Sundays. I normally start work at 10.30 and I ask my supervisor what parts he'd like me to work on. So, for example cleaning the rust off something I use this machine called a grit blaster. It's a machine, which blasts grit around which lifts rust off, and then once all the rust is off, I then take the part into the paint shop where I then use a primer that help prevent rust. After the primer, they put on a coat of undercoat and then they use a gloss for the full paint. I like knowing the work I do there helps maintain one of the carriages and wagon that are on the railway.*

*Maybe hopefully one day in the future I could get a promotion at work, promoted to maybe having a job doing the packing and maybe one day to getting to use the forklift truck and other machinery. I think promotions come just when you get a vacancy. Also, I would like to have a relationship one day. I like how the balance of life is. I feel I could be doing more. More time at work but not full time.*

*I would suggest someone with learning disability speaking to someone who can help people who have got a learning disability to find a job. That's what made the difference for me, knowing that the employment support provider was trying really hard to get me a job.*

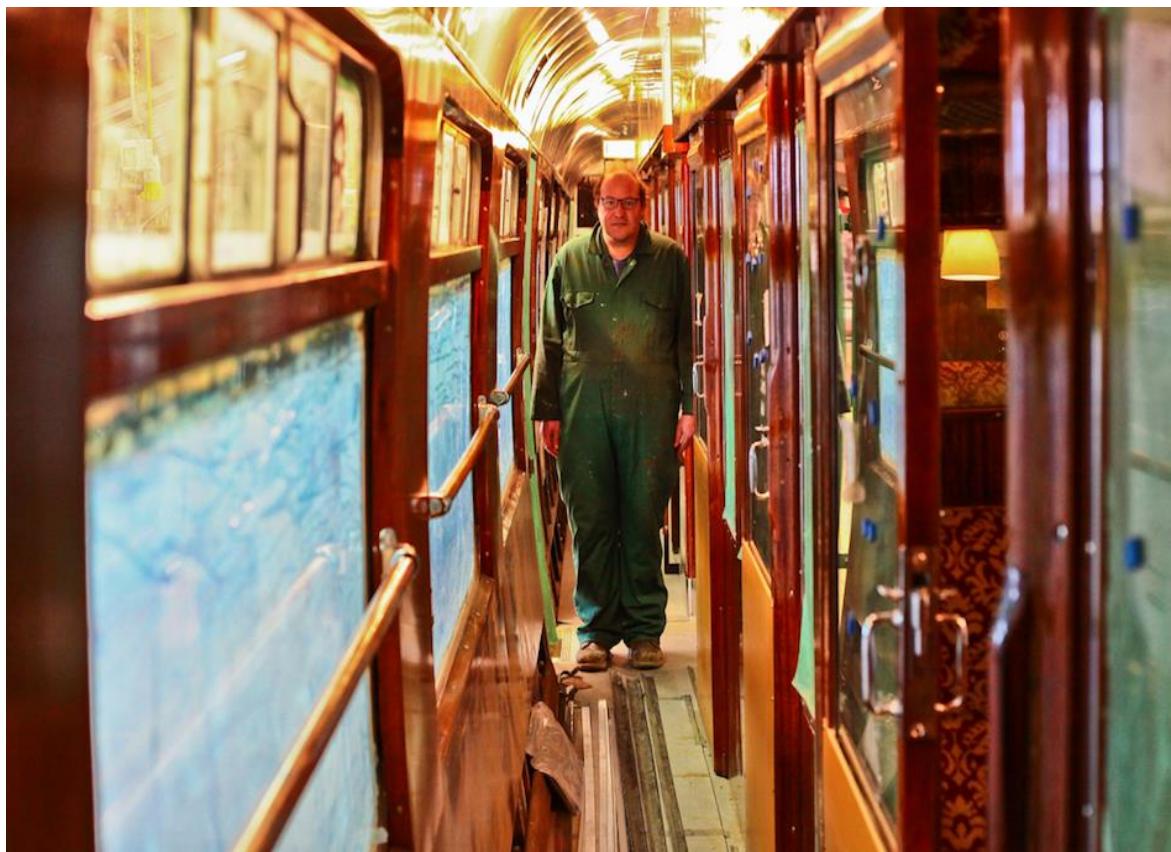
## Illustration 10 and 11. Working man (originals in colour)



## Illustration 12 and 13. Working man



## Illustration 14 and 15. Working man



## **5.6 Tabitha's story: a school catering assistant**

*My first job was a paper round and then a waitress while I was at school. At 16 I worked at the place that shut down, you remember Happy Eaters? I used to work there.*

*Then the craziness, I worked at Gatwick aircraft grooming. It was hard, because I'm not good with timing. I did a month's trial. I did like it, but it was a challenging job, 12 hours, four days on, four days off.*

*I used to work as a dinner lady as well as a lollipop lady. Before that I used to be a nurse, not a nurse but I used to be a domestic, but I used to do nursing as well, so it crossed over somehow. So, I'll just leave it as domestic staff. I used to work for the NHS on a psych ward at one time and then the place shut down.*

*Then I wanted to join the army. When I went home and said to my mum. I think I was 19, I was like, 'I'm going to go and I'm going to join the army' and she was like, everybody sat there and was like 'Why?' I was looking at my parents and my parents were like 'Ok Tabitha, so let's get this right, give you a gun?' I never got in. They say you have to be super fit. I did all the tests and I passed. Funny to find out. You know for real, I really wanted to join.*

*I'm proud of the lollipop job I did but I can't do it anymore, it's just not relevant. My sister got me the lollipop job, that's before she died. The lollipop lady, I used to chat a lot with the lollipop lady, and she goes, 'I'm looking to retire Tabitha and I think you know the roads better than we do, do you want to take over from me?' Now my sister spoke to me about it and my sister wrote in the application.*

*I worked on the public roads. I wasn't scared of cars, I wasn't scared of the abuse you get, it just comes with the job, you know? I think the scariest thing I was most worried about was a child getting hurt, that was my biggest thing, while they were under my watch. But I managed to do it for six years.*

*I did enjoy it, they were lovely. I mean they were nice. But, that's not what I wanted to do; it's never what I wanted to do. No, what I wanted to do was teach nursery school or something.*

*I tried nursery at one point, I thought I could get into nursery, that's when it hit me, I had a disability actually. What happened was I was told I had to be more aware; I had to look out for things. I was aware and not aware, you know what I mean? Aware of my surroundings. I forget things that are so normal, it's hard, sorry. It's really complicated. You know, people don't see it because I used to just carry on and just cope with it. The weirdest thing is I used to work well with high pressure, but now, because it's so high pressure all the time.*

*I know working with kids is. I taught through scouting at one point, I was a volunteer, but it's not what I wanted to do. Always, my job was, I wanted to work with children, and if it weren't for the dyspraxia, dyslexia or whatever I have I would have been working with children ages ago. I love working with children, because, as it was what I wanted to do initially. I mean not feed them.*

*After this, what work I don't want is easier to say than what I do want because what I do want is kind of impossible. It's not realistic. When you think of realistic you think this is what I'm doing, this is what I know. I don't know, I'm like in my thirties and I have no idea what to do. No idea and yeah, my sister had one dream and it was to be a lawyer, but I couldn't do that, I couldn't do law. But if anything does happen, I just want to work basically and to cope by myself because I'll be honest with you, I've relied on my parents for a long time. And I don't know what to do because they keep waking me up, they keep saying 'Come on Tabitha go there soon' and I'm like 'No no no', but it's that 'No no no' that's annoying.*

*In terms of the help I've had, I used to have a buddy, he worked for another charity, he got head hunted he was so good, and he used to help me along with basic stuff, like time. You know what I mean? He'd ring me up and say, 'Tabitha you're not at work yet' and I would be like 'Oh my god!'. They are*

*given a set of criteria for six months they say they will stay with you, that's why this employment support provider is really good too. The other charity did actually get me the job; it was my first dinner lady job. In this first job I was clumsy, and I don't even know why I'm a dinner lady here, I have a lot of help. I've got a whole nice group of people.*

*Sometimes it helps if your family tries - yeah, family and friends - because when you do it on your own it's pretty damn hard. When I came back, I found it pretty hard, the fact that there's no bus from here. We used to have to drive down every morning and then I'd have to jump out and get a bus. Then I got a house down there, it didn't work out.*

*I come from a culture that when you're young you get pushed hard into things so then I had to go back to a system. When I came from living overseas, I stayed there a few years and then I came back, so culturally it was just really difficult. I spoke English but is was not as polished as it is now, so it's very very very confusing, because I got my words wrong.*

*There was the time I was at the job centre for two years and that's bad enough. What they do is after two years they give you two options. You go into college again and I went to college again and I did an English class and Maths. Oh god, I also worked in a school as a cleaner, so you see, I did that for about two years. Lots and lots of different types of jobs. And it just makes you think, why do I keep going back to school?*

*I did college, another two years in basic life skills and then I re-did my GCSEs as well, because my GCSEs was really bad. So, I did something different. And basically, I took myself back to school and then I worked and then back to school and then I did work on top of that. And then we just kept moving house and I started moving places.*

*Basically, I've always been in and out of work, this is what people don't understand is quite hard. The only reason I'm doing really well at the moment in my job is my team. If I didn't have my team, wow. I am still a dinner lady but in a different school. This one I used to go there when I was*

*a kid, I went there when I was about nine. As soon as I went the first person said, 'It's nice to see you' and this woman came up to me and said, 'Hi Tabitha, I haven't seen you for a long time' and I was like 'Huh?' And she's like 'I've known you since you were nine' and it was like great.*

*I get the bus at 9.06am. Then I have to run to number ten, which is the other end. So, I literally ran from my bus today, got on another bus, which was late as well, and then run into the other side. So basically, I spend my time running. I go, and I sit in the library a bit, and then run inside, then start. It's 11.30am until 1pm, that's it, and then I get the bus back and it depends on whenever one chooses to come. Because it's like different buses, I'm constantly on the bus, it's just tiring but I don't mean to be like that you know.*

*With the job I have set jobs, thanks to my line manager. She's very good, so what she does is she sets me jobs, so it's 'Tabitha does the milks, waters' and this, I can do that, and I'm also the dish washer, so it's good. When you come in you need to sign in and wash your hands for 20 mins, you're dealing with a lot of things, is it 20mins? I have to wear this black and white uniform; you have to work in the heat with this black uniform and this hat. You have to tuck your hair in. Can you imagine what mine would be like? And when you're ready you get your milks done, so you get the milks, you do your 16 over 20 or whatever it is. Onto the trolley, so straight after that you rinse it out, get the trolley, go out to the bin, put it in the thingy, put it outside, take everything, it's a very hard job.*

*I clear the plates. Then you've got the moment when you're running around; you've got two sides, two sides full of plates. It's piles. We've got infants, juniors and then the older ones that come in, they don't need much assistance but the little ones on the other hand. You've got the bowls; you've got the plates, you've got everything.*

*Oh yeah, I forgot I have to set up the fruits and buckets of water. We tell everyone, we put soap there just a little bit, but the kids are not allowed to drink, it's obvious! And clear the rest of the rubbish, take it outside, go*

*through a security gate, come back and then by the end of it you're like ok 'can I go home now! You serve on top of it as well; you have some bread on top. If someone is missing, we all cover.*

*Normally we get everything ready, we set out our things. And then while you're doing that you have to make sure everything is right, and then you do the washing, and you're always washing and so at the end of the day you're really tired.*

*That dishwasher gives me trouble! No basically, mine had snapped on the door. When it works it's a dream but when it's not its 'ahhh'! I do the dishes, plates, we have bowls as well, but the other girls take care of those. I do the collection as well.*

*So, you know the thing is when I was younger, I thought It was just one job you know? This job is you've got this you've got that and while you're doing this the kids are like 'We're hungry can I have some milk' and you're like 'Ok', and you go out and you have to make sure everything is filled and while you're in and out the girls are serving. You've got to be on it, as my friend used to say, she used to come up to me and say 'Babe, babe, on it please' and be like 'Ok'. This bit you're behind! One of my mates at college was like 'Tabitha swim, swim, swim'.*

*The others are really nice, when I was feeling really really bad, they were really sweet about it. I always try to stay on top of things. My line manager, she's really sweet and has known me for about 2 years.*

*Basically, we told her, when I first got there, I have difficulties sorting things out. And she thought of ways to help me with the job. The job used to be complicated at one stage; you had to put white plates, red plates, and separation of cups. You have to do 100 of this and 100 of those. Ok you have different colours and what she has done is make things a bit easier for us.*

*With my disability one minute you're spot on, the next minute... When I'm spot on, I'm spot on and when I'm not, I'm terrible. I think today got a bit irritating for me because I couldn't get the knives and forks ready in time, and I get a bit annoyed because I just feel like, you sit there and think I really want to get this done for the kids because you think about it and maybe if they were your kids.*

*The rest of the team they are very hard working and I won't knock it. First thing they come in they're like 'We have to help you', 'We've got to help everyone'. If I get a little behind, they will step in straight up. I had a really bad day and they all stepped up. And I was like, 'Uh...' It sounds like I really love my team. Yeah, to be honest with you I like my team, not so much the job. The kids are polite which is great. They have their moments... They remind me so much of my nephew and nieces.*

*If I had a bad day my boss is like 'you're doing fine', you know. I get so paranoid I'm not catching up because I've got this routine that's like we need to catch up, so sometimes the children don't come in on time. So, you're like, you've got things and she'll be like 'You know what you're doing'. Am I happy? Yes, I am.*

*The best bit of my job is working with those girls. They are really good. When I first got to the school it was really weird, I got a big hello. I've got the group who are really nice, I've got the gate keeper who is really nice. It's my team and that's what I'm going to say, it's my team.*

*I did meet them outside of work for a Christmas dinner or something. I did go a couple of times, I met the rest of the team, which is the other lot, and they're very nice. We've got two sections, we've got the upper lot, the ones with upper management, we only meet at Christmas, balls or something, prize giving.*

*The best job I've got is the one of I've got now, it's easier to cope with it's not as manic as the others I chose. I mean the lollipop lady, I loved it, I got to a point, there's certain jobs that can't last forever, everybody grows*

*around you. You feel like everybody is taking off and you're like stuck in the same. I got to the point where I thought every day... the only thing I did love about it was the way the children used to respect you. Again, see, working with children. It's like I'm always working with children and that for me makes me happy.*

*The children are different, whereas with the lollipop lady I had the sweetest little ones who used to come and talk to you, I used to be called 'yellow pot'. This little kid couldn't understand how I used to just stand in front of traffic.*

*What am I most proud of in my job? I think I've mentioned it so many times, with my job I'm actually glad I'm actually doing something. That's why, I'm proud of doing something, working. If I didn't have anything to get out for I wouldn't get out. I've never asked my family what they think, all I've done is basically worked.*

*Yeah, I keep myself at work because I become useless if I don't. There's working and putting in commitment. It's the same, I don't know what it is, I think I've spent too much time talking with my parents because I'm beginning to sound like them. 'We like to see results.' We've always been competitive and plus we came from a different country, so you can imagine how much we had to catch up and we had so many different systems because when I came here, I wasn't very good at English. I couldn't speak it at one point, my mum helped me a lot with that and I used to listen to people and I used to sit there, and everyone would be 'What are you doing?' and I'd be like 'Listening', and they'd be like 'what?'*

*What do I do with the money I earn? Pay rent. Just joking. No basically, it goes into the places it's needed, like rent, always done it rent first, then this, then that and I've always been paying things. I ask my mum to help with money. It's because I don't go out anyway.*

*In the future I would like more hours, yes, more hours. When I first started, I thought I'm going to be manager and I'm going to work it out. I would love more hours, you know the reason, I wanted to do more hours. I'd want to*

*have two jobs and at least get my life in focus. I'll do anything. I've done so many jobs. I didn't even think back until you reminded me of all those jobs, I've been employed but then I haven't kept it so long. I feel like I've been working all my life, but no, just kidding.*

*I'd like two jobs I could do without stress. Stress is the most annoying thing. I mean, to be always striving. I've got sisters who are like interior decorators, I've always feel like I'm competing with my sisters, because the other one did law, the one that died, the other one's got kids, she's got this, she's got that. They all have things they have and it's just tough and we've always been competing since we are little. It's hard not to compete with them.*

*I'd say to someone with LD looking for work, 'Try everything, don't give up, even if it's too hard and seems awful sometimes you just knuckle down.' I mean with the education the problem is you get too educated and everyone thinks you're alright. So just knuckle down and just carry on I suppose, stop getting distracted.*

*I don't know what will happen in the future, we will probably turn into space things. I've never thought of the future. In the dreams of the future it's coping and getting along with things. Being able to keep going. After my sister died, it's just been like that. I know it sounds stupid, but you know, she died a long time ago, but it still feels there. I don't know what's going to happen to the future. You know? If I know what's happening, oh that will be good.*

*It's just the future is so difficult, and nothing ever turns out, it's like saying you can get hit by a bus the next day and it's like the future is a bit iffy anyway. You know what, I thought that when I grow up and she grows up and I always thought we'd move in and out with each other because she could cope with my dyspraxia more than the others, the people I live with now. When you have diabetes on top, and that's scaring me about the diabetes, and so when you ask me about the future it's like that's an iffy one.*

**Illustrations 16. Never think doing a job is easy**  
(Stills from the film)



**Illustration 17 and 18. Never think doing a job is easy**



## **5.7 Jennifer's story: a waitress, charity shop worker and cleaner**

*I've lost count how long I've been working at the charity shop, about ten years. The other charity shop has been for two years and then at the 'drop in' for four years.*

*In the cleaning job I normally get there at quarter to 10 till 12pm and I check the dishwasher. It says clean or dirty and if it's clean I empty it and if it's dirty I leave it and there is a list of jobs I follow. I clean the kitchen, wash the floors, Hoover the 'drop in' area, and wipe the tables. I like this job best because I suppose I know when I come in what I have to do, and I've got a list instead of me asking the staff 'what do you want me to do' and I just get on with it.*

*In the other charity shop just down the road, I do steaming and hanging up the clothes and sort the books out and am on the till (it tells you the change and that). At the other shop I'm mostly on the tills and also, I hang up the clothes and cost out the children's books. I like sorting the books out, small books are 69p and large books are 99p. With the books it's quite heavy, cause you have to lift them and take them outside, that's quite tiring. With the steaming after an hour your hand gets quite hot.*

*At the other shop people are very nice and friendly and this lady who I work with she's actually just got a new job and she left last week, and I got on really well with her. In one job the people have a nice socialising thing, so we sometimes get together.*

*There's a lady who manages the one charity shop and a chap who manages the other. They're all right, they are mostly upstairs and I'm downstairs. At the end of my shift the staff normally say 'Thank you' for what you've done. They appreciate what I've done. I'm proud, like you know; I've done something to help in the community.*

*I am happy in the new charity shop, but I don't know if I told you that the other one is coming to an end because they are closing the shop? And in a*

*way, before it happened, I was getting a bit fed up with it as I've been doing it for a long time. I feel half in half about it, and everyone keeps saying 'What are you going to do?' 'What are you going to do?' And I say 'Oh, play it by ear and just see what happens'.*

*It's this Saturday coming that the shop closes so Thursday will be my last day. I'm ok today but when Thursday comes, I will be a bit um... The manager, he's been there a long time, I've no idea what he's going to do, whether he's going to do another shop or go somewhere else.*

*Before, I was at that shop for two mornings, Wednesday as well as Thursday, and I thought I want to have a change because I got a bit fed up with it. The other shop opened I went in there and said it would be nice to help you out.*

*When I spoke to my support workers, they said 'It's not worth looking for another voluntary job because at the moment you're looking for paid work.' They've got another charity shop run by the same organisation and if I do that and if another paid job comes up, I'll have to tell them I can't do the voluntary job.*

*I suppose I started looking for paid work because, like, I had ESA [ESA refers to the employment and support allowance] for a year and then they stopped it, and then this year my support workers did an appeal and I went to a meeting and the decision said that they couldn't continue it. Luckily my family has been helping me financially. Even with a job I don't know I might still need their help.*

*I think before this supported employment provider I had this lady from a different organisation. A bit like the current supported employment provider and they helped me a lot finding me voluntary work in the first charity shop.*

*Last year I started working at a French restaurant for four months but unfortunately it came to an end in December. I did it from 6 o'clock to 10pm on a Friday. It was ok, it was very close to home so normally I walked*

*there, and they gave me a lift back. When I arrived, I was helping to lay the table, set it up and then I light the candles. That's my favourite bit. Then we'd just wait till people came. I did a couple of orders but one evening my dad and his friends came down and I was looking after them the whole evening which was good experience.*

*In the beginning they got me to do the butters, so I did it at the beginning of the evening and put it on the table and gave meals out. Some evenings it was busy. We had about 40 people for a birthday so that was really busy. It was very like, what's the word, adrenaline; you're like you know always on the go. I got £4.65 an hour with tips. I suppose I used the money from the job to put towards my Christmas presents because it was coming up.*

*I don't know why it came to an end, they didn't need me and other things. I think that at the beginning, I need to think about things, I need to take my time to think about and at first, I wasn't that keen to help on a Saturday and then it was too late when I was.*

*Another paid job I did a Victorian enterprise down on the sea front for three summers. When I got there, I helped with the boards to describe it, it's like people can put their head through it and you can take a picture. Also, there was a coconut shy and so we'd try and get people to come and have a go.*

*The help I've had to find a job from the supported employment provider and starting with them since July last year. So, they've been helping me look for jobs. If you've got a learning disability, it's much more harder. I suppose it's helped me be a bit more confident. One of the employees sent me a form and I got a bit anxious and said, 'I can't really do this form' and they said 'Don't worry we can make a date and then I'll come and do it with you'.*

*I don't know, we actually tried three jobs. One cleaning job, and one poolside assistant and that was a telephone interview, that was interesting. And then, the poolside one, was interesting because I like swimming and I've got four nieces and nephews, it would have been a Saturday afternoon. I wouldn't mind, but I didn't get it. And then there was a cleaning job which*

*we applied, and they invited me for interview and there were a lot of questions as well, but the work consultant said I wasn't that enthusiastic, my body wasn't, I don't know.*

*It was the manager of the drop-in centre, she helped me to prepare for it before I went to it. It did help a lot, but I don't know. We got there in plenty of time, went to the café just down the road and when we got there, there was only one chap and he said the manager had to go because she had a driving lesson and he wasn't that qualified to do an interview. So, he only asked me one question. And then we went. He said 'Have you had experience in this work before' and I said, 'Yes I have'.*

*I don't know if I've got a favourite work experience. It's quite hard isn't it to say they're all about the same. It's quite hard really to say what job I would want to do. It's difficult, cause like, I did a floristry course at college for two years and I did work experience in a florist and that's what I wanted to do. I didn't get it. So, anything, anything really.*

*The florist course was once a week I think it was two years. I seem to remember when I started the course, I did work experience at a national known florist. That was ok and then I went to this other one that was independent, and I really enjoyed that. I liked the independent shop because they were really friendly people and they did things slightly differently.*

*When they had the flowers delivered, I'd usually cut the ends, tidy them up. They did try and help find me a job in a florist but like again I was very slow and apparently you have to be quite quick.*

*I also did a childcare course that was interesting, and I did work experience at a nursery. It was ok, it was alright. I don't know, it's like I enjoyed it, but it wasn't for me. But after that I did an afternoon at an after-school club with slightly older children. It was good, like I remember when we used to go and pick the children up from school and usually, they have tea there and activities.*

*I know my husband wants me to have a paid job and my mother in law. She desperately wants me to get a paid job, but my family, my family doesn't are not that pressurised, not like my mother in law. She was over in April and she said, 'Have you found one' and 'How are you getting on' and I said, 'No, I'm still looking' and one time she came with me to a meeting and I wish she wasn't there, and she was like interfering and it felt uncomfortable.*

*I think we did have to go to an assessment last year with the job centre. It was very nerve racking and daunting. The first time was with my support worker and the second time is with someone from the employment support provider.*

*I hope in the future to have a part time paid job for 10, 14 hours a week. I don't know what kind of job because I've been looking for so many, I've been looking for so many jobs and because something which we found I had my hopes up and then it just didn't happen.*

*I suppose, I'd say to someone like me, 'Don't give up, I'm sure there's a job out there and you know just be confident and be brave'. It's quite hard to be brave because sometimes when I meet new people, I'm quite shy.*

*(Jennifer has subsequently secured a paid job in a supermarket)*

**Illustration 19. Waiting to bloom (original in colour)**



## **5.8 Kenneth's story: a cleaner**

*The last paid work I did before this one was as a cleaner, so obviously I had that experience to draw on and knew that I could do it by having done some cleaning before. But that was back in 2009 so it was a long time without doing any paid work. I got dismissed from that job and left unwillingly. The same went for the same kind of job I did in 2007, just two years before that, and similarly I left again through no choice of my own.*

*It's no great secret to anybody and I'm not ashamed, my employer felt that I was spending too long to clean certain areas, because I have high standards. I've always believed in quality over quantity and I can't do both. I say to people I can't work quickly and competently, its either one or the other with me, and they wanted me to work both quickly and competently and I couldn't. It was much the same story with the other job too and eventually I enjoyed what I was doing and got satisfaction from doing it and it was taken from me unfairly and it was unjust, and I couldn't challenge their decision.*

*Those two positions were the only paid work that I've had in some time, as far as working to a contract that's the only paid work I've had in 19 years since I was diagnosed with depression and started taking medicine for it. So, I've actually spent less than a year in paid employment in the last 19 years.*

*Quite a bit of my paid work has been in retail up until my diagnosis with depression in early 1999. It was quite timely in that it came just after a very stressful time, which led to a nervous breakdown following the only full-time job I've ever had. It was as a milkman of all things working for the same firm and same place as my dad. My dad was instrumental in getting me that job soon after I left working at a supermarket, after a year of part time work at the end of '98.*

*My job as a milkman was full time and lasted about four months. I was sacked from this job. It was very stressful. It goes to show how little insight I*

*had into my own mental health, which was already deteriorating back then but I couldn't see it, because it had quite a degree of responsibility put on me, you know, which I couldn't cope with.*

*I went very quickly into the job because I was put on Jobseekers Allowance and had the pressure to find a replacement job as soon as possible and because the pressure from family as well at that time. I landed a job working in the kitchen of a restaurant here in the town and that lasted as little as a week or two, so I quickly resigned from there.*

*If ever a job brought together everything that doesn't suit me, it was being a milkman. Because of the need to serve customers, the need to go out in all weathers, to start early in the morning, the need to drive. There was an unpredictable element of the job as well, needing to deal with customers with their changing orders. You had to get money out of difficult customers sometimes and deal with traffic on the roads, all those sorts of things.*

*It was at a time when I hadn't long started driving anyway. I was only 21 when I got that job and I was kind of thrown in at the deep end. I had another milkman who I shadowed for a couple of days but then I was left on my own with all these customers and this big round to cover. All that retail customer service, customer facing work I've done has gone a long way to contributing to a hatred of doing any sort of customer facing sort of work which I will never do again. It has fed my distrust because of this belief that the customer is always right. For me it's harder than the average person to summon any charm, you know just to keep them on side. And in those professions, I had to work with some intimidating people, I was at another supermarket before my last supermarket job and I had a rather bullying manager to deal with there. All the while dealing with colleagues because you're out there working, but then you have to come back to a depot where you've got to order products for the next day, and when you go into the staff room there is the necessary banter. Every place of work has a culture and often that is not touched on. It's fine you've got the qualifications but for me it's the added dimension and worry about finding it hard to get on with colleagues or if you're in customer service too, maybe customers. That is a*

*big ask but for many years I found it hard to explain to my parents or brother those difficulties without coming across as work shy and a moaner.*

*You know, my family were very hostile to the idea of me becoming unemployed due to my mental health, due to depression. Following losing three jobs in quick succession between October '98 and March '99 they wanted me to go straight to work. Initially I kept it secret I was seeing a shrink and a community psychiatric nurse, but they were initially hostile to the idea of me being unemployed and as they saw it doing myself a great disservice. But I needed to recover.*

*Since that time (and still now) I've been working with a visual impairment charity, except for a two year break in the noughties, since 2005, and I've been with a charity shop down the road for a year before, so I was doing two volunteering jobs. Additionally, once every six weeks I was working with the talking news service (also voluntarily). So, volunteering in three places but doing very little of it. I worked at the visual impairment charity up until last September, just a couple of hours a week once a week, and three hours with the charity shop and one hour once every six weeks to come in and read for the talking news in their studio. So yeah, up until three years ago that's all I was doing. There was a bit of thinking really, I could be doing more to help myself and move forward.*

*I don't want to give the impression that support agencies weren't in anyway supportive, because I managed to secure my first voluntary work I ever did in a charity shop through one support agency. Or it might have been another one, again there's been a certain degree of crossover with some of these, because I've seen so many people in supportive roles it's as if they're all kind of intertwined. As a result, the feelings I have are always one of disappointment, disillusionment of things not quite working out, me ending up feeling like I've not fully pulled my weight, and feeling like the people, the job coaches, support workers, whatever you want to call them haven't pulled their weight. So, I've done a drama course, which I now regret not taking any further, and I've since done courses in IT through adult education. I pursued a career, I did a photography course too after I left*

*school. One was a City and Guilds and another which I think is a BTEC, which I think, was more like an art course, which I dropped out after just two terms, so I didn't even complete a year.*

*I did start off working outdoors here doing some gardening, really, although as you can see there isn't much of a garden. This opportunity arose through being referred to the employment support provider. Starting with them I just wanted to get back and thought the time was right to do some paid work. Certainly, the DWP were encouraging me, with the change to Employment Support Allowance. The key word was support and I was not getting any support. Initially, there was something appealing about working outdoors but I didn't really stop to consider that it would be problematic sometimes.*

*The weather is a big bugbear for me generally, with not knowing what to wear and through all the moaning I was doing with the managers here. It was sort of mutually agreed they wanted to retain me, and I did think of quitting as I often do with jobs and other things and I reflected on it and I thought I don't really want to leave. The management have been very supportive and encouraging as they're aware of my issues and are willing to be more accommodating than the average employer would. So, it was agreed as the previous cleaner left that I would take that on board along with another cleaner already doing some work here and I accepted. It's been about 2 years now and also, I managed to get more hours as well, increased to six from three. I'm here Tuesdays from about 11.30am; I aim to start between 11 and 11.30am. They let me be flexible fortunately, but I always do my 3 hours. I start at 11 or 11.30am and finish at 2.30pm or 3pm and the same on Friday, so that way there's an equal balance in the week.*

*I've now got a kind of schedule, which I didn't have at the beginning, of areas to clean and where I focus on and areas of priority, which are the bathroom here and the W/C next to the office where hygiene are most considered. Also, the stairways as well which are less of priority, so I always aim to do one side of the building, the stairways and the halls one*

*week and the other side the following week, so there's two-week rotation.*

*And the manager's office and also the office next door.*

*The most problematic thing is not the cleaning per se. Where I get a problem in every place of work, and here is no exception, are the peripheral things which I don't think people always take consideration of. There's always lots of talk about are you qualified for the job. But for me there's these extras and the biggest of them is people, like staff / colleagues.*

*Dealing with a particular place of work and this place hasn't always been good for my mental health.*

*In a place like this people are moving about, you've got staff, you've got residents. Some places call for me to work close to them in the communal areas. People come in and out of their flats. In the office next door, it's quite a narrow space and I've had to work around other people occasionally and clean and there have been moments of difficulty where I've got in people's way and vice versa. On these occasions I've not been able to clean where I want to when I want to, and I've then got upset and had to leave and if that happens it's then a question of where do I go? Because sometimes I've come in with an idea of what to do and it's hindered by the unpredictability of finding that there are too many staff there. If the previous day I've seen the office is in need of a clean but the next day I can't clean because there's lots of staff going in and out all the time. On another instance I came in and to my surprise there was someone from outside working in the corridors where I wanted to work as well, and with alarms going off and that sort of thing bothered me.*

*The work consultant helped me a bit in that respect, just taking note of whenever I can't clean in a certain place or if it's difficult and just moving on to something else, avoiding particular situations where conflict might occur.*

*It was only about 5 years ago that I received a diagnosis of Asperger's syndrome, which at least it put my actions and stupid decisions and tomfoolery into perspective, it gave an explanation. I say I am neuro-different with learning difficulties. If you've got a learning disability with*

*much more obvious signs of need you will get more help and more tailored support than if you're in this vague middle ground area that I and people like me exist in. Why is it only the very old or the very young with mental health problems or the very disabled that end up getting the most support? Why is it never those in a kind of nether world or who are approaching that middle age in that 30 something or 50 something bracket? It's like nothing exists for people like me, that's the way it feels, there's no support there. It's assumed that everybody has sorted themselves out if they're not 'normal', for want of a better expression, in my age group.*

*I often catch myself working in such a way or behaving in such a way. From what I've seen of other people working, how I work might be considered weird or unusual. I try and organize the way I work here and yet somehow; I slip back into old habits or don't stick to my own routine. It's like I'm incapable of following my own or anybody else's instructions. Again, it's not cleaning. I can never get done as much as I want to. This is a problem in countless jobs; I'm badly organized. I often find myself spending too much time cleaning a sink, for example, or the bath or the shower, or being rather too fussy cleaning the banisters. But that's a focus of people with Asperger's, we can hyper focus and be consumed with detail.*

*If I've ever asked for clarity on things, my thoughts are hard to get into words so that other people can understand them, so I don't get the answers I need so I'm left with answers that don't really help me.*

*The manager excepted, I've not really found the staff to be that friendly towards me, with one or two exceptions. They've probably been advised to say as little to me as possible for fear of upsetting me or keep me at arm's length and I'm not a very chatty person anyway. It's funny with me because I'm not a very friendly person, I don't like chatting to people much and yet I get upset whenever I feel ignored, I get annoyed. I'm just contrary like that. Outside of work the only time I went along to a Christmas party at the football club the first year was here. I felt so out of place, not just because of my own not liking social events anyway but because everyone else felt so much more important than me. I'd only been here six months, and just*

*having started that summer I felt weirdly apart from everybody and nobody introduced me to anybody, and if they did you had to launch into a big explanation of what I'd done before. I felt really low down in the pecking order really low down in terms of importance.*

*The same goes for the visual impairment charity, if you're not directly involved with the people the charity is set up to support, like the support workers you've probably met today, then it's almost as if, I feel, you don't matter. You're a peripheral person and because I have this difference, the Asperger's and mental health which now people know only too well about because of my behaviour here, I think you just mentioned the word disconnect and that very much describes me, disconnected.*

*There's no understanding of how people like me struggle with the world of work. But you know the government the DWP put great store into work. It's a strongly engrained cultural thing where work is the one thing that gives people their reason for living. It's like if you don't work or you're doing a very menial level type of work for a very short length of time like I do, that somehow, it's one step up from being a complete layabout or scrounger.*

*People put rather too much, in my opinion, on work. It's as if you're judged entirely on what they do for a living, if they work at all. It's usually the first thing people want to ask. You know I was watching a programme this morning that was about the whole American dream; it's perhaps not the same as here. It's one of the first questions people ask if not, 'How are you?' 'What do you do?' 'What do you do for a living?' 'What do you do?'*

*The government believe that work alone is the harbinger, or the bringer of self-esteem, yes, self-improvement, it's a good thing. It brings self-confidence it makes a person, gives a person reason. But in my place and in my experience the world of work has been a harbinger of depression. It's bought precious little but misery to my life. It's somehow hyped up to be this great thing, it's supposed to bring you self-esteem and a sense of purpose in life and yes it brings, but ultimately, it's just a means to an end so you can get paid to pay the bills. But it's not the be all and end all and it's*

*certainly not given me much joy in my life. In fact 80% of all the depression I've ever had has come directly or indirectly from work. I don't enjoy coming to this place. Half the time it's with a sense of dread I come to this place.*

*I don't like this place, I don't like half the people who work here and yet I've got to be proud of what I do, and I feel trapped being here because if I weren't here what else would I do? Where else would I work? And THAT [capital inserted by Kenneth] other place of work would bring just as much misery probably. The more people I have to interact with in a place the worse it is. I could never work in one of these great multinational companies or office blocks or, god forbid, a large supermarket my mum works in with all the levels of management and the politics and backstabbing that goes on and all the rest of it. I hear all these horror stories from my mum about how she's been treated so badly over the years and she's a strong woman. How would I cope in a world like that? I wouldn't last five minutes, and she agrees with me.*

*I think the world of work is all right if you're neuro-typical but if you're not. It's alright if you have a learning disability, they will get support because they've got a proper disability and look like they have and act like they've got a disability. For me, like I said last week, existing in this 'no man's land', what am I to do? I need support, but I don't look like I need support at the same time and it's a horrible confusing world to inhabit, and it makes me really angry and it makes me annoyed in the way the world of work is so geared.*

*If I left here, I might find myself in a position where the work consultant said, 'I don't want to support you'. Then I'd have to explain myself and the next time Job Centre Plus want to get me in for one of their so-called work focused interviews. They'd want me to explain how I left my last bit of paid work and they'd pressure me to find paid work as soon as possible with one of their experts, one of their people. And somehow, they think pressuring someone into finding work is the key to someone's salvation. Whereas it would probably make my depression worse; their way of trying to help a person is counterproductive. There you go, rant of the day over.*

*I'm proud of the standard of my work. I mean I would take issue with anybody who says I don't do a good job. From all my modesty I always come away with a sense of achievement. And that's the thing about the sort of work I do, cleaners, people who do low end jobs someone has to do and if you've left a place looking better and more hygienic than when you arrived, that's something to be proud of. The manager is pleased with what I do but I don't know about other staff.*

*What's best about the job is being able to work alone. So, the time always goes by quickly because I'm always moving about and it's keeping me fit at the same time. Sport doesn't appeal to me and when other things I do to keep fit like cycling and swimming can be a particular bind, it's like killing two birds with one stone. The satisfaction of doing the work itself with also the awareness that I'm keeping fit and active at the same time.*

*I know how much I earn an hour and that I'm entitled to amount of paid leave in line with how many hours and how much rate of pay I get. I've got an account that it's paid into along with my ESA which fortunately hasn't changed lately in line with what I'm earning here because it's under a particular threshold. It all goes into the same pot for bills and luxuries, sometimes, as well, but I'm never in debt and if anything, I'm rather too careful.*

*Right now, on a percentage scale I would say I'm 50-60% happy. What might improve this level of happiness may be to clean a different type of place and buildings and layout and lighting. I would prefer not to have to come into contact with any of the residents here or see any of them some of whom annoy me and because right now I'm not very tolerant of people generally and sometimes that intolerance has spilled over into how I have talked to staff and people. What would tip it upwards would be seeing fewer people here, staff and residents, and cleaning in a different type of place.*

*I've been thinking a bit about long-term employment, thinking only yesterday that I lack aspiration because it's easy for me to get stuck in a rut.*

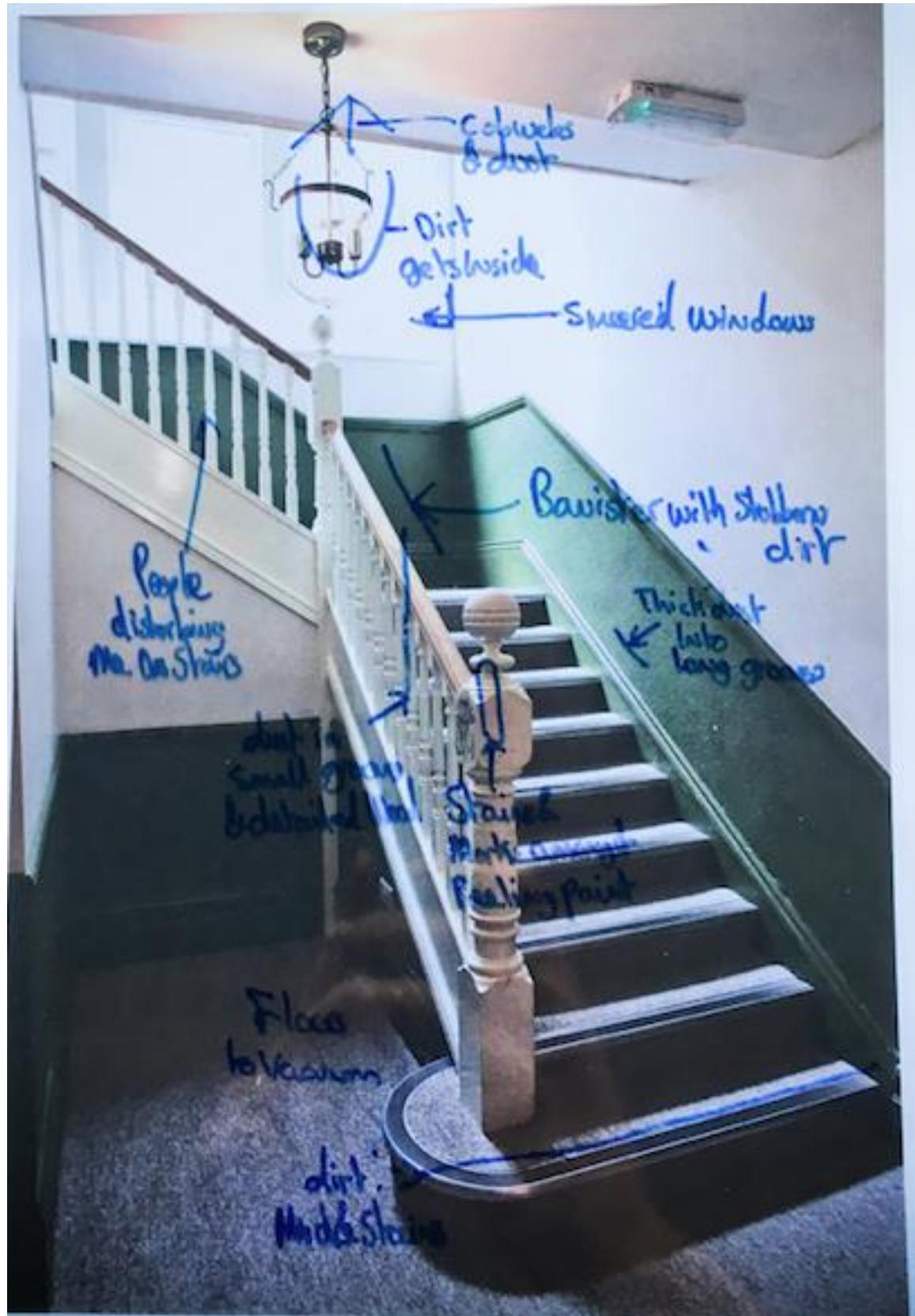
*But at the same time unless I make the effort, which I don't usually do, I'm not in the habit of being a very proactive determined person, I could stay here doing this for the rest of my working life and I don't want that.*

*In the short term I'd like to be able to cope with some more hours and perhaps work somewhere differently or as well as here, but in the longer term to do something that would make me more proud, more satisfied. It's frustrating and it doesn't help that in my working history I've done so many types of voluntary things. I've been supported by so many different agencies and been on quite a few different programmes that it just feels like they all merge together after a while. Yes, dates might be fine but it's what happened and why that's so hard to recall, I have no emotional memory. I'm not sure I've ever had any good help around work. Nothing I can think of right away. I've had lots of support [names five supported employment providers] but nothing sticks out. Getting a desired job feels more like a dream at the moment, such as working as an actor, or as an author, or as writer or taking up studying psychology for myself. They're all subjects I've got an aptitude for or an interest in. Even I have a desire to do something that's better than this in the long term. I think it's time to aim a bit higher and get out of the rut of doing menial work because that all I've ever done is really menial work.*

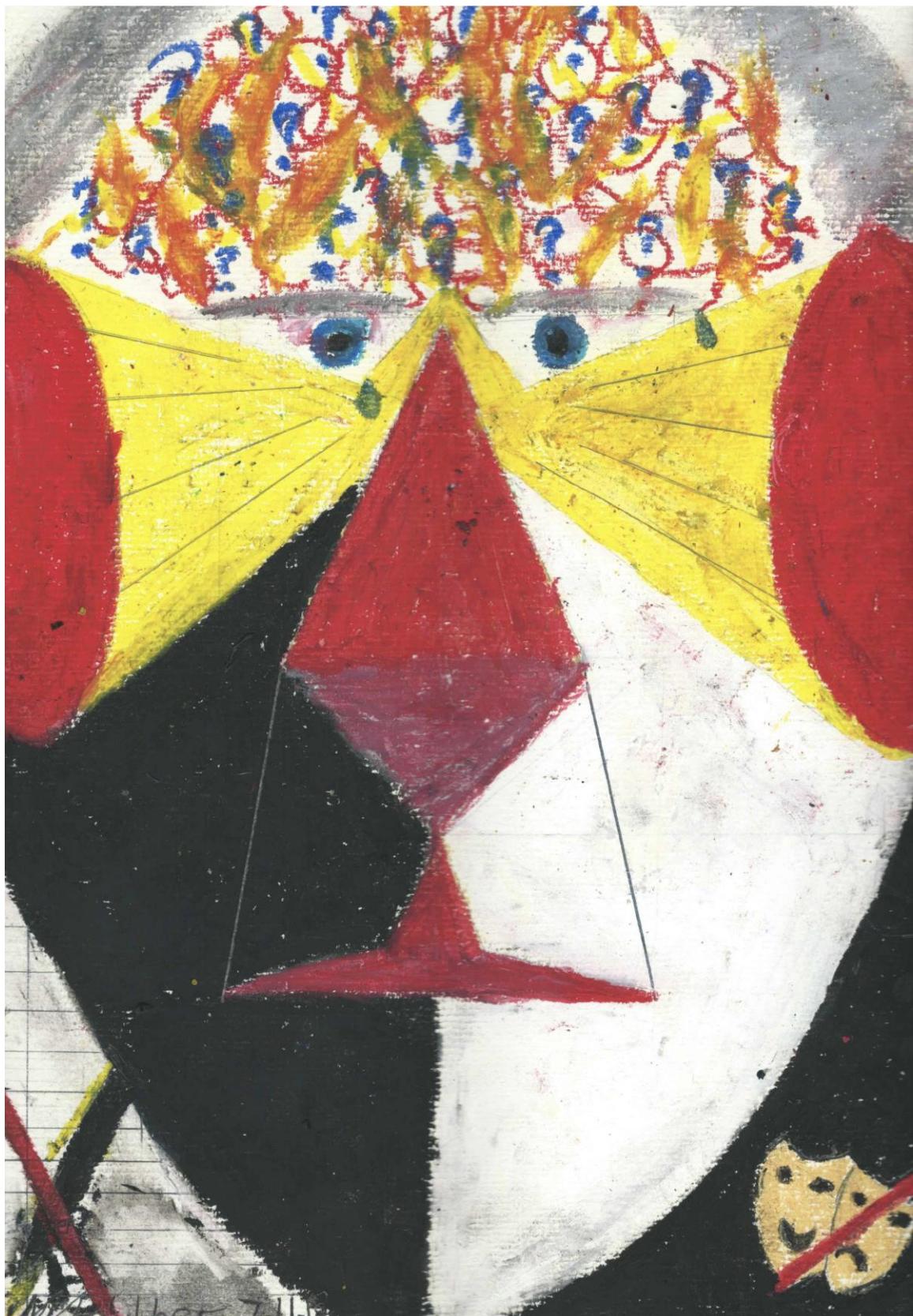
*My family, they're aware of my work but I'm not sure what they think. I think they're pleased for me that I'm doing some paid work and making that progress towards being a bit more useful in society generally, and not being as idle as I once was or as work shy. I think they're a bit more proud of me than they used to be.*

*I would say to someone in a similar position to me 'Ask yourself what your skill set is and what it is that you'd really like to do, and if the two meet then go for it, then look into that, look into paid work in those areas.'*

## Illustration 20. Working with an analytical eye (original in colour)



**Illustration 21. Kenneth's self-portrait (original in colour)**



## **5.9 Summary**

This chapter presented the first stage of research findings contained within the collaborators' co-created individual narratives and visual work stories. The collaborators, as well as having commonalities, had varied individual demographics and these were experienced most significantly in the way that they engaged with the photographer and me. This included the collaborators' self-defined disability, their interests in and outside of work and their choices when engaging in the research. Holding as closely to their spoken accounts as possible, these first-person narratives, considered alongside the diverse range of visual images, support the research aim of giving voice to the research collaborators.

It was the collaborators' work stories that formed the content of the public exhibition. Although the visual components of the work stories formed the primary focus of the exhibition, the full narratives were available through the exhibition catalogue (Ramsey, 2018). Consideration was given to where the exhibition, *Work[able]*, should take place and a public library was chosen. This was because a public library is a community resource and keeper of stories, and in addition to being a place to share stories, it also provided greater potential for the public to sit and read the narratives.

In the subsequent chapter, the second stage of analysis and findings will be outlined. Here I, as the researcher, considered the work stories through applying the hermeneutic reduction and hermeneutic circle. In this process the participants' commonalities will be evident through the emergent narrative frames. In Chapter 6, the phenomenological reduction will be summarised and the five narrative frames specified, explored and discussed empirically as they emerged from within the work stories and in discussion with the collaborators in the group meeting.

# **Chapter 6. Work[able]. The quest for paid work**

## **6.1 Introduction**

In Chapter 5, the first stage of analysis was presented in the form of the six collaborators' work stories, in both narrative and visual form completed through the application of the creative collaborative partnership method. This chapter summarises the process of applying the hermeneutic reduction (outlined in Chapter 4) showing how it explicated new knowledge to inform people with IDD, their social networks and the practice of supporting people with IDD in relation to employment. This final stage of analysis and findings are outlined in three parts. Firstly, the hermeneutic reduction is described (section 6.2), followed by the five narrative frames, which are contextualised empirically in the work stories (section 6.3) and then the discussion with the collaborators in a group meeting is detailed (section 6.4). The narrative frames are comprised of 'the quest to do', 'finding a good fit', 'navigating bureaucratic seas', 'finding both friend and foe' and 'the forging of identity'. Brief accounts taken from my reflexive diary will be included at intervals throughout the text, reflecting the intersubjective experience with collaborators that informed this stage of analysis.

## **6.2 Applying the hermeneutic reduction**

In the exploration of phenomenology as a methodology in Chapter 3, it was evident that there were no specific, clear protocols on how to engage in phenomenological analysis (Finlay, 2011). As applied in this thesis, hermeneutic reduction has included spending time immersed in the lived experience of each collaborator's work story (narratives and visual images) as well as my reflexive diary, while adopting the phenomenological attitude or stance of critique, naiveté and wonder (Heidegger, 1962). Furthermore, metaphors, scripts and themes were drawn from spending time with individual narratives and considering the collective work stories, utilising what Finlay (2011) described as the secondary narrative analysis. Similarly, van Manen's (2016) 'existentials', which he described as theme types to guide reflections on the data, were contemplated in

relation to the lived experience of work as a phenomena. These included lived space, lived body, lived time and lived human relationship. The mechanisms outlined by Finlay (2011) and van Manen (2016) were utilised in applying the hermeneutic circle to the collaborator's work stories (See the reflexive account below). A summary of the hermeneutic reduction process is provided in the analysis overview (Table 6.1), where examples from the narratives are listed and linked numerically to individual emerging ideas and then to the collective formation of the five narrative frames.

#### ***Reflexive account 8 – The hermeneutic circle***

I cannot escape the narrative frame of a journey as I immerse myself back into the narratives and images in this second stage of analysis. I recognise that this is, of course, a fore-conception in that the visual tool I used (the job story map) gave this sense of journey, and the narrative structure of past, present and future, through the format of the semi-structured interview that has affirmed the journey theme. In this respect, when I go around the hermeneutic circle, considering the individual parts of the collaborators' stories and the whole thinking of all six collaborators' contributions, I return to this narrative of a journey. Specifically, a quest narrative emerges but I'm questioning if this is coming from me, or the narratives.

In my mind, I see a populated job story map which is very real, formed by the landscapes that each collaborator has described of their experience, i.e., experiencing prejudice and support in their physical environment work settings. The motion of this journey is, at times, communicated in an intense way as a pursuit of action in the quest for paid work. At other times it is quiet and unassuming, towards a place where there is belonging and acceptance after navigating extreme landscapes including challenges, rejections and acceptance, as well as encountering those that help and those that don't. In this way, I can see the frames are emerging from the collaborators' narratives within the structure of my path.

**Table 6.1 – Analysis overview**

Research collaborator	Job and visuals	Emerging empirical evidence ( <i>numerical references linking to reduction and collective narrative frames</i> )	Hermeneutic reduction and narrative analysis - individual	Hermeneutic circle leading to emerging narrative frames
<b>Mark</b>	<b>Assistant caretaker, groundsman, volunteer (P/T or weekend work)</b>  <b>Title – Working man</b> Six portraits, two in each setting – active and static	'It was frustrating when I had applied for a job and they didn't reply or told me they couldn't offer me the job. So, I just kept on looking. At times I did feel a little bit fed up. But well, I just kept on looking' (1 and 2) 'I normally sit in the canteen and relax' (3) 'The most important part of my job is to make sure I get everything nice and tidy.' (3) 'I feel proud I'm helping to keep the warehouse clean and sometimes do people a favour' 'helping everyone' (3 and 4) 'I don't mind the term learning disability' (4) 'I do find it hard to talk to people at times' (4) 'The work consultant used to be a member of staff at the Centre and he referred me to them. It was both our idea to look for paid work' (5)	Quest narrative emerging in 'just keeping looking' (1) Managing multiple failures of applications over time, revealing resigned understatement 'little bit fed up' (2) Belonging in his present work and working environment indicating competence in 'doing' and relaxed in the role including helping others (3 and 5) Visuals suggest a sense of belonging in the lived space of his work settings – choice to be in the pictures self-identifying as a 'working man' (4) Work Consultant role and the importance of good individual support (5)	<b>The quest 'to do' (1)</b> <i>Mark 'kept on looking'</i> <i>Tabitha describes the pursuit of relentless work-related activity.</i>  <b>Navigating bureaucratic seas (2)</b> <i>Both describe protracted journeys of overcoming.</i>  <b>Finding a 'good fit' (3)</b> <i>Mark indicates belonging, competence and contentment.</i> <i>Tabitha describes the challenge of her work and belonging in her team.</i>
<b>Tabitha</b>	<b>Catering assistant (P/T)</b>  <b>Title – Never think doing a job is easy</b> Short film of Tabitha engaging in tasks at work	'What I do want is kind of impossible, it's not realistic' (1 and 4) '...lots and lots of different types of jobs' (2) 'There was the time I was at the job centre for two years and that's bad enough. What they do is after two years they give you two options. You go into college again...' (2) '...the future is a bit iffy' (2 and 4) 'I thought it was just one job' (3) 'What happened was I had to be more aware' (4) '...when I'm spot on, I'm spot on, when I'm not I'm terrible' (4) 'I'm actually glad I'm doing something, I'm proud of... I'm working'. (4) 'Sometimes it helps if your family tries yeah, family and friends, because when you do it on your own it's pretty damn hard' (5) '...love my team if I didn't have my team, wow' (5)	Multiple barriers, constant work-related activity and seeking of paid work but the unfulfilled quest emerging (1 and 2) The imperfect fit with current work revealing itself. Positive belonging with her team but struggling with the job not being 'easy' (3) Self-aware relating to impairment and self-identification with her struggles (4) High support from her social environment but also family pressure and a lack of reciprocity with work colleagues (5)	<b>Forging of identity (4)</b> <i>Both describe the importance of the work role and challenges of IDD.</i>  <b>Finding both friend and foe (5)</b> <i>Importance of social support.</i>

**Table 6.1 – Analysis overview**

Research collaborator	Job and visuals	Emerging empirical evidence ( <i>numerical references linking to reduction and collective narrative frames</i> )	Hermeneutic reduction and narrative analysis - individual	Hermeneutic circle leading to emerging narrative frames
Jennifer	<b>Volunteer cleaner, voluntary shop worker (P/T)</b> <b>Title: Waiting to bloom</b> A split image – top Jennifer as a florist, bottom image Jennifer doing current work as a cleaner	'I'm proud like you know I've done something... in the community' (1) 'It's quite hard really to say what job I would want to do. It's difficult, cause like, I did a floristry course at college for two years and I did work experience in a florist and that's what I wanted to do. I didn't get it. So, anything, anything really' (1 and 4) 'I've been looking for so many jobs and because something which we found I had my hopes up and then it just didn't happen' (2) 'The work consultant said I wasn't that enthusiastic, my body wasn't...' (4) 'I was like very slow and apparently you have to be quite quick' (4) 'I know my husband wants me to have a paid job and my mother in law. She desperately wants me to get a paid job' (5)	The unfulfilled quest emerging with unrealised dreams and quiet resignation; but still seeking 'to do' (1) A lot of work-related activity, floristry training and work experience and 10 years volunteering not leading to paid work (2) or finding a good fit (3) Identifying her impairment related to her body and the lack of ability to support her work dreams (4) Evidence of both social support and social pressures (5)	<b>The quest 'to do' (1)</b> <i>Disappointment, disillusionment and relinquishing the hope of the ideal paid job.</i>  <b>Navigating bureaucratic seas (2)</b> <i>Engaging with many structures and services without much progress towards paid work.</i>  <b>Finding a 'good fit' (3)</b> <i>Both narratives describe poor fits in their current positions. Jennifer due to lack of paid work and Kenneth in his paid work.</i>
Kenneth	<b>Cleaner (P/T)</b> <b>Title: Working with an analytical eye</b> Image of the staircase with the details Kenneth sees written onto it	'Existing in this 'no man's land' what am I to do?' (1 and 4) 'The feelings I have are always one of disappointment, disillusionment of things not quite working out, me ending up feeling like I've not fully pulled my weight, and me feeling like the people, the job coaches, support workers... haven't pulled their weight' (2 and 4) 'I don't enjoy coming here for one moment. I don't like this place...I feel trapped being here because if I weren't here what else would I do?' (3) 'I think they're pleased for me that I'm doing some paid work and making that progress towards being a bit more useful in society generally, and not being as idle as I once was or as work shy' (4) 'can be hyper-focused consumed with detail' (4) 'You know, my family were very hostile to the idea of me becoming unemployed due to my mental health...' (5)	The unfulfilled quest emerging, alienated in a 'no man's land' with disappointment with systems of support (1 and 2) The description of multiple work-related activity and support structure that provided limited success in bringing him to the work he wanted (2) Evidence emerging of a poor fit – not liking work but feeling trapped (3) Identity, clear in self-identifying as neuro-different, with identity linked with economic value, 'Work shy', 'moaner' (4) The unpredictable social environment hindering in addition in part to being a source of support (manager and work consultant) (5)	<b>Forging of identity (4)</b> <i>Both narratives describe positive and negative influences of work and seeking paid work.</i>  <b>Finding both friend and foe (5)</b> <i>Predominant descriptions of the negative impact of the social environment.</i>

## **6.3 Five narrative frames**

Five narrative frames emerged from being immersed in the work stories during the hermeneutic reduction: ‘the quest to do’, ‘finding a good fit’, ‘navigating bureaucratic seas’, ‘finding both friend and foe’ and ‘the forging of identity’.

These will be discussed below with direct reference to the collaborators’ work stories. Alongside this, the impact of the intersubjective process that occurred during the joint meetings with the collaborators will be discussed and highlighted through extracts from my reflexive diary. In my experience, it was often in this intersubjective space between collaborator, researcher and photographer, that metaphors or scripts initially emerged relating to the collective narrative frames.

### **6.3.1 The quest ‘to do’**

While dwelling with the lived experience of the six collaborators’ work stories, I was drawn to the often-relentless pursuit of work-related activity that led to the ultimate action, which was to ‘do’ a specific job, or, for most collaborators, any paid job. This frame refers firstly to the pursuit or journey that each individual had taken in seeking work alongside, for some, achieving the goal of the quest and gaining a job they valued (‘a good fit’). In every collaborator’s narrative, the often-challenging pursuit of work bought to my mind the metaphor of an expedition or trek. They all described overcoming barriers, including experiences of success and failure, unmet expectations, rejection and ‘knock backs’. All the collaborators shared stories of resilience in setting themselves on the quest towards the goal of paid work.

Emerging from the collaborated narratives was an exhortation to ‘do’ or a desire ‘to do’ something: to be productive, to undertake paid work and achieve the action of ‘doing’, in a work setting, for financial remuneration. Therefore, the focus on a specific job was not the quest. In fact, it was evident that often the abandonment or putting aside of a specific work aspiration had occurred at some point in most of the collaborators’ stories. The pursuit was exemplified by Jennifer, who, as the only collaborator who had recently lost her paid work, stated she would do ‘anything, anything really’ (page 151) as paid work. Furthermore, the nature or amount of the financial remuneration appeared to be secondary to the act of doing a paid job. Again, this was exemplified by Jo and Tabitha not being able to identify the amount of pay they received, as their finances were managed by a family member. Additionally, when considering the hours worked, none of the

collaborators were working in a paid job full time and all of the collaborators, whilst articulating a desire for increased hours, stated that they did not want to work full time. The empirical data associated with this narrative frame of 'doing' a paid job is detailed below, as well as the evidence of the quest narrative.

The apparent relentless pursuit of work and 'doing' appears most evident in Tabitha's narrative. Tabitha alludes, in the tone and content of her story, to a frenetic pace in the sheer number of jobs that she had experienced as well as the number of jobs applied for. She stated that she had held 'lots and lots of different types of jobs' and catalogued them numerically, in addition to listing many jobs that she had applied for in many walks of life e.g., the police, army etc. She also described going to work, then to college and back to work again, indicating a consistent stream of activity.

Similar statements indicating intense levels of consistent 'doing' in the pursuit of a paid job can be found in other collaborators' stories. Mark stated 'I kept on applying for jobs in that time. I know I've applied for a large number of jobs' (page 130). Similarly, in Jo's narrative, he noted 'I was signing on at the job centre for 3 or 4 years' (page 115) and in Jennifer's narrative, 'I don't know what kind of job because I've been looking for so many' (page 152).

For all collaborators, the long nature of the journey and the constant 'doing' was, perhaps inevitably, communicated alongside experiences of success and failure. These experiences were exemplified in Mark's statement, 'It was frustrating when I had applied for a job and they didn't reply or told me they couldn't offer me the job. So, I just kept on looking' (page 130-131). Similarly, in Ruth's statement, 'It was an awful long time to get to where I wanted to be' (page 119) and her evident sense of success is exemplified in her recommendation to others '...You're going to get there eventually and it's going to be great' (page 124).

In other collaborators' stories, the 'doing' had not led to them achieving the goal of their quest. Their journeys were continuing, as their current aspirations had not been fully achieved. However, in the stories where the quest had not been achieved, there was equally an emphasis on the importance of 'doing something'. Tabitha stated, 'I think I've mentioned it so many times, with my job I'm actually glad I'm actually doing something. That's why, I'm proud of doing something, working. If I didn't have anything to get out, I wouldn't get out' (page 143). Similarly, Jennifer, when initially talking about her voluntary work stated, 'I'm

proud, like you know, I've done something to help in the community' (page 148).

When thinking about her hopes for the future and paid work she stressed the importance of 'doing' over her desired job:

*It's quite hard really to say what job I would want to do. It's difficult, cause like, I did a floristry course at college for two years and I did work experience in a florist and that's what I wanted to do. I didn't get it. So, anything, anything really. (Jennifer, page 151)*

Furthermore, even though Kenneth was unhappy in his work, relating in part to relationality and spatiality, the fear of not doing was strongly communicated, 'I don't enjoy coming here for one moment. I don't like this place...I feel trapped being here because if I weren't here what else would I do?' (page 161).

Furthermore, within all the collaborators' narratives were references to the positive associated benefits of 'doing' a job. These included, providing a structure and routine to the day, as well as contributing to improved self-esteem (detailed more comprehensively in 'finding a good fit' and 'the forging of identity') and, as highlighted above and the risks of 'not doing'.

In the visual images constructed in the workplace, the 'doing' of the role was understandably a key part of representing their work story for all collaborators, although this was represented in a broad variety of ways. Tabitha's film revealed her 'doing' in real time, taking part in the tasks required in her job, demonstrating the corporeality of her lived experience. Similarly, Jo chose to represent his work routine with pictures of his environment as he interacted and moved around it, including blank squares that represented when he might stop for a break or to talk to someone. In this respect, a temporal element is indicated. Additionally, Kenneth's visual image leads the reader through his workspace and spatially lived experience, when viewing an area of his working environment. Furthermore, Mark's and Jennifer's static portraits revealed them and their lived body, in space and time, taking part in the process of doing. In some of Mark's images, he is not interacting with objects within his environment but rather stands, concretely, in his workspace. Conversely, Ruth's visual images allude to her work tasks through objects associated with her working environment, i.e., clinical files, rather than by providing a direct image of herself in action; she explored her lived experience in a nuanced way. Furthermore, in most of the images shared, including those of collaborators (albeit indirect), no observable physical impairment was evident. As

a researcher, I wished to highlight this as it indicated a lack of representation of the broader experience of people with IDD. This will be discussed in the context of related literature in the next chapter.

#### **Reflexive account 9. Fusion of horizons: Jennifer**

We sat on a bench in the sunshine when I read Jennifer's story back to her following the interviews (with the photographer present). It was a beautiful day and due to Jennifer being quite quiet, the photographer had limited interaction with her in this first meeting, only having heard a little about her story on the way to the meeting. As I finished reading the story out loud, there was a tangible sadness between all three of us and without prompting, the photographer began to talk to Jennifer about her experience as a florist and her pleasure in this prior to the disappointment. She and Jennifer equally seemed to know immediately, even before discussing it in detail, that Jennifer would want to represent this hoped-for job alongside the ones she was doing. Equally, as the photographer and I talked on our return journey home, we both articulated the sense of hopelessness that felt present when finishing the story, and the connection we all shared in the soft and beautiful parts of Jennifer's story, like lighting the candles being her favourite part of her job in the café.

#### **6.3.2 Finding 'a good fit'**

The focus of the quest illuminated in the work stories is to gain a job that is 'a good fit', specifically a job that the collaborator was happy and content in. The pursuit of such a job was found in each collaborator's story, either because it had been achieved and they had found the right job for them, or because it was identified as the ongoing goal of a continued quest by the individual. Of the six collaborators, there appeared to be an equal split between those who had a sense of having found 'a good fit' in their work (Jo, Ruth, and Mark) and those who were still searching (Tabitha, Jennifer and Kenneth). Where collaborators described finding 'a good fit', their narratives featured or were characterised by arrival, belonging, contentment and competence. Alternatively, the features that emerged from those

collaborators who had not achieved a good fit in their work, or (as in Jennifer's case) did not have paid work at the time of the study, included a sense of disquiet, discontent, unsettledness and ongoing pursuit of something more. This is expanded on below with reference to the collaborators' narratives, initially exploring those who have found a good fit.

Within Jo's, Ruth's and Mark's stories, a sense of enjoyment and competence in their role and sense of belonging in the workplace emerged. This was communicated in several ways, through revealing a confidence and competence in the tasks and work schedule as well as familiarity with the people they worked with. These were presented not only in the narrative but also in the visuals and were followed by a sense of contentment that their journey was complete and that the future held hope, but not pressure. Jo initially outlined the satisfaction he felt about his work, followed by a comment demonstrating his sense of competence in his work tasks:

*Out of all the jobs I've had I enjoy this job most, you go round talking to more people, at college you were just getting on with it. (Jo, page 117)*

*I check the toilets are clean; check the basins are clean, check the toilet rolls and towel rolls as well..... I was a bit wary of the blocked toilet the first time I did it but once I'd done it once it was ok. (Jo, page 116)*

Jo took the pictures that formed the collection of images presented in his story. This decision was made when the photographer asked Jo what he would like to photograph on the site where he worked. During the walk around the site with the photographer and me, Jo stopped to talk with people, appearing relaxed and confident in his work setting, displaying a sense of belonging. Similarly, Mark's portraits (that he requested be taken in each work setting) show him present, active and confident, as he chose to directly interact with his work tools and objects. He also communicated a sense of having arrived and contentment within his work settings and the people around him. He communicated a recognition of his contribution in work and feelings of being valued in this, even though there was no indication of interaction with his colleagues outside of work:

*I get two 15 min breaks and half an hour for lunch. I normally sit in the canteen and relax. (Mark, page 131)*

*I feel proud I'm helping to keep the warehouse clean and sometimes do people a favour. (Mark, page 132)*

*The best bit of this job is walking around helping everyone. Helping set the pitch up. (Mark, page 133)*

*I like knowing the work I do there helps maintain one of the carriages and wagon that are on the railway. (Mark, page 133)*

Ruth also communicated a sense of satisfaction and competence in her work, recognising her contribution and being content with her relationship with others in her work setting. She similarly revealed limited interest in additional contact with colleagues, either in the workplace or outside the workplace:

*What's most important is knowing that I've made a difference and helped the company. Because they are saying it's a lot neater now, when I started it was an absolute tip. (Ruth, page 122)*

*I'm not really that talkative. I'll say hello to people in the office, sometimes they'll offer me stuff. But I'm not really that much of a talkative person. My boss is friendly to me; it seems like a good environment. (Ruth, page 122)*

When considering the collaborators who didn't communicate 'a good fit' in their jobs, a sense of dissatisfaction emerged from their stories. They communicated both difficulties with carrying out the tasks required and, notably, an ongoing pursuit of something more or something else: the unrealised quest. Tabitha articulated a sense of liking not the job role but rather the team, when she said, 'to be honest with you I like my team, not so much the job' (page 142). Furthermore, she communicated her ongoing quest and her challenges in addressing this when she said:

*After this, what work I don't want is easier to say than what I do want because what I do want is kind of impossible, it's not realistic. When you think of realistic you think this is what I'm doing, this is what I know. I don't know you know I'm like in my thirties and I have no idea what to do.*  
(Tabitha, page 138)

Tabitha talked consistently throughout her narrative about the intense nature of her role, encapsulated in the title she wished to have for her images and video, which was 'never think doing a job is easy'. She talked of the challenges in

carrying out the tasks required of the role and the need for adaptation and team support to get the job done. In her narrative she describes what her manager 'has done is make things a bit easier for us' and explains that she has been given 'set jobs' from her manager and shares tasks with 'the girls'. Within this, a potential mismatch between her skills, her capacity and the occupational demand of her job are observed. Conversely, Kenneth articulated an ability to carry out the job of a cleaner but a dissatisfaction both with the way the role was perceived, i.e., as menial labour, and what he terms the 'peripheral' aspects of the role, which he identifies specifically as the people in the environment and the requirement to interact with them, as detailed in the quote below. The nature and expansiveness of the job and its associated social demands, e.g.: from the children, are equally picked up by Tabitha.

*So, you know the thing is when I was younger, I thought it was just one job you know? This job is you've got this you've got that...while you're in and out the girls are serving.' (Tabitha, page 141)*

*The most problematic thing is not the cleaning per se. Where I get a problem in every place of work, and here is no exception, are the peripheral things, which I don't think people always take consideration of.*  
(Kenneth, page 158)

*In a place like this people are moving about, you've got staff, you've got residents and some places call for me to work close to them, in the communal areas people come in and out of their flats...sometimes I've come in with an idea of what to do and it's hindered by the unpredictability of finding that there are too many staff.'* (Kenneth, page 158)

Jennifer, who at the time of interviewing was still applying for paid work and had a recent experience of job loss, equally communicated a sense of disappointment. This related not only to her initial experience of losing her job as a waitress and her future ambition but also to her past disappointments with regards to her desire to be a florist. Within her story, she touched on the feedback she had received relating to her physical capabilities for the role of a florist:

*They did try and help find me a job in a florist but like again I was like very slow and apparently you have to be quite quick.* (Jennifer, page 151)

In this respect, within each of the collaborators' stories that communicated 'a poor fit', they highlighted a potential mismatch between their work, their working environment and their individual capability to do the job. Furthermore, the work stories communicated the impact of experiencing a 'poor fit', the continued quest the collaborators were on and its negative relationship with their mental health and wellbeing, as exemplified in Tabitha's and Kenneth's quotations below.

Similarly Jennifer, who was the only collaborator who had lost her paid work prior to the interview, referred to being 'a bit anxious' (page 150) about form filling, feeling pressurised by some members of her family to apply for work and to finding being assessed at the job centre 'nerve racking and daunting' (page 152).

*I'd like two jobs I could do without stress. Stress is the most annoying thing. I mean, to be always striving. (Tabitha, page 144)*

*This place hasn't always been good for my mental health. (Kenneth, page 158)*

In her visual images, Jennifer's aspirations for the future were articulated alongside the current reality of her work setting, while both Tabitha and Kenneth articulated a desire pictorially to communicate the complexity of their work and the challenges they faced, as well as what was supportive to them. It was only Ruth that included the achievement of success in her pictures, when she wrote on one, 'Trust your instincts and be persistent, you're going to get there eventually and it's going to be great' (page 124).

### **6.3.3 Navigating bureaucratic seas**

The third narrative frame that emerged from the collective stories related to 'navigating bureaucratic seas', involving the social, cultural, structural and physical environment. Challenges associated with the physical environment were exemplified by Jo, who reported difficulties with travel as he lived in a rural location and wasn't independent on public transport. However, the majority of collaborators outlined their experience of navigating bureaucracy and social systems. This was expressed in all the collaborators' narratives to a high degree, with an intensity to the bureaucratic interactions that appeared to be excessive. Furthermore, at times outcomes were ineffective and contrasted strongly with the amount of time and effort invested. Jo, for example, had signed on with a disability adviser at the job

centre for between three and four years, yet had never been found paid work. Similarly, all collaborators detailed, often as a matter of fact, the experiences of negotiating authority and administration; manoeuvring through red tape and official structures and being treated as part of a system rather than as an individual. This demonstrates, as Ruth, Mark and Jennifer stated explicitly, that it is harder to find work if you have IDD.

The collaborators conceptualised their experience in different ways. Some appeared resigned or possibly ambivalent, accepting of the bureaucracy that had shaped their experience, while others articulated anger and resentment in relation to the social or bureaucratic structures that they had to negotiate. When spending time with Jo, Mark and Jennifer, an ambivalence or paradox emerged from their lived experience and I identified this as a tone of understatement in their stories. Jo spoke of work having to 'let me go' from a voluntary job and then 'let me go' from another job (page 115). He stated, 'yeah so that helps' (page 115), regarding the specialised adviser at the job centre, who hadn't been able to support him to find him work over a number of years. Similarly, in the opening line of his story, where he referred to signing on at the job centre for three or four years, he stated, 'It was not too bad going there' (page 115). In his story, Mark said 'It was frustrating when I had applied for a job and they didn't reply or told me they couldn't offer me the job. So, I just kept on looking. At times I did feel a little bit fed up' (page 130). Jennifer stated that she felt a 'bit fed up' (page 148) having worked for over ten years in a charity shop and she described without overt criticism one of her experiences of applying for work:

*It was the manager of the drop-in centre, she helped me to prepare for it before I went to it. It did help a lot, but I don't know. We got there plenty of time, went to the café just down the road and when we got there, there was only one chap and he said the manager had to go because she had a driving lesson and he wasn't that qualified to do an interview. So, he only asked me one question. And then we went. He said have you had experience in this work before and I said yes, I have. (Jennifer, page 151)*

Within Tabitha's story, her constant interaction with bureaucratic structures was consistently articulated. She outlined the processes promoted by the job centre for work-related and education opportunities:

*There was the time I was at the job centre for two years and that's bad enough. What they do is after two years they give you two options. You go into college again and I went to college again and I did an English class and Maths.* (Tabitha, page 139)

Furthermore, she went on to state, ‘*And basically I took myself back to school and then I worked and then back to school as well and then I did work on top of that*’ (page 139). Similarly, Mark noted, ‘*I did used to see people from the job centre for a few years, but they were not really helpful in finding paid work*’ (page 131).

Within Ruth’s and Kenneth’s stories there was a clearer communication of their feelings of disappointment and anger about negotiating the processes and procedures for gaining and sustaining employment. Ruth stated how she was put forward for jobs irrespective of their suitability and had her hopes raised only to be disappointed:

*I wasn't a 100% sure what job I wanted to do but then they put me on the work programme for two years which was a lot of false promises, they said they'd get me a job but that never materialised.* (Ruth, page 119)

*It's like they suggested all sorts of things. It does hurt; it does make you feel like shit.* (Ruth, page 119)

Similarly, within his narrative Kenneth talked about the merging of the many support providers and the subsequent disappointment relating to their interaction with him. He was also the sole collaborator to articulate explicitly the broader social expectation and pressures experienced in relation to work:

*I've seen so many people in supportive roles, it's as if they're all kind of intertwined and as a result, the feelings I have are always one of disappointment, disillusionment of things not quite working out...* (Kenneth, page 156)

*There's no understanding of how people like me struggle with the world of work. It's like if you don't work or you're doing a very menial level type of work for a very short length of time like I do that somehow you know, it's one step up from being a complete lay about or scrounger.* (Kenneth, page 160)

Within their narratives, the collaborators additionally communicated the fundamental importance of getting specific factors right and the difference it made in supporting them into work. This was exemplified by Jo, when he communicated the vital importance of gaining 'Access to Work' money to fund his journey to work by taxi. Other examples were given: Mark noted that he knew the work consultant from another setting and that this had enabled him to get a referral to his services; Tabitha highlighted that she had received positive support from her manager and peers in her current work setting; and Kenneth, though not happy in his job, communicated the importance of having a manager who understood the challenges he experienced in the working environment. The sense of overcoming protracted bureaucratic challenges in the journey towards work was echoed in the aspirational recommendations made by the collaborators to other people with IDD gaining employment. These recommendations appeared to be voiced in a different tone and their call for individual resilience in anyone with an IDD looking for work will be discussed in the next chapter.

*To someone else who was like me at the job centre looking for work I'd say 'stick at it; something might turn up like it did for me. (Jo, page 117)*

*I would say to someone in a similar position to me ask yourself, what your skill set is and what it is that you'd really like to do, and if the two meet then go for it then look into that, look into paid work in those areas. (Kenneth, page 164)*

*I suppose, I'd say to someone like me, 'don't give up, I'm sure there's a job out there and you know just be confident and be brave.' It's quite hard to be brave because sometimes when I meet new people, I'm quite shy.*  
(Jennifer, page 152)

*I'd say with LD looking for work, 'try everything, don't give up, even if it's too hard and seems awful sometimes you just knuckle down.' I mean with the education the problem is you get too educated and everyone think you're all right. So just knuckle down and just carry on I suppose, stop getting distracted. (Tabitha, page 144)*

*I would suggest someone with learning disability speaking to someone who can help people who have got a learning disability to find a job. That's what*

*made the difference for me knowing that the employment support provider was trying really hard to get me a job. (Mark, page 133)*

*To someone else who was like me trying to get work I'd say, 'trust your instincts and be persistent, you're going to get there eventually and it's going to be great!' (Ruth, page 124)*

In the visuals created as part of the collaborators' work stories, this narrative frame was notably absent. Jennifer's image, 'waiting to bloom', illuminates the mismatch between her current voluntary work and her aspirations in employment.

#### **6.3.4 Finding both friend and foe**

The bureaucratic environment also formed the basis for the fourth narrative frame surfacing from the work stories. This related to the lived human experience of relationality, or the role of people in supporting or restricting access to and engagement in work: 'finding both friend and foe'. The presence or absence of support contributed strongly to the sense of success or failure in pursuing the work goal. It appeared to be highly significant, certainly to some collaborators, in their sense of belonging and 'fit' within a work setting. This frame draws on the potential for anyone in the social environment to be positive, negative or ambivalent in supporting the person towards or in employment. Furthermore, it was found that the experience of family could be both positive and negative. The importance of the social environment and 'finding both friend and foe' occurred in all the narratives, in work-related settings, families and in relation to support providers. However, it did not appear in the visual images or video forming part of the work stories. Consideration was given to ensuring (for confidentiality purposes) that people other than the collaborator didn't inadvertently appear in the visual images or video and none of the collaborators requested that the visual component of their story include other people. The experience of this narrative frame will be explored below, alongside the societal influence on the importance of work.

The collaborators' experiences of support were variable, with job centres, supported employment providers and educational work-related programmes described within the narratives. The perception of the support provided, as well as its success, can be defined by whether the goal of supporting a person to overcome barriers and gain employment was achieved. Collaborators also

referred to the lived experience of these relationships, specifically with the individuals who supported them. Tabitha referred to a buddy from an ESP who 'was so good' (page 138); Mark noted that the work consultant had known him from when he worked in the centre and suggested his referral; Ruth talked about the opportunities presented by the ESP of being a trainer and working in their office; and Jo referenced the work consultant in the following terms:

*Two years ago, I came to the employment support provider who tried to find other things, but it was getting there and back to these places that was difficult. So, the work consultant had a word with her work colleagues and had a chat and they sort of made up the job for me.... The most helpful support to finding work was probably the 'Access to Work' funding, getting there, the taxi money. The most helpful people were the employment support provider as they helped me find this job. (Jo, page 115)*

The importance of good relationships in the working environment and with the employer was similarly highlighted. Within Tabitha's narrative, the presence and absence of support was exemplified in her experience of identical jobs in two different schools: in the initial one she said she was 'clumsy' (page 140) and did not get a 'big hello' (page 142) like she did in the second school, which she had attended as a child. She noted:

*The best bit of my job is working with those girls. They are really good, when I first got to the school it was really weird, I got a big 'hello'. I've got the group who are really nice. I've got the gatekeeper who is really nice. It's my team and that's what I'm going to say, it's my team. (Tabitha, page 142)*

Conversely, poor relationships were equally communicated. Kenneth, although indicating that he experienced a sense of support from his direct manager, observed a dichotomy in his relationship with his work colleagues, noting:

*The manager excepted, I've not really found the staff to be that friendly towards me, with one or two exceptions... It's funny with me because I'm not a very friendly person, I don't like chatting to people much and yet I get upset whenever I feel ignored, I get annoyed. (Kenneth, page 160)*

However, Ruth's experience of a 'stalker problem' communicates a sense of relational vulnerability and malevolence in the working environment, indicating a

lack of support. She stated, 'But they were like, 'oh he's had a problem with other girls' and I'm like how about you let it be known that it's not right?' (page 119) Similarly, an experience of ambivalence emerged from the narratives in relation to the social environment. One instance of this was articulated by Jennifer (referred to in full in navigating bureaucratic seas):

*...the manager had to go because she had a driving lesson and he wasn't that qualified to do an interview. So, he only asked me one question. And then we went. He said, 'have you had experience in this work before' and I said 'yes I have'. (Jennifer, page 151)*

Within all the collaborators' stories, family members and their role or opinion was communicated to a greater or lesser extent. Of the six collaborators, Kenneth and Mark reported living alone, while Ruth, Tabitha, Jennifer and Jo lived with members of their family. Experiences of familial support and pressure were articulated within the stories and detailed below.

Evidence of relational support underpins many of the narratives, often noted in passing. Jo talked of his nan attending the job centre with him for years and working with his dad, uncle and brother voluntarily in a boat yard. He also described having had work experience with his grandad, stating that, 'My grandad used to be a gardener so sometimes I used to go out with him' (page 115). Similarly, Ruth spoke of her mum finding her work and Tabitha of her sister supporting her application to be a lollipop lady stating, 'Sometimes it helps if your family tries yeah, family and friends, because when you do it on your own it's pretty damn hard' (page 139). Conversely, pressures from family were expressed, as detailed below by Kenneth, Jennifer and Tabitha:

*You know, my family were very hostile to the idea of me becoming unemployed due to my mental health... Initially I kept it secret I was seeing a shrink and a community psychiatric nurse, but they were initially hostile to the idea of me being unemployed and as they saw it doing myself a great disservice. But I needed to recover. (Kenneth, page 156)*

*I know my husband wants me to have a paid job and my mother in law. She desperately wants me to get a paid job... She was over in April and she said, 'have you found one' and 'how are you getting on' and I said 'no I'm still looking' and one time she came with me to a meeting and I wish she*

*wasn't there, and she was like interfering and it felt uncomfortable.*

(Jennifer, page 152)

*I'd like two jobs I could do without stress. Stress is the most annoying thing. I mean, to be always striving ..... They all have things they have and it's just tough and we've always been competing since we are little. It's hard not to compete with them.* (Tabitha, page 144)

Finally, within the social environment, the experience of a societal influence from governmental pressures was also expressed by Kenneth when he stated:

*The government believe that work alone is the harbinger, or the bringer of self-esteem, yes, self-improvement, it's a good thing. It brings self-confidence it makes a person, gives a person reason. But in my place and in my experience, the world of work has been a harbinger of depression. It's bought precious little but misery to my life.* (Kenneth, page 161)

### **6.3.5 The forging of identity**

The final narrative frame that was illuminated within the work stories was that of 'forging of identity'. Within the collaborators' stories, references to identity emerged initially through the explicit questions asked by the researcher. The collaborators were asked what the label of IDD or learning and intellectual disability meant to them, as well as being asked about the impact of their IDD on their experience of work as a phenomenon. Similarly, the narratives contained references to what appeared to be imposed labels about having a disability and economic worth.

All collaborators talked about how they would label their disability, with Jo, Mark and Jennifer identifying with the term 'learning disability', while Ruth preferred the term 'learning impairment' and Kenneth 'neuro-different'. Tabitha did not identify with an umbrella term but described herself as having dyspraxia and dyslexia. Furthermore, all collaborators identified how they experienced their specific impairments. Mark highlighted difficulties with communication; Jo described challenges with reading and writing; Jennifer stated that she struggled to respond quickly; Tabitha stated that she found being alert within the working environment difficult; and Kenneth described finding some interactions with people difficult. Ruth was the only collaborator to say that she felt her learning impairment helped her be better at her job. The quotations below reveal the collaborators' experience

of their impairment in their working environment and their self-identity in relation to the 'disability' label. These reveal the role of corporeal and spatial lived experience in shaping identity:

*Telling people, I'd either say I've got a learning disability or I'm not very good with my reading and writing. (Jo, page 115)*

*I don't mind the term learning disability. With my learning disability I sometimes do forget to take care, watch out when the forklift truck is approaching. Sometimes I forget to take a look before I go out onto a main aisle and sometimes, I do need to remember health and safety.*

*Sometimes, because I've got a learning disability, I struggle to find the right words and sometimes I get a bit nervous. (Mark, page 132)*

*So, they've been helping me look for jobs. If you've got a learning disability, it's much more harder. (Jennifer, page 150)*

*I suppose, I'd say to someone like me, don't give up, I'm sure there's a job out there and you know just be confident and be brave. It's quite hard to be brave because sometimes when I meet new people, I'm quite shy.*

*(Jennifer, page 152)*

*I prefer the name Learning Impairment I just find it impairs life, I just find it a more polite term, more positive. Disability sounds a bit demeaning at times. (Ruth, page 123)*

*The Learning Impairment doesn't affect my job, not really, if anything it helps.... it shows who's a lot more organised, you're analytical you look over things and this is because of my Learning Impairment. (Ruth, page 123)*

*I would say I am neuro-different with learning difficulties. (Kenneth, page 159)*

*I often find myself spending too much time cleaning a sink for example or the bath or the shower or being rather too fussy cleaning the banisters. But that's a focus of people with Asperger's we can hyper-focus and be consumed with detail... I don't get the answers I need so I'm left with answers that don't really help me. (Kenneth, page 160)*

*With my disability, one minute you're spot on, the next minute.... When I'm spot on, I'm spot on and when I'm not I'm terrible.* (Tabitha, page 142)

*I tried nursery at one point, I thought I could get into nursery, that's when it hit me, I had a disability actually. What happened was I was told I had to be more aware... Aware of my surroundings I forget things that are so normal, ah.... it's hard, sorry. It's really complicated.* (Tabitha, page 138)

The features relating to identity emerged as shaped or forged through interaction with work-related pursuits and the working environment. Tabitha, for example, spoke of having recognised her own difficulties for the first time when she was working in a nursery, recognising that she wasn't adequately 'aware' to do the job, while conversely Ruth commented on how her learning impairment had supported her aptitude in her work, as she was more 'organised'. Other labels were also observed in the narratives, including imposed labels associated with having a 'disability' and economic worth, but their presence in the visuals was limited to Ruth's. Examples of imposed negative terminology found in the narratives are detailed below:

*I don't want to go round carrying cards saying, 'I have this that and this please be careful', you can look a bit of an idiot. I think that if it's really going to affect you in life, to be honest. 'She's a moron, don't speak to her she's weird'. Mainly it's what I think people think but some people just give me stares sometimes. I think sometimes I look threatening. I don't like to say 'I'm special, treat me different', I don't want to do that. I want to be treated like everybody else.* (Ruth, page 123)

*Yeah, I keep myself at work because I become useless if I don't.* (Tabitha, page 143)

*It's like if you don't work or you're doing a very menial level type of work for a very short length of time like I do that somehow you know, it's one step up from being a complete lay about or scrounger.* (Kenneth, page 160)

Implicit to the narratives and visuals was the identity of the collaborators in their role as worker. The presentation of this role occurred in a number of ways, including identifying with their work names, e.g., assistant caretaker, or having images or a film of them in their work setting. With some collaborators the role

was presented explicitly in the titles chosen for their work, such as Mark's 'working man' and Jo's 'a day in my working life'. All collaborators highlighted a sense of pride, satisfaction and belonging in their work setting explicitly within their narratives, as detailed in the quotations below. Within these quotations a sense of satisfaction is evident, even for those who experience challenges in managing in their working environment.

*I know I've done a good job cause people do say I've done it really well.  
My family thinks it's good I've got a job there. (Mark, page 132)*

*The children are different, whereas with the lollipop lady I had the sweetest little ones who used to come and talk to you, I used to be called 'yellow pot'. This little kid couldn't understand how I used to just stand in front of traffic. (Tabitha, page 143)*

*They appreciate what I've done. I'm proud, like you know, I've done something to help in the community. (Jennifer, page 148)*

#### **Reflexive account 10. Fusion of horizons: Ruth**

*Last week the photographer and I met with Ruth... My mind was buzzing when we left, I think we all left uplifted having created something!*

*The idea (at this point) for Ruth is a file from work (in a highly confidential area) full of her own story, full of poignancy, intrigue about her own challenges and full of life. Ruth's 'file' could itself have been stored in this place of work if her family hadn't been able to support her, or her experiences had been different due to her vulnerability, and yet here she is supporting others. Equally, the file being about order and work being what Ruth needs to bring routine to her life. In her job she is simultaneously ordering and being organised herself. She is in some way subverting the file's essential use.'*

## **6.4 The group meeting**

Following the identification of the narrative frames through the phenomenological reduction, a group meeting was set up with all the collaborators to establish if the

frames had resonance and to discuss the exhibiting of the work stories. The research collaborators, the photographer and I were present at the meeting. When the narrative frames were described, the collaborators agreed a sense of resonance with them and their work stories, although some frames were felt to be more relevant to some collaborators than others (see reflexive account 11 on the group meeting, below). All the collaborators agreed with the narrative frames, 'the quest to do', 'navigating bureaucratic seas' and 'finding a good fit'. Two collaborators did not recognise the frame 'the forging of identity' as being consistent with their experience and two collaborators did not feel they had encountered a 'foe' in their work journey. However, they acknowledged that these frames did resonate with other collaborators. The group suggested that it would be beneficial to produce an easy to read summary of the research findings and recommendations to share with other people with IDD, as an outcome of the project alongside the exhibition (Appendix 13).

The discussion relating to the exhibition included a great deal of decision-making. This was the first time the collaborators had met each other, so they presented their images and basic details of their story with the support of the photographer and myself. Then, the following decisions were discussed or revisited:

- The exhibition images and the content of the exhibition catalogue to be shared (Exhibition catalogue - Ramsey, 2018)
- Ideas for the title of the exhibition and a vote to agree on one
- The terminology for the exhibition and exhibition catalogue
- The level of disclosure of identifiable collaborator information
- The position on press or media involvement
- The private view date and who should be invited
- What the collaborators hoped visitors to the exhibition would take away from it

Prior to the group meeting, the work story narratives and images had been individually agreed with the collaborators, alongside the decision to take part in the exhibition of the work stories. The collaborators were unanimous in wanting

to be part of the exhibition. They all wanted to share their full work stories in the exhibition and catalogue, to allow the public to read their stories in full whilst viewing their visual images or film. *Work[able]* was agreed by everyone, from a number of options offered by the collaborators and me, to be the title of the exhibition. The collaborators chose *Work[able]* due to its contrast to the word ‘disable’, and they chose ‘learning impairment’ as the terminology to describe them as collaborators in the exhibition.

In discussion of identifiable information, all collaborators wished only to share their first names in the exhibition and exhibition catalogue, with further identifiable information removed from their work stories as part of the ethical requirements of the research. In addition to the exhibition being publicised on the library website (where the exhibition was held), the collaborators stated that they were happy with it being publicised more widely, agreeing that the university communications team could circulate a press release. The collaborators had private view invitations to circulate to their own networks and agreed that I could invite people from the partnering ESP, the university, the advocacy group who had supported the early work on the project, colleagues and friends. When the collaborators talked about what they hoped people would take away from the exhibition, although not everyone contributed directly to the discussion, all agreed that they wanted people to ‘understand’ what it was like for them to find and be in work and to recognise that they could do work.

#### **Reflexive account 11. The group meeting**

*Presenting the frames went well though understandably, people reflected on the parts that resonated with them, so other parts were difficult for them to connect to. In the meeting process, Jennifer struggled with identifying herself with the themes, I think as she's still looking for work. She was quite down on herself and I felt for her in the context of the other collaborators being in work. However, generally there was a sense of camaraderie, some humour and some quietness, i.e., Jo responding only to direct questions.*

*Sharing the visuals as opposed to the full story in the group really allowed an immediate connection to occur that otherwise would have been hard to achieve. Considering how worried I'd been leading up to the meeting that it would be meaningless and tokenistic as so much was riding on one meeting and it had been so hard to organise, it really did feel meaningful and a real coming together, although more time or another meeting would have been valuable to hear more of their thoughts on the themes and feed into the easy-to-read summary.*

## **6.5 Summary**

Within this chapter, the five narrative frames that emerged from the work stories were outlined and empirically located within the content of the work stories.

These five narrative frames of ‘the quest to do’, ‘finding a good fit’, ‘navigating bureaucratic seas’, ‘finding both friend and foe’ and ‘the forging of identity’ were drawn from within the collaborators’ occupational lived experience, in keeping with the interpretive phenomenological perspective. This was applied through the hermeneutic reduction, the hermeneutic circle and the reflexive diary, which demonstrated the intersubjective process inherent in this phase of the data analysis.

In the narrative frames, the quest ‘to do’ was defined as the pursuit evident in all collaborators’ narratives to find and engage in any paid work. Finding a ‘good fit’ was the realisation of this quest: finding a job where a sense of arrival, contentment and belonging in a role and working environment was secured. For the collaborators who had not found a good fit but who were in paid work, having a job ‘to do’ even if it was a ‘poor fit’, was prioritised over mental wellbeing.

All the research collaborators described protracted and extensive journeys navigating bureaucratic seas, where they were processed as part of a system as opposed to receiving personalised support. In this respect, the social environment emerged as crucial in its ability to support (be a friend) or restrict (a foe) someone’s opportunities and wellbeing in their work. Finally, illuminated within these findings was the forging of identity that appears to arise from the person’s interaction with the environment. Both self-identification and being labelled by others arose from within the narratives, highlighting the complexity experienced by the person with IDD in accessing work.

When reflecting on the narrative frames, an underlying mechanism became evident that existed within the research collaborators’ experiences relating to the physical, social and cultural environment and identity. The implications of this and other findings will now be extrapolated in the discussion chapter, in relation to the current literature base pertaining to work in IDD and occupational therapy literature.

# **Chapter 7. Discussion**

## **7.1 Introduction**

The preceding two chapters outlined the findings from this research. The narrative and visual work stories of the six collaborators were presented alongside a description of the data gathering process in Chapter 5. Chapter 6 provided insight into the application of the phenomenological reduction and details of the five emergent narrative frames, comprising ‘the quest to do’, ‘finding a good fit’, ‘navigating bureaucratic seas’, ‘finding both friend and foe’ and ‘the forging of identity’.

In this chapter the findings will be discussed both in relation to the literature on work and people with IDD and in relation to the research aims. The aims were to illuminate the lived experience of having IDD on engaging in paid employment and to gain knowledge that would inform people with IDD, their personal networks and workers who support people with IDD in relation to work. This chapter is organised into three sections beginning with, ‘Understand me’, which explores identity and the experience of working with an IDD, including the worker role. This is followed by ‘Belonging versus stress and striving’, which considers the experiences of the collaborators’ good or poor fit in their work setting in relation to the relevant literature. The final section, ‘Redefining work and employment support’, discusses the findings in relation to the literature associated with gaining and retaining employment for people with IDD.

As the interpretivist position is explicit in the construction and discourse of this chapter, I have not included a reflective account but have rather aimed for transparency throughout in referencing my position as researcher. As stated, this study has aimed to do research inclusively but is not fully inclusive, so this chapter was not co-constructed with the research collaborators. However, in acknowledgement of their partnership and with the desire not to disassociate them from their findings, their names and, where relevant, quotations from their work stories have been included.

## **7.2 ‘Understand me’**

Central to this research and specified in its aims has been the desire to listen to and share the voices of people with IDD about their experiences of paid work.

The work stories of Jo, Ruth, Mark, Tabitha, Jennifer and Kenneth were presented in Chapter 5, illuminating their experiences. These stories provide a unique contribution to knowledge: they are the first collection of occupational narratives of people with IDD and these six research collaborators form part of the small population of people with IDD who are, or in Jennifer’s situation were, in paid work.

As outlined in the introduction and in the literature review of this thesis, there is a very limited base of research that has inclusively sought the voice of people with IDD and their lived experience of employment. This section’s title ‘Understand Me’ has been taken from the Mencap campaign *Here I am - I am not a learning disability – understand me* (2016). It also encapsulates the hope articulated by the collaborators in the group meeting that the research and exhibition would lead to an increased understanding of their experience and ability to work. The experiences of the collaborators, both in their stories and in the narrative frame ‘the forging of identity’, will be outlined in relation to the politics of disability identity and the worker role.

### **7.2.1 Beyond self-identification: the personal is political**

What people with IDD choose to call themselves is complex. There is a varied set of issues relating to terminology, categorisation, labels, badges, self-identification and classification. In conducting this research, I wrestled with the question of terminology and was concerned about labelling. I wanted to hear from the research collaborators themselves about their experience and how they identified. The concrete application of this has included constructing interview questions about the collaborators’ experience of having an IDD in work (specifically, ‘What things about your learning disability affect how you do your job?’) and establishing the terminology to use in the research, the thesis and the exhibition. In an editorial in the *Journal of Intellectual Disabilities*, Northway (2018) summarised issues surrounding terminology in two ways, firstly stating that categorisation was necessary due to the world of services, budgets and

policies where resources are restricted. But secondly noting that labels can potentially lead to people being negatively identified, resulting in them being stigmatised or experiencing the impact of taken for granted assumptions. Within these two perspectives, self-identification is evident by its absence. Conversely, in this research, issues surrounding identity were explicitly and implicitly communicated within collaborators' work stories and the full complexity of having an IDD and working was evident. In consideration of this and the corresponding narrative frame, 'the forging of identity', I was drawn to the feminist concept of the personal being political (Hanisch, 1970).

Taken from her now seminal essay in the history of feminism 'The personal is political', Hanisch (1970) argued for the need to listen to all women as they have something to say, even if they are apolitical. This is now identified as central to ensuring that every woman's experiences, injustices and needs are given the validity and recognition they deserve (Hall, 2018). It is in recognition of listening to the collaborators' stories of seeking and gaining employment that this concept has emerged within this research. The collaborators exemplified, both through the act of living their lives and through their narratives, opportunities and experiences of injustices. These were encountered as they engaged in the public sphere, overcoming structural and societal barriers of prejudice and apathy. Furthermore, I will argue that simply acknowledging issues of identity and the personal as political for people with IDD is insufficient if changes to injustices are to occur. This will be addressed through consideration of its implications for occupational therapists. I will discuss how the structural features have equal if not more importance than individual actions in supporting and addressing injustices for people with IDD. Furthermore, I will extrapolate, with reference to occupational therapy literature, how we, as therapists, are situated in and form part of the structural which supports or impedes.

In their work stories, the six collaborators demonstrated highly individualised perspectives about the impairments they experienced and their self-identification in relation to disability. As highlighted in the previous chapter, these terms included 'learning disability', 'learning impairment', 'neuro-different' and a description of having dyspraxia and dyslexia rather than the use of an umbrella term. Furthermore, some collaborators shared their perceptions of these labels and their appropriation. For example, Ruth stated that she found 'disability' as a term demeaning, preferring 'impairment' (page 123), while Kenneth's inclusion in

this research had been questioned by him based on his uncertainty about identifying with the label ‘learning disability’. Additionally, the collaborators spoke with clarity regarding the impairments they faced that were associated with their IDD, such as difficulties with reading and writing, travel and talking with people. The way the collaborators spoke about their identification with a disabled identity varied. Ruth and Kenneth, being highly articulate, challenged the labels applied to their lives, while others communicated their experiences less explicitly in describing their sense of difference.

Monteleone and Forrester-Jones (2017) observed a sense of difference in their study exploring the meaning and experience of disability with 15 people with IDD, despite their participants’ lack of ability to articulate their experience fully. They concluded that their participants lacked knowledge of common terminology related to IDD and this could negatively impact on self-esteem, potential political empowerment and person-centred action. They state, as does Northway (2018), that developing an understanding and vocabulary to describe disability concepts is necessary for people with IDD in order to support participation in a broader dialogue and challenge dominant paradigms.

While the findings of Monteleone and Forrester-Jones are valid in delivering their objective to explore their participants’ experiences of disability, it could be argued that self-identification and challenging the disability paradigm is currently being undertaken by people with IDD. This was demonstrated by the self-advocacy group People First, who chose the term ‘learning difficulties’ while also challenging the use of labelling with the maxim ‘labels are for jars not people’ (2017). Shakespeare, when discussing the politics of disability identity, observed the paradox implicit in the choice of being part of a ‘disability collective’, while equally rejecting the ascribing of labels (2014, p.95). In this respect, he refers to ‘labels and badges’ to describe being given a label that may be negative or stigmatising as opposed to choosing a name or badge linked with a collective identity (2014, p.95).

In this research, some collaborators described the experience of having labels ascribed whilst others communicated an experience of being different. Northway (2018) observed in her editorial, that in the history of labelling and terminology relating to people with IDD ‘Each term has, in its time, been viewed as appropriate but over time has developed negative connotations’ (p.4). This is

unlikely to change, as exemplified by Ruth's narrative, when she used the labels 'idiot' and 'moron' (page 123). In applying these terms to how people might perceive her, she echoed the negative terminology used during institutionalisation (Allen and Fuller, 2016). It was painful to hear Ruth use these terms during the interview, as well as striking that they were labels applied at a time before she was born. Yet, they were at the forefront of her mind when she sought to communicate concerns about how she might be perceived.

Notwithstanding this connection with negative labelling, Ruth's story and co-created visual images embody the narrative frame 'the forging of identity'. In her narrative and in Chapter 6 when I refer to my reflexive diary, Ruth spoke of being so much more than a label or her job in choosing to use a clinical file (an object she interacted with in her work) and subvert the idea of her being a 'case' or 'patient'. This assertion by Ruth revealed a potential for communicating a challenge to a disabled identity. It referenced at once a collective experience or badge, while self-identifying with being more than a label. Similarly, other collaborators, such as Mark and Jennifer, explicitly communicated their identity beyond a label in their work stories and images, demonstrated by their chosen titles, 'working man' and 'waiting to bloom'. These experiences echo Shakespeare's (2014) suggestion that many people do not want an identity defined by a label or badge but rather wish to be 'seen as ordinary members of society, free of limitation or classification' (p.97). This sentiment was equally evident in Ruth's narrative when she stated, 'I don't like to say I'm special, treat me different, I don't want to do that. I want to be treated like everybody else' (page 123) and highlights an injustice as it demonstrates a belief of not being treated like everyone else.

Self-identification, which emerged from the collaborators' work stories, contributed to an individual's potential to communicate their identity or assert their common humanity. Consequently, not all of them assumed a 'disabled identity' as part of the collective; this is defined by Oliver (2013) as self-defining as a disabled person, having an impairment and experiencing imposed restrictions on life. However, Oliver (2013) cautions against individualised perspectives of disability identity, observing that the risk in not holding to a collective identity is that it could undermine the collective political voice.

Shakespeare (2014) has challenged the nature of collective disability politics and identity politics beyond the population of people with an IDD. He states that activism, namely 'to make the label into a badge, is to make the ghetto into an

oppositional culture', emphasises otherness and difference, which he argues leads to a group adopting a position of victim (p.104). Shakespeare (2014) instead states that the focus of disability politics should be post-identity politics, aimed at making disability and impairment irrelevant in seeking commonality with non-disabled people, and promoting equal status and inclusion as opposed to separateness. I am drawn to this perspective and its pursuit of commonality between disabled and non-disabled people. Pragmatically, I am aware it is difficult to imagine how equal status and inclusion can be achieved, beyond the rhetoric, without using collective language or terminology to identify people who need individual adaptations or systemic changes. Certainly, within the work stories of the collaborators in this research the importance of reasonable adjustments is repeatedly highlighted with regard to changes to working practices and work settings. Certainly, Shakespeare (2014) himself also acknowledged both the individual and structural factors that impact the life of a person who has an identified impairment and the importance of a diagnostic label in leading to effective educational and medical support, as well as rights under the law.

I choose the word 'forging' when constructing the frame 'the forging of identity' due to the emergence within the stories of the often-robust interaction between the environment and the person, as they pursued their goal of becoming a 'worker'. In this regard it is suggested that the collaborators' interaction with the environment has a 'political' component belonging to the concept of 'the personal is political'. The political environment in this context is defined as interacting with the implications of governmental policy, public services and the labour market in the UK, where injustices occur. Without exception all the research collaborators engaged with protracted public sector bureaucracy in their attempts to access work, which will be examined further in section 7.4 Redevising work and employment support. In this respect their work stories illustrate the personal experience as political. This includes explicitly: Jo, Tabitha and Mark highlighting their attendance of the job centre for years without finding work; Jennifer's experience of the job centre being 'nerve racking and daunting' (page 152); Ruth's two year work programme which included many 'false promises' (page 119) and Kenneth's sense of all the numerous work support provision he had received being 'intertwined' and leading to 'disappointment' (page 156).

The application of the political will now be discussed in relation to its implications for occupational therapists. This broader description of the political environment resonates with an occupational understanding of the interplay between the environment and the person, outlined in occupational therapy literature (Taylor, 2017a), and with Shakespeare's (2014) model of disability that addressed the complex interaction between the individual and the structural. In Kielhofner's Model of Human Occupation (MOHO), occupational adaptation or the extent that a person is able to adapt in response to the challenges they face is seen as a dynamic interaction between occupational identity, occupational competence and environmental impact (see Illustration 22).

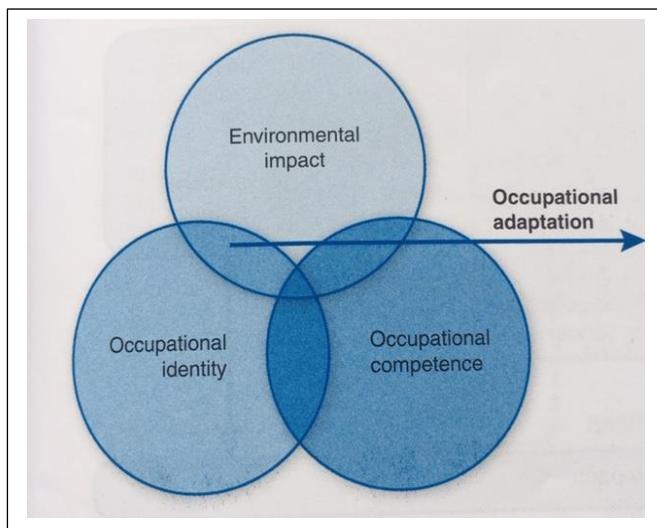


Illustration 22. Occupational adaptation (Taylor, 2017a, p.117). Original in colour

Interestingly, while the environment has always been present in his model, it has only recently been drawn into an understanding of occupational adaptation.

Taylor (2017a) notes that in the 2008 version of the model Kielhofner proposed, occupational adaptation constituted an interrelation of two elements, occupational identity and occupational competence (Kielhofner, cited by Taylor, 2017a). However, the impact of the environment was later included as a crucial third element in supporting occupational adaptation, in recognition of the role that opportunities, culture, politics, and economic conditions of the social and physical environment had in changing, both positively and negatively, occupational adaptation (de las Heras de Pablo et al., 2003, cited by Taylor, 2017a).

Therefore, there is a risk of the environmental or structural influences not being given as much focus as occupational identity or occupational competence in practice. This highlights the importance of occupational therapists drawing on an

ecological, as opposed to solely individual construct of resilience and of recognising themselves as part of the ecological, social and cultural structures (Hart et al., 2016) that support or restrict the people they support. This opinion is also echoed by Whiteford (2011) when she revisited occupational deprivation and called for therapists to go further in addressing the complexity encountered in cultural, social and legislative norms.

The systemic issues within the social and cultural environment highlighted in models of occupational practice (Taylor, 2017a), theories relating to ecological resilience (Hart et al., 2016) and occupational justice and occupational deprivation (Whiteford, 2011; Wilcock and Hocking, 2015) resonate with a complexity of practice recently examined by the RCOT in the UK. Pentland et al. (2018) describe occupational therapy practice as a complex dynamic process and proposed that it met the criteria for a ‘complex intervention’. The term ‘complex intervention’ was initially devised by the Medical Research Council at the turn of the century (MRC, 2000) and has led to subsequent updates in guidance (Craig et al., 2008) and its application in practice (Moore et al., 2015). Devised out of a necessity to address complex issues such as obesity or smoking, complex interventions are defined as having a significant number of interacting components, difficulties of behaviours, organisations and groups involved in intervention and variability in outcomes. There is also an expectation of flexibility in the application of interventions provided (Craig et al., 2008). Furthermore, complex intervention processes have been welcomed as mechanism to apply a systemic approach to diverse issues (Moore et al., 2015).

In their description of contemporary occupational therapy practice, Pentland et al. (2018) outline features impacting on clinical work, including: causal assumptions related to ‘doing’ and its capacity to bring about change for a person; implementation content, which relates to the intervention practices employed by occupational therapists; mechanisms of impacts and types of change, including those that are understood and those that are unexpected; outcomes and transitions, namely the consequence of intervention; and context, which is referred to as being interchangeable with the word environment. However, context also refers to the characteristics bought by the person in the situation, both the person receiving treatment and the therapist. Therefore, in their model of occupational therapy practice Pentland et al. (2018) apply the principles of

complex intervention, acknowledging a systemic understanding of the therapist in the context of the micro and macro environment (see Illustration 23).

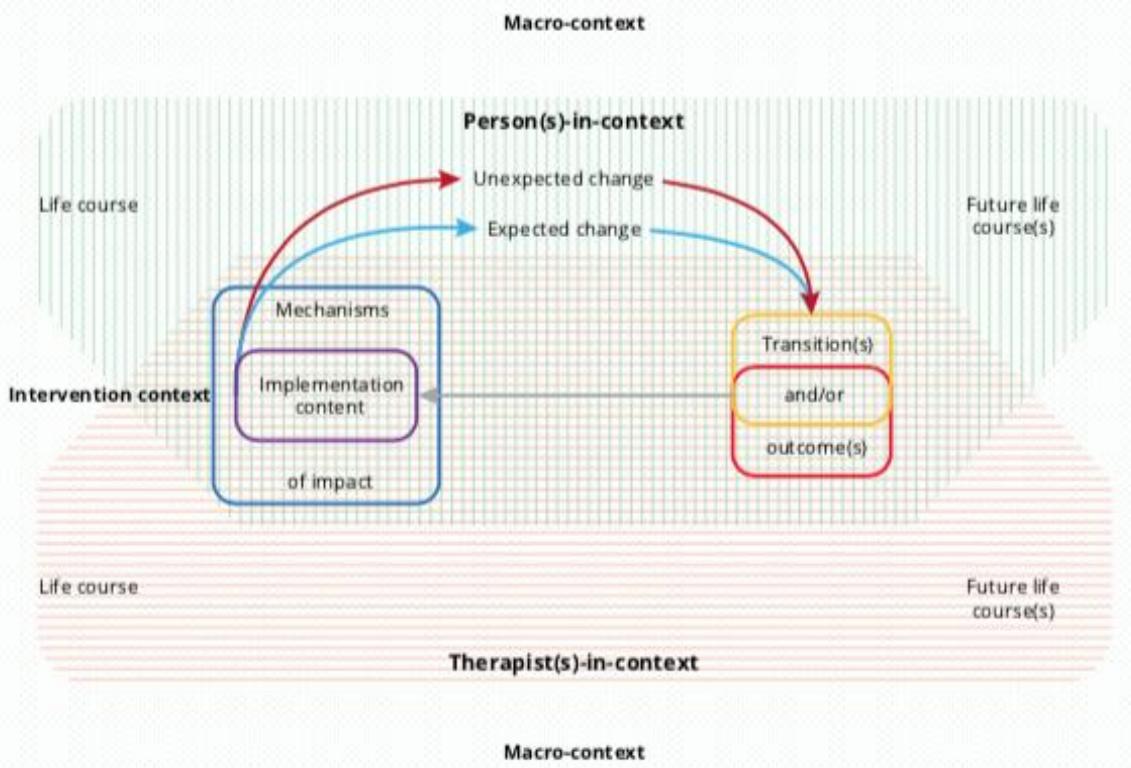


Illustration 23. Visual representation of the model of occupational therapy as a complex, dynamic process (Pentland et al., 2018). Original in colour

I suggest that this model is highly valuable in showing the context or structural features impacting practice and the situatedness of the therapist. It is also valuable in communicating the inter-related relationship we have in addressing the barriers faced by the person we support when working with people with IDD. However, and perhaps inevitably, the complexity of meaningfully utilising this expansive and wide-ranging model in practice may be challenging for time-pressured therapists. Furthermore, applying the concept of complex interventions to an individual practice model could be argued to be contradictory as by its nature complex interventions apply a systemic understanding of issues of which the therapist is only one part. Nevertheless, without this or another means to develop a more expansive understanding of the structural, occupational therapy continues to risk drawing predominantly on a reductionist medical paradigm (Molineux, 2011; Fisher, 2013; Wilcock and Hocking, 2015).

Jansson and Wagman (2017), in their exploration of Hannah Arendt's (1958) *Vita Activa*'s contribution to occupational science, observe that the 'action' modality

forming part of *Vita Activa* and defined as the activity that takes place between people, is less obvious in occupational science literature. This is pertinent as ‘action’, as defined by Arendt (1958), operates in the public sphere where humans achieve freedom and human’s unique specificity is revealed. In this respect it links to the political, as argued in this thesis. Furthermore, while fully acknowledging the complexity relating to disabled identity as highlighted by Shakespeare, I recognise my situatedness in the political and social environment of the NHS and that my preconceptions impact on my interactions with people with IDD in my work and shape their experience of their impairment and disability. Therefore, acknowledging the person and how they wish to self-identify should be an essential part of intervention, alongside appreciating my potential to support or hinder ecological resilience as part of the political environment with finite resources. The therapist could commence with a conversation that provides the person with IDD the opportunity to self-identify, including choosing not to have a ‘label’ and thereby challenging categorisation. Subsequently, the therapist’s own disability paradigm and potentially ‘taken-for-granted assumptions’ about the identity of the person they are supporting could equally be challenged (Northway, 2018, p.22). Furthermore, this might open a discussion relating to the impact of the person’s impairments and the barriers they face, whilst offering the therapist an opportunity to acknowledge these barriers and discuss with them how they may be addressed. In this respect, the therapist would adhere to Shakespeare’s (2014) model of disability in working with the person and their experience of their impairments within their structural context. This is perhaps in contrast to employment services who, through the influence of normalisation, risk ignoring the person’s impairments and the environmental barriers.

An additional area where occupational therapists and other workers involved in the political environment relates to the inclusion of people with IDD is employment research, policy and service redesign. As observed in the literature review, there has been an increased call for the involvement of people with IDD within specific papers relating to employment. Indeed, recommendations have been made to: include people with IDD in the design of employment services (Siporin and Lysack, 2004); increase an understanding of people’s experience of social inclusion (Lysaght et al., 2012a); gain an increased appreciation of their experience of employment support (Dempsey and Ford, 2009); and construct

self-report measures regarding qualitative accounts of the person's experience of work (Akkerman et al., 2016).

Although these recommendations are to be commended, they remain strikingly belated by comparison with other areas of health care. Within mental health studies, for example, the direct involvement of people with a mental illness in research relating to employment is well established (Kennedy-Jones, 2005; Boyce et al., 2007; Johnson et al., 2009; Secker et al., 2009; Urlic and Lentin, 2010; Cameron et al., 2012; Williams, 2012). Furthermore, within the literature, the nature and experience of periods of mental illness are openly discussed as part of the study (Kennedy-Jones, 2005; Boyce et al., 2007; Johnson et al., 2009; Secker et al., 2009; Urlic and Lentin, 2010; Cameron et al., 2012; Williams, 2012), while in the majority of studies involving people with IDD the impact of their disability on work is not directly addressed. Published testimonials by service users and survivors of mental illness in employment are noted to be few in number (Williams, 2012).

Addressing the deficit in the involvement of people with IDD in the re-designing of services and research is of significant importance in tackling the political environment, as current policy continues to highlight the inequality for people with a disability in accessing employment (DWP and DH, 2017). Furthermore, these failings exist alongside questions relating to whether the policy objective of paid work for people with IDD is achievable or economically viable in its aim to liberate people with IDD from poverty and isolation (Johnson et al., 2010). This will be explored further below, in the discussion of working with an IDD and the social identity involved in the role of '*worker*'.

### **7.2.2 Work[able]**

Chapter 6 described the choice of the exhibition title *Work[able]* by the research collaborators, directly challenging the word 'disable'. In this respect, the collaborators strongly communicated the importance to them of indicating their potential to work as well as their role and status as a worker or employee. This was also highlighted explicitly in the title of Mark's images, 'Working man', and in more subtle ways in other participants' narratives. This will be discussed below in

relation to occupational therapy literature and the connection between work and citizenship inherent in current policy.

Johnson et al. (2010) communicate powerfully the challenge posed by the centrality of paid work in IDD policy, specifically relating to the idea that it can protect against social exclusion. Observing that policy makers are likely to be right in recognising that work can provide social identity, they equally caution that when people with IDD find work, it is likely to be low paid and lack many of the benefits people often gain from being in paid employment, such as variety, interest, social and geographical mobility, companionship and sufficient money to purchase services or goods (Johnson et al., 2010). This resonates with elements of the findings of my collaborative research, where all collaborators were in low paid and low status work that impacted on their ability to be financially independent of welfare benefits. Furthermore, irrespective of their potential desire to work beyond part time hours, it is unlikely that the collaborators in this study could earn sufficient money to be independent of support from benefits and therefore financially independent and secure.

The findings of my collaborative research regarding low pay and poor financial independence for people with IDD in employment echo those found in other studies exploring work-based outcomes for people with IDD (Jahoda et al., 2008; WHO, 2011; Simonsen and Neubert, 2012; Lindstrom et al., 2014).

Consequently, the 'good life' proposed in policy and examined by Johnson et al. (2010) in relation to financial autonomy and betterment has not been achieved. Indeed, they question whether it is achievable within the current labour market (Johnson et al., 2010). Furthermore, evidence of social and geographical mobility was not found in the research collaborators' narratives. However, elements did emerge from the research related to variety, interest, companionship and social identity as a worker within the work setting, particularly but not exclusively for collaborators who communicated a sense of a 'good fit' in their job and working environment. Jo, Mark and Ruth all noted their contribution and connectedness to others through, for example, doing people a favour, making a difference or chatting to people in the working environment. They equally demonstrated a variety in their job or in the number of job roles they had held and an interest in what they were doing. Furthermore, all collaborators communicated a sense of pride in their work and external value and recognition of the jobs that they were doing, demonstrating the recognition of their worker role in the public sphere,

with its associated status (Johnson et al., 2010; Wilcock and Hocking, 2015; Taylor, 2017a).

In occupational therapy practice, human occupation is understood to operate within the broader social and physical environment that supports or restricts the person (Townsend, 2003; Wilcock and Hocking, 2015; Taylor, 2017a). Taylor (2017a) observed that people with disabilities are often hindered from taking on roles due to lack of opportunity, difficulties in performing the roles or find themselves limited to potentially unwanted, marginal roles as a result of their disability label. An additional unwanted societal value that has been used to evaluate the worth of many people with IDD who are not in employment is economic (Johnson et al., 2010).

In Kenneth's narrative, negative and stigmatised labels were described, including 'scrounger' and 'lay about' (page 160). Tabitha alluded to similar language when she stated that if she gave up her work, she would be 'useless' (page 143). The word 'useless' notably echoed a study by Banks et al. (2010), which explored the impact of job breakdown on people with IDD. They observed that people with IDD found job loss traumatic and that this was identified specifically as having a negative impact on self-esteem, with people calling themselves 'lazy' and 'useless'. This reflected the negative and binary image of people with disabilities portrayed by the media and outlined by Crow (2016). Crow suggested that people with disabilities found themselves defined as either 'scroungers', 'immoral benefit claimants', or 'superheroes', following the global recession of 2007–2009 and Britain's hosting of the Olympics in 2012. Identifying a binary portrayal of people with disabilities she notes that this leads to a lack of representation of people situated in the context of their whole lives. The negative labelling evident both directly and indirectly in some of the narratives in this study reveals the pervasive nature of media influence, with individuals being defined and valued in relation to their economic contribution to society. These references were particularly evident in the narratives of collaborators who were continuing their quest towards a good fit in their job and showed part of the negative 'political' environment impacting on identity for people with IDD. The 'superhero' terminology and labelling was not directly evident in the collaborators' stories. However, it could be argued that the exhortation to other people with IDD to draw on their personal resilience in pursuing work, at the end of the narratives, does have echoes of the 'superhero' image.

## **7.3 Belonging versus stress and striving**

In ‘Understand me’, the experience of having an IDD in work in relation to identity was presented. This section will focus on the role and function of work, reflecting on the breadth of the narratives shared in the collaboration with Jo, Ruth, Mark, Tabitha, Jennifer and Kenneth. Specifically, it will consider the findings in relation to the literature under the headings ‘The nature of doing’, ‘A good fit and belonging’ and ‘A poor fit, stress and striving’.

### **7.3.1 The nature of doing**

Within the narrative frame ‘the quest to do’, the exhortation towards ‘doing’ or the desire ‘to do’ something, specifically the action of ‘doing’ in a work setting for financial remuneration, emerged from every story. I appreciate that the strength of ‘doing’ within the narrative emerged very strongly for me due to its importance and centrality in occupational therapy. Wilcock, discussing occupational science and occupational therapy, stated that ‘doing is so important that it is impossible to envisage humans without it’ (1999, p.3). Similarly, ‘doing’ is present in the philosophy surrounding phenomenology. Arendt, in her book *The Human Condition* (1958), communicated that human interaction in the world can be understood through acts of doing, summarised as work, labour and action and collectively referred to as *Vita Activa*.

In Chapter 6, ‘the quest to do’ was the focus of many of the images in the work stories. Mark’s and Jennifer’s portraits in ‘working man’ and ‘waiting to bloom’ showed them in their work location, paused in the act of ‘doing’ in the environment. Similarly, Tabitha, in her film ‘work is harder than you think’, showed herself in action, ‘doing’ many of the aspects of her role. Furthermore, Jo, although absent from the images in person, included in a ‘day in my working life’ the environment, tools and objects he interacted and worked with as part of his routine of ‘doing’. Similarly, Kenneth described in the writing on his image, ‘working with an analytical eye’, what and how he addressed the ‘doing’ of his work in the environment.

In addition to being strongly articulated in my collaborative research the desire to do is also found in relevant literature and was observed in relation to both unpaid and paid work. Many studies that have explored the role and function of work for people with IDD have found that productive work is valuable irrespective of remuneration (McGlinchey et al., 2013; Lindstrom et al., 2014; Monteleone and Forrester-Jones, 2017). In the study by McGlinchey et al. (2013), for example, the term ‘perceived work’ was created to describe the experience of people with IDD attending a day service that they identified as work. Similarly, Lindstrom et al. (2014) highlighted the primary attribute of work when they used a quotation from a carer in their study for the title of their paper: ‘Just having a job’. This resonated with the findings of my collaborative research, which located how important voluntary work was for three of the six participants. It constituted a sense of pride and this was exemplified by Jennifer who wasn’t doing a paid job at the time, but who articulated the value of ‘doing’ work in people’s lives. As articulated by Wilcock and Hocking (2015), this is a universal need for all.

In addition to the universal need ‘to do’ (Wilcock and Hocking, 2015), there is perhaps a societal pressure ‘to do’ work, experienced as a demand or requirement for people with IDD and inherent within policy drivers (Johnson et al., 2010; DWP and DH, 2017). This societal pressure demonstrates, as Arendt (1958) and Wilcock and Hocking (2015) outline, that ‘doing’ does not exist in isolation but rather within a broader world. Within Arendt’s construction of *Vita Activa* action is defined as ‘*the one miracle-working faculty of man*’. For Arendt (1958, p.246), action is defined as taking place between people in the public sphere and is identified as being of great importance for exercising our political capacity and the opportunities and dangers this offers. Furthermore, Arendt (1958) cautions that within western society, the action modality is less recognised or valued in comparison to work and labour, indicating that the potential for political strength in action may not be acknowledged or acted upon as much as it could be in the public sphere. Jansson and Wagman (2017) acknowledge that the pluralistic perspective outlined by Arendt (1958) resonates with ongoing discussions in occupational science associated with a move away from individualistic focus towards a participatory perspective. My perspective corresponds with that proposed by Jansson and Wagman (2017), both in terms of my collaborative research and my occupational therapy practice with people with IDD. I recommend that a shift takes place in practice that at once embraces occupation and the personal experience of the people we support, whilst

addressing the structural barriers. I propose, therefore, that as therapists we should openly acknowledge the political in the experience of people with an IDD and the potential of Arendt's (1958) 'action' for the people we support. This will be expanded on below in relation to the occupational therapy paradigm.

The emerging paradigm in occupational therapy since the 1980s has been one of refocusing on people as primarily occupational beings (Wilcock and Hocking, 2015; Jansson and Wagman, 2017). This is an altered perspective by comparison with the mechanistic paradigm operating from the 1960s to the 1980s, which focused on the capacity of the body's systems from an individualised perspective and was influenced by the medical model (Molineux, 2011; Fisher, 2013). However, as Molineux (2011) and Fisher (2013) observed, although the emerging model relating to people being occupational in nature was encouraging, occupational therapists were not necessarily understanding or applying the construct and therefore were perhaps not addressing occupational needs in practice. This was evidenced by Di Tommaso et al. (2016) in a recent inductive phenomenology study exploring perceptions on occupation with 16 qualified occupational therapists. The research found that the therapists' practice was impairment-based and that work-based cultures hindered the use of occupation (Di Tommaso et al., 2016). Although the body of research located in the literature review relating to occupational therapy and employment for people with IDD is small, it does not support Molineux's and Fisher's (2011) observations, as they indicate an occupational focus to intervention despite the methodological limitations discussed in Chapter 2 (Siporin and Lysack, 2004; Kahlin and Haglund, 2009; Smith et al., 2010; Ineson, 2015; Cockley and Bryze, 2018). However, evidence of the mechanistic paradigm outlined by Molineux (2004 and 2011) and Fisher (2013) and communicated as part of the individualised model of disability was evident in the focus of three of these five studies (Kahlin and Haglund, 2009; Smith et al., 2010; Cockley and Bryze, 2018), indicating that the individual and often impairment based perspective continues.

In contrast to the individually-focused articles which concluded by stating the benefits of occupational therapy intervention (Cockley and Bryze, 2018), a work-based programme (Smith et al., 2010) and an assessment tool respectively (Kahlin and Haglund, 2009), both Ineson's (2015) and Siporin and Lysack's (2004) conclusions led to identifying political issues and called for social change. Ineson (2015), when discussing her experience of trying to support a person with

a severe IDD into employment, highlighted the ‘chasm’ between the aspirations of policy and the reality and called for workers to be tenacious in supporting people with IDD into employment (p.63). Similarly, Siporin and Lysack (2004), when exploring the quality of life outcomes of three women with IDD in sheltered employment in the US, concluded by stating that occupational therapists need to become increasingly knowledgeable about issues surrounding work-related activity and advocate for changes in policy. Therefore, these authors demonstrated, despite weaknesses in their studies, evidence of inclusive research principles and a commitment to the issue that was important to the people involved: being for them and supporting social change (Walmsley, 2004; Nind, 2014). Consequently, I would argue that seeking to do research inclusively appeared to lead the occupational therapist researcher towards a broader understanding of the issues and, as suggested above, toward the political, in calling for social change.

Current occupational therapy guidance, although seeking to be client centred and holistic as with the MOHO (Taylor, 2017a), does not always achieve this in practice. This may be due to the fact that many assessment tools utilised by therapists working with people with an IDD do not support partnership working directly with the person. Current practice often involves the therapist completing an assessment after discussion with the person (if possible), their network, and following observation of the person engaged in activities or occupations. In this respect, limited assessment tools in IDD are routinely jointly constructed physically with the person to encourage participation, although goal setting and guidance are consistently adapted to support communication needs, i.e., easy read formats. However, it is possible to incorporate the individual and structural into an appropriate assessment tool when working with someone with IDD in relation to work. This is equally relevant to any worker supporting employment opportunities for people with IDD, although I also acknowledge and recognise that it can be difficult to challenge within modern work settings (Molineux, 2011; Di Tommaso et al., 2016). The role of support services will be discussed further in section 7.4, Redefining work – employment support.

### **7.3.2 A good fit: belonging**

The narrative frame ‘finding a good fit’ refers to a job where the collaborators experienced contentment and competence, a place, both physically and metaphorically, where the quest to work had been achieved. I observed in Jo’s, Ruth’s and Mark’s stories a sense of fit emerging from the way they communicated their ability to do the job, their sense of belonging in the work environment and their relationships to other people in their workplace. Their experience of a good fit builds on the knowledge held in existing literature in this area. My collaborative research is the first to bring in individual narratives about life experience and the employment life course, including details of the features of a good fit in work.

In literature addressing outcomes for people with IDD in employment, an improvement in quality of life measures was generally found (Kober and Eggleton, 2005; Verdugo et al., 2006; Jahoda et al., 2008; Beyer et al., 2010; Conroy et al., 2010; Flores et al., 2011; Akkerman et al., 2016). However, the definition of quality of life was variable, with Flores et al. (2011) proposing that this was a ‘catch all’ term for numerous personal and social features and factors relating to the working environment. Furthermore, the definition of quality of life or quality of work has not been defined by people with IDD in the literature and self-reports from people with IDD have often been only fleetingly observed through occasional quotations, but not elaborated on.

Although the collaborators who experienced ‘finding a good fit’ did not articulate this in direct terms, they demonstrated through their narratives’ features. This was identified in evidence of interactive occupation, as defined in occupational therapy literature (Wilcock and Hocking, 2015), inclusion (Lysaght et al., 2012a) and features of a good life as defined by Johnson et al. (2010). In occupational therapy literature, Wilcock and Hocking (2015) define the features of occupational interaction as ‘doing, being, belonging and becoming’ (p.134). Positioning occupation as being central to health, defined as far back as 1946, they refer to the fact that WHO defined health as a state of wellbeing as opposed to an absence of infirmity or disease (WHO, 1946 cited by Wilcock and Hocking, 2015). They argue that in order for a state of wellbeing to be realised, ‘doing’ is required to provide meaning and purpose in addition to socialisation, motivation and self-esteem (Wilcock and Hocking, 2015). In their discussion of features of

positive health outcomes, they state the need for people to be offered meaning, choice, satisfaction, purpose and achievement alongside belonging (Wilcock and Hocking, 2015), echoing the experiences of Jo, Ruth and Mark and their good fit in their work. Similarly, these collaborators' experiences resonate with the features associated with inclusion as defined by Lysaght et al., (2012a) 'belonging, reciprocity and need fulfilment' (p.1339) and by Johnson et al. (2010), when they assert that work can provide 'companionship, relationships, intrinsic interest, and a sense of belonging and contribution that brings benefits' (p.109).

While it would be idealistic to suggest that Jo, Ruth and Mark communicated in their narratives all the features of a good life, inclusion and occupational interaction, a significant number of the features were present in their lived experiences. However, alongside Jo's, Ruth's and Mark's descriptions of their pride in what they did and their positive interaction with their peers, they did not articulate relationships that extended beyond work, apart from all staff events. Inclusion in the work setting has long been seen as needing to be redefined; to go beyond just being present within it (Humber, 2016; Lysaght et al., 2012b). However, while the literature has identified increases in relationships and social networks in the work setting, this has tended to be with other people with an IDD (Forester-Jones et al., 2004; Siporin and Lysack, 2004). While concerned not to oversimplify the experience of the collaborators in this collaborative research, some articulated a desire to build relationships with work colleagues outside of work and others stated they did not wish to, as might be the case throughout the working population. Therefore the idea that this should be a blanket indicator of inclusion is questioned. However, this is not to negate the possibility that the collaborators were facing exclusion from out of work activities and relationships, although this was not seen in the narratives. Jo, Ruth and Mark expressed features associated with job satisfaction in line with Akkerman et al.'s (2016) findings in their systematic review, i.e., good support from colleagues and managers, as well as an absence of stigma. The social features of the environment will be discussed further in section 7.4.2.

In addition to highlighting features associated in the literature with the outcome of a good fit in work, including aspects of a good life and inclusion, the collaborators' work stories provided new insights relating to the nature of positive occupational adaptation. Within the current literature base and as outlined in the literature review, the nature of jobs undertaken by people with IDD remains

relatively unexplored. Often jobs are mentioned in name only, with limited information about the role and the tasks entailed and with no details regarding the adaptations to the role or reasonable adjustments, e.g., to the working hours being undertaken. Similarly, although supported working practices are described in relation to the development of the work role, employer support and job coaching (Ellenkamp et al., 2015), only one study was located that included, in part, quotations containing first person experiences of this support (Wilson, 2003). As previously stated, Taylor (2017a) presented a definition of occupational adaptation that included the interaction of occupational competence, occupational identity and environmental impact. Defined as the subjective meaning of a person's occupational life, occupational identity includes an individual's interests, sense of capacity, role identity, values, motivation and decision-making (Taylor, 2017a), while occupational competence is proposed to be 'the degree to which one sustains a successful pattern of occupational participation that reflects one's occupational identity' (Kielhofner, 2008, cited by Taylor, 2017a). Within this model, the impact of the environment describes the dynamic interaction between the person and the opportunities and restrictions of the structural features of the environment, social, cultural and political.

Occupational adaptation is defined here as having a positive occupational identity and the correspondent occupational competence constructed over time through the dynamics of a constant interaction between personal factors and environmental impact. (Taylor, 2017a, p.118)

This thesis adopts the MOHO (Taylor, 2017a) as the foundational understanding of occupational adaptation and observes its compatibility with constructs of personal and ecological resilience (Hart et al., 2016) and the extended perspective of the political as outlined in the initial section of this chapter. Furthermore, there is symmetry with the concept of 'occupational capital', which is defined as 'a combination of accessible external opportunities and supports for occupational participation and internal capacities and skills to access this.' (Cameron et al., 2016, p.281). This concept offers a dynamic description of occupational adaptation, allowing a quantifying of the occupational capital that is available to a person both in relation to their own capabilities and the resources and support available to them.

Within Jo's, Ruth's and Mark's narratives this expanded understanding of occupational adaptation is demonstrated. All three collaborators described cyclical experiences of job success and failure, a letting go and honing of interests and values, the forming of the worker role identity and the making of necessary decisions within their work setting. The application of these characteristics, in conjunction with the impact of the environment, revealed the practical features that supported occupational competence. This included, for example, Jo's part time job being created (or 'job carved') specifically for him, with one to one support being provided initially to help him to learn his role and the specific tasks that were new to him, like filling the toilet role dispenser and unblocking a toilet. Within Ruth's and Mark's work stories, similar experiences of adaptation to task and environment were shared. However, perhaps most significantly, all three collaborators indicated a synthesis between their role and its demands, i.e., the level of difficulty, environmental pressures, time engaged in the role and aspirations associated with work. An appreciation of the need to balance the features understood within occupational adaptation, resilience and capital are valuable findings for workers supporting people in relation to employment, including occupational therapists.

A further factor in Jo's, Ruth's and Mark's work stories is evident by its absence. None of the three collaborators highlighted limitations associated with reduced autonomy or a lack of choice relating to their current work. These features, namely the inability to exercise autonomy and choice (Siporin and Lysack, 2004), are evident in Tabitha's, Jennifer's and Kenneth's stories and indicate a poor fit in their work setting, as explored below.

### **7.3.3 A poor fit: stress and striving**

In their exploration of occupation and health, Wilcock and Hocking (2015) defined occupational deprivation as being denied access to occupation, which they outline as an essential need for a human being. They propose potential causes of occupational deprivation that resonate with the collaborators' work stories and these are a lack of citizenship, discrimination and economic, resource-based and ideologically driven restrictions. The issue of access to occupation remain highly relevant to people with an IDD, as employment rates continue to be low even when compared to other people with disabilities.

Therefore, significant occupational injustices exist in relation to accessing paid employment (DWP and DH, 2017).

Wilcock and Hocking (2015) go on to state that years of research have established ‘without doubt’, that not being employed is associated with poor health outcomes (p.293). Furthermore, poor health outcomes have equally been identified as associated with the quality of work experienced by a person (Wilcock and Hocking, 2015; Taylor, 2017a; Taylor, 2017b; WHO, 2018). In Chapter 5, Tabitha’s, Jennifer’s and Kenneth’s narratives revealed a poor fit in relation to their work and concerns in regard to mental health and wellbeing. In addition to Kenneth stating that his current work setting was ‘not good for his mental health’, other statements made in the stories included, ‘stress is the most annoying thing. I mean, to be always striving’ (Tabitha), with Jennifer describing engaging with the job centre as ‘nerve racking and daunting’. These expressions of stress and striving led to my identifying disquiet in my interactions with these three collaborators. The challenges identified in their lived experience are associated with an absence of features of inclusion, defined by Lysaght et al. (2012a) as ‘belonging, reciprocity and need fulfilment’ (p.1339) and by Wilcock and Hocking (2015) as ‘doing, being, belonging and becoming’ (p.134).

The level of challenge in the collaborators’ lived experience of their job roles indicated a lack of fulfilment of their hopes or dreams. Although all collaborators identified a letting go of work aspirations, Tabitha, Jennifer and Kenneth communicated a disconnect between their hopes and their current reality. They described that the jobs they wanted were ‘impossible’ (Tabitha, page 138), ‘not realistic’ (Jennifer, page 138) or ‘like a dream’ (Kenneth, page 163), leading to Jennifer’s conclusion that she would do ‘anything, anything really’ (page 151), indicating a direct impact on occupational identity.

The findings in associated work-related literature resonate with Tabitha’s and Kenneth’s experiences that there was no choice regarding staying in a job and being dissatisfied with the menial nature of the work (Siporin and Lysack, 2004; Iriate et al., 2014). Notwithstanding the challenges detailed in the stories in Chapter 5, Tabitha, Jennifer and Kenneth revealed evidence of significant individual resilience, with all communicating pride in what they were doing at that point, whether paid or voluntary work, and offering exhortations to others; I believe their courage and resilience are illuminated within their narratives as they

were in the other three collaborators' stories. However, all collaborators also communicated significant evidence of ecological resilience in relation to the importance of the specific support they received.

It is unclear how important resilience is for people with IDD who want to enter employment. Although resilience is a feature identified with people with IDD (Goodley, 2005), research in this area is limited to date (Hart et al., 2014). However, the developing perspectives in resilience literature are highly relevant to people with an IDD and to this research. Hart et al. (2016) united research and practice relating to resilience with an inequalities approach and highlighted the shifts in resilience definitions over time, from purely individual characteristics to an ecological understanding, including the interaction between the person and the environment. The authors drew on Bronfenbrenner's human ecology theory, stating that 'an ecological understanding of resilience places both the individual and the adversity within a dynamic multi-level context...' including social, cultural and economic factors (Hart et al., 2016, p.2). In applying an ecological understanding of resilience to the work stories of the collaborators in this research, clear examples can be seen alongside the individual experience of resilience. All collaborators communicated examples of positive or negative interactions with people, systems and attitudes that either facilitated or limited their access to work. However, when I asked what they would say to someone in their position looking for employment, four of the six collaborators encouraged people towards individual resilience. Ecological resilience featured only in Mark's story when he recommended seeking help from a specialist worker for people with IDD. However, within the narratives as a whole, evidence of recommendations relating to ecological resilience were communicated, exemplified in a statement by Tabitha: 'Sometimes it helps if your family tries - yeah, family and friends - because when you do it on your own it's pretty damn hard' (page 139).

In further consideration of the collaborators' recommendations to other people with IDD, I was struck that this encouragement was understandable, as each collaborator had been required to endure a journey of adversity before gaining a job. However, equally, I wondered if the dominant narrative about individual action or resilience within current policy (Johnson et al., 2010; Hart et al., 2016) had manifested itself in their advice to others. Hart et al (2016) highlighted this as 'responsibilising individuals' (p.1) to overcome adversity as opposed to

challenging the systemic inequality in society. Johnson et al. (2010), though not directly referencing resilience, challenged employment related policy for people with IDD, which asserted that a change in attitude could overcome barriers to accessing employment.

In terms of belonging, becoming and reciprocity, Kenneth's and Tabitha's narratives communicate a mixed picture, including references to the supportive features of the environment, reflecting ecological resilience. Both had positive relationships with their respective managers and Tabitha, equally, with her peers. However, Kenneth observed a feeling of being unappreciated by other staff and Tabitha communicated a reliance on her manager and staff team to support her in her work, indicating a potentially reduced reciprocity. Furthermore, both Kenneth and Tabitha communicated the challenge within their lived experience of work, exemplified in Tabitha's title that 'work is harder than you think' and in Kenneth's difficulty in working with people in his work environment. These statements illuminated the occupational demand associated with their work roles, their challenges in achieving occupational adaptation (Taylor, 2017a) and the potential disconnect with their occupational competence, indicating reduced occupational capital. This experience echoes this quotation by a leading self-advocate: 'Business wants people who are numeric (sic) and literate. Fine, some people can do that but there are some people who are never going to be able to do that – What are we going to do?' (Interview with the Chairperson of London People First, 19<sup>th</sup> May 1999, quoted in Dowse, 2009, p.571 cited by Johnson et al., 2010).

The realities of people with IDD having the capability to find and perform paid work on a parallel platform to people without an IDD, was explored by Johnson et al. (2010), leading them to conclude that the broad acceptance of the policy of work for all is idealistic. They call for work and citizenship to be redefined and the centrality of paid work in current policy to be questioned, echoing the 'chasm' between policy aspiration and experience observed by Ineson (2015). The proposal to redefine work and citizenship is well made and is articulated in similar fashion by Shakespeare in his consideration of disability and employment (Shakespeare, 2014). However, neither Johnson et al. (2010) nor Shakespeare (2014) provide details of how work should be defined or how any new definition would be received or alter the current labour market. Notwithstanding this current lack of clarity, I would argue that addressing this question is not only an

imperative relating to people with IDD. In a report commissioned by the government, Taylor (2017b) explored the nature of ‘good work’ in Britain and suggested that there was ‘one-sided flexibility’ in the labour market, favouring the employer (p.51). The report went on to urge that the ‘voice’ of employees and workers is heard in the workplace, quoting a CIPD submission to the review (CIPD cited in Taylor, 2017b). ‘Having a voice is essential not just at the moment of entering an employment relationship, but as it progresses too’ (p52).

The Taylor review (Taylor, 2017b) has rightly been criticised for not tackling the precarity and abuse of the poorest paid in British society that occurs in modern working practices (TUC, 2018). It has also been condemned for not going far enough in its recommendations, in terms of proposing robust enforcement and regulation that would challenge managerial prerogatives (TUC, 2018). However it does highlight, alongside associated literature, the fact that the issues affecting the collaborators in this research are being experienced by many people in Britain (Taylor, 2017b) and in the international labour market (for example, WHO, 2018; Macken, 2019) and that discussions relating to the role and definition of work would benefit all. Why this is necessary is outlined in the next section, which addresses the current failings in the system that emerged from the collaborators’ work stories.

## **7.4 Redevising work and employment support**

This section will explore the collaborators’ experience of factors that helped or hindered them in finding and retaining work, in relation to the narrative frames ‘navigating bureaucratic seas’ and ‘finding both friend and foe’. This will be discussed firstly in engaging with the findings relating to employment support services and secondly in addressing the impact of social support on employment outcomes for people with IDD.

### **7.4.1 The contradiction of complex employment support**

Oliver (2013), in his re-visiting of the social model thirty years on, observed that the model had ‘barely made a dent in the employment system’ internationally (p.1025). Like Shakespeare (2014) and Johnson et al. (2010), he stated that

although the disabling barriers had been identified in the labour market, the solutions outlined largely involved the individual taking action or making changes. In this respect Oliver (2013) resonates both with resilience literature that argues for an ecological rather than individual perspective (Hart et al., 2016), and the importance of supporting occupational capital through enabling occupational participation, by drawing on internal and external factors (Cameron et al., 2016). The narrative frame ‘navigating bureaucratic seas’ was the first to emerge in interviews with the collaborators and when rereading their stories. I found the protracted longitudinal nature of these work-related journeys and the significant requirement to navigate complex system of support almost Kafkaesque in their complexity and illogical characteristics. This led me to be frustrated by the paradox at the core of the narratives relating to bureaucracy and the marketisation of employment support services for people with IDD, namely that currently services devised to provide ‘support’ to individuals were in many situations at best, ‘unsupportive’ and at worst, latently ineffective.

*Valuing People and Valuing Employment Now* (DH, 2009a and 2009b) placed paid work at the centre of policy, within a narrative of personalisation and person-centred planning. Furthermore, personalisation continues to be fundamental to recent policy development in the *Work, Health and Disability Green Paper: Improving lives* (DWP and DH, 2017). However, as communicated in the experiences of Jo, Ruth, Mark, Tabitha, Jennifer and Kenneth, meaningful personalised support is shown to be an exception as opposed to routine practice, notwithstanding their IDD-specific work consultant who supported them into their uncommon position of being in paid employment. Nevertheless, they outlined a broad range of issues in their narratives. Issues included, for example: for Jo, Mark and Tabitha, ineffective support from the job centre meaning that they had attended for years without getting a job; a lack of listening by an employment service, involving Ruth talking of being pigeonholed and let down regarding jobs she was considered for; a negative working environment without peer or management support for Tabitha, in her first role as a school catering assistant; Jennifer’s experience of being in a voluntary cleaning job for years without review or discussion of payment; and all their experiences of moving through numerous specialist ESPs. Kenneth described these as having become intertwined to him as there had been so many. The research collaborators’ experiences are not unique but are supported in the literature, where numerous work settings were identified with variable support available and differing criteria relating to eligibility

for services (Simonsen and Neubert, 2012; Holwerda et al., 2013; Wehman et al., 2014; Southward and Kyzar, 2017). However, these studies did not look at the experience of people over an extended timeframe as this was beyond the remit of their research.

The nature and effectiveness of employment support and the workplace environment remain relatively unexplored in the literature. Within my collaborative research the collaborators, in their work stories, have repeatedly illuminated the importance of the working environment. Specifically, all six collaborators stated that their work consultants from the ESP were important in supporting their journey through provision of individualised support, echoing the findings in the literature which highlight the value of trained workers (Nord, 2016; Moore et al., 2002; Butterworth et al., 2012). However, there remains a significant lack of studies and therefore knowledge regarding the nature and effectiveness of this support. Although outside the remit of this research, the collaborators' experiences demonstrate the variety of support and cyclical nature of employment success and failure that many of them experienced. Alongside the research findings from the collaborators, the limited research that has examined the effectiveness of employment support workers has demonstrated that further research in this area is necessary. It was encouraging that Nord (2016) found that engaging in three vocational skill services, including placement support, as part of the vocational rehabilitation service in the USA, led to a 16 times greater likelihood of being in employment. However, the fact that this benefit was not felt by those defined as having cognitive impairments, suggests further research is required into the content of the training and its capacity to address the specific needs of people with higher levels of impairment.

The study by Butterworth et al. (2012) was one of the few to compare outcomes in a group of paid employment support providers who received employment support training with those that did not. They found that those trained gained improved outcomes in terms of additional working hours and pay for the people they supported. Similarly Rusch and Dattilo (2012) in their metaanalysis of seven literature reviews observed the general lack of awareness of the tools used with people with IDD in supported employment, while Wilson (2003) outlined in his exploration of supported employment for people with IDD the inadequate addressing of individuals' impairments. This limited knowledge regarding

employment support indicates that there is complexity that requires exploration and untapped potential in developing the effectiveness of existing services.

Limited research has been found that evaluates the effectiveness of employment support services and concerns have been raised at the lack of research focusing on the impact of the working environment on people with IDD (Ellenkamp et al., 2015), which is often considered to be a ‘homogenous independent variable’ (Jahoda et al., 2008, p.15). The impact of the social and cultural environment and its implications will be expanded upon in the subsequent section. However, within the collaborators’ stories, the impact of the physical environment was communicated particularly, but not exclusively, in terms of its capacity to support or hinder the worker’s role. An example of this included Ruth’s and Kenneth’s respective capacities in their work settings to distance themselves from the social environment: Ruth was able to work away from people and interact largely when she chose to, while Kenneth did not know who would come out of the doors in communal areas and had to access busy rooms to clean them, which he found stressful. Evaluation of the physical environment and how it affords or restricts occupational engagement for a person is a fundamental aspect of occupational therapy assessment; environmental or task adaptation a principal feature of intervention (Taylor, 2017a). There is a need to reassert the importance of the environment to occupational therapists working with people with IDD, and for further research in this area to be carried out.

The deficit of knowledge regarding the experience of the working environment for people with IDD and the poor understanding of what constitutes good employment support have been identified as important, as they are significant in the collaborators’ protracted journeys. This is a concern due to the potential poor health outcomes for people who are either not gaining the employment they seek or who are experiencing a poor fit in their employment setting. It has been highlighted here, as most studies located were not longitudinal in nature and had not focused on the person’s experience directly. Holwerda et al. (2013), for example, reviewed job retention after six months, while Lindstrom et al. (2014) explored the career progression of transition age adults with IDD over a four-year timeframe, following on from education. Only Wilson (2003), in his paper exploring the role of normalisation and supported employment concepts, shared three case studies of people in employment, which included narratives collated with people with IDD, their families and employers / employment support

workers. These provided evidence of people's experience of protracted access to work, failures in the workplace and varying support from employers and ESPs.

Although no studies were located that compared individuals categorised as unemployed with an IDD with the broader population seeking employment, similarities were found in comparing literature and the research collaborators' experiences. This related to the experience of changing working environment (Worrell et al., 2012; Cooper and Lu, 2019); the complexity and ineffectiveness of employment support services (Herd et al., 2005; Jordon, 2018); and insecure work situations and poor working environments (Taylor, 2017b). The working environment globally has altered significantly in recent decades due in part to increased automation, information and communication technical development and the growth of the platform or gig economy (Cooper and Lu, 2019). This has contributed to new features entering the working environment such as excessive availability to work or overwork being prevalent worldwide (Cooper and Lu, 2019). Similarly, fundamental changes have been identified to employment relations in the UK as a result of the global recession in 2007 (Worrell and Cooper, 2012). These have included increased prevalence of temporary employment, layoffs and involuntary early retirement (Worrell et al., 2012). Current insecurities in the working environment and the 'one-sided flexibility' being offered in favour of the employer (Taylor, 2017b) have also been highlighted previously in this thesis. However these features, although evident in the narratives of the research collaborators, do not address the question of securing employment.

Jordon (2018) presented a 'complex picture' in the findings of his sociology research study, when he undertook fieldwork embedded in two 'Work Programme' centres supporting the unemployed in the north of England. In his findings he highlights three areas that echo, in part, the collaborators' experience of seeking support around employment, concluding that the Work Programme is 'a largely pointless scheme, resented by many participants but providing a basic social service for others' (p583). Furthermore, his findings provide insight into the experience of the participants and the staff in the Work Programme. Jordon (2018) interviewed and observed staff and participants of the Work Programme and noted that participants felt pressure from the administrative regime, which threatened sanctions including the suspension of benefits. Similarly, the Work Programme centres, which were operated on limited budgets, saw staff being

expected to issue strict directives towards work that participants were compelled to complete before their next meeting. Within the study limited or no success was indicated in reaching the goal of the Work Programme, which was to support people into long-term employment (over 6 months), although short-term contracts were secured. However, the demographics of the participants were not detailed, although reference was made to a number of them receiving sickness benefit. In this respect, they may have experienced additional barriers to engaging in the Work Programme and labour market. Nevertheless, Jordon's (2018) findings support those of other critics of the work programmes in high income countries, including Canada (Herd et al., 2005), where welfare reform has been found to have become administratively punitive in its application. Herd et al., (2005) propose that there is a ritual of degradation of the person by applying policy through administration. Furthermore, this resonates with the experience of the six collaborators in this research in demonstrating overly bureaucratic and often ineffective support structures.

The degree to which these factors affect people with an IDD in comparison to other demographic groups and the larger unemployed workforce is not known. However, the low number of people with an IDD in employment, the additional barriers they face due to having an IDD and the experiences described in the research collaborators' work stories indicate that these systemic issues may disproportionately impact this population. This is exemplified in Jo's narrative in Chapter 5, when he notes that he had a specialised advisor at the job centre during the years of his attendance with his grandmother and that this 'helped', when it was clear that it did not lead to work. It was in fact the case that paid work was achievable only when creative individualised support was deployed by the IDD-specific ESP. This included constructing an appropriate job for Jo with 'Access to Work' finances to overcome the challenges of travelling by facilitating a taxi. Therefore, although not included as an aim of this research, this thesis highlights the value of good individualised support, including an understanding of the barriers faced by the individual and as Wilson (2003) argues, consideration of the needs associated with the person's impairment. In this respect, each participant's narrative insightfully observed the fundamental importance of addressing the right issue in order to get appropriate individualised support. This was exemplified when Tabitha observed the importance of having good support from her manager and peers in her current work setting compared to the last. These experiences, which fill the collaborators' work stories, signify that a

number of ‘support’ services are not supportive or personalised and constitute a barrier to accessing work. Furthermore, this limits the potential for individualised support that recognises a person’s needs, and the expertise they have in their own lives, restricting their potential to be partners and drivers of the support they receive. It is understood, particularly in the case of the many references to job centres in the narratives, that this limitation in support might be associated with resources, such as inadequate amounts of time and insufficient knowledge of the needs of people with IDD.

#### **7.4.2 The importance of social factors in supporting employment**

In this section, the findings from the research relating to the narrative frame ‘finding both friend and foe’ will be discussed. Initially, the positive features of the social environment will be considered in terms of their support for people with IDD finding and retaining employment. The negative impact of the social environment will then be discussed, as it relates to my collaborative research and relevant literature. Within this discussion, the social environment is defined as the people in an individual’s life and the quality of interactions provided, including support, in addition to societal or community practices and attitudes (Taylor, 2017a). The cultural and societal attitudes that have formed part of the collaborators’ experience of the employment environment have been more broadly discussed in section 7.2. The experiences held in the narratives of the Jo, Ruth, Mark, Tabitha, Jennifer and Kenneth included both positive and negative experiences of the social environment, including references to their families, work peers and managers, ESPs and the community, and these will be discussed below.

The primary consensus about social features in the work-related literature, despite methodological differences, included a positive correlation between being in employment and living alone or living with family members (Moran et al., 2001; Wehmeyer and Bolding., 2001; McGlinchy et al., 2002). However, this may no longer be the case as this research was conducted almost twenty years ago and further research exploring this issue was not located in work related literature. Nevertheless, these findings were echoed in the research collaborators’ living situations and supported the premise that people with increased needs, indicated by increased levels of support, complex comorbidities or greater levels of

impairment, are less likely to be in paid work (Martorell et al., 2008; Ineson, 2015; Nord, 2016; Bush and Tasse, 2017). Furthermore, the collaborators identified direct assistance from families in finding work, exemplified in Ruth's and Tabitha's work stories when they referenced how their mother and sister respectively practically helped them to find and secure paid jobs. Similarly, Jo's grandmother provided practical and emotional support when attending the job centre. Therefore, active practical and aspirational support from families was identified in the collaborators' work stories. The support of families was also found in the work-related literature (Lindstrom et al., 2007; Timmons et al., 2011; Lindstrom et al., 2014; Petner-Arrey et al., 2015; Blustein et al., 2016; Rossetti et al., 2016; Gilson et al., 2018). In fact, this literature suggests a dependency on family members' active involvement in combating the barriers, both practically and attitudinally, that surround their sons or daughters' access to post-education resources (Petner-Arrey et al., 2015; Rossetti et al., 2016). Furthermore, this suggests that professionals supporting people with IDD into employment should support parents to advocate for their children in relation to work, and encourage their social networks, in order to avoid burnout in caregivers (Petner-Arrey et al., 2015).

Critically, the majority of these studies focused on transition age adults (usually identified as being between 16–25 years of age) who had moved from children's to adult services, therefore the longer-term role and support of families throughout adulthood remains relatively unexplored with only one study addressing the adult population (Gilson et al., 2018). For this research, Gilson et al. (2018) carried out a questionnaire with 673 family members of people with IDD and/or Autism in the USA, exploring their expectations, concerns and preferences about employment for their family member. In their findings, they identified that family members preferred integrated paid employment over sheltered employment options and also that they valued qualitative features of the work, including social opportunities and personal satisfaction, over pay, working hours and benefits. This directly echoed the findings in transition age adults (Blustein et al., 2016). Furthermore, although Gilson et al. (2018) addressed their questionnaire to families supporting adults with IDD, the make-up of the demographic who responded were predominantly supporting younger adult family members, with 47.4% being between 22 and 29. This notwithstanding, while the socioeconomic status of families has been negatively correlated with knowledge and awareness of services (Raghavan et al., 2013),

the experience of most parents of children with IDD remains unexplored. Parents who take part in research are likely to be self-selecting and potentially not representative of diverse family compositions. Furthermore, the findings of these studies reflect family members' hopes for their sons and daughters which appear to resonate with the role and function of work to support principles of community inclusion as a priority over financial security. However, this requires scrutiny through further international research, as current research largely originates from the USA.

All collaborators articulated the value of supportive employers and peers in the social environment on gaining and retaining work. This was articulated notably by Tabitha, who recounted her experience of having the same job in two different schools, with her current role being positive due to the support of her manager and peers. Although no specific research could be identified that followed a person with IDD through various work settings, some research has examined the outcomes of people with IDD in different working environments (Kober and Eggleton, 2005; Beyer et al., 2010). Within these two studies, quality of life outcomes were compared and found to be higher in open employment by comparison with supported employment (Kober and Eggleton, 2005), and lower in supported employment by comparison with day services (Beyer et al., 2010). However, the exact role of the social environment relating to quality of life outcomes was difficult to quantify in these work settings, and I would argue that it may in fact be impossible, as no one social environment would be the same as any other.

The potentially positive role of supportive managers and co-workers has been identified in work outcomes for people with IDD (Flores et al., 2011; Akkerman et al., 2016). Akkerman et al.'s (2016) findings resonated with some of the collaborators' experiences, detecting higher levels of satisfaction when participants experienced factors linked with inclusion such as belonging, an absence of stigma and good support from managers. Similarly, Flores et al. (2011) observed the benefit of effective co-worker and supervisor support on improved quality of life outcomes. Timmons et al. (2011), when looking at what factors influence people in their choice to work, found that gaining the admiration of others and being a member of the community were important, as articulated by the collaborators in this research.

The collaborators in this research communicated the importance of their relationships with specific work consultants in all their stories, exemplified by Mark, Jo, Ruth and Tabitha. Within the associated literature, an exploration of the positive personal relationship between worker and individual with IDD in work was not found. Again, this indicates a significant gap in the literature in relation to the evaluation of supported employment providers and individual practice relating to the impact of the role of a job coach.

Melling (2015), when highlighting current policy failures in the employment rate of people with IDD, proposed that a significant positive cultural shift was required in people's perceptions and expectations of people with IDD. However Johnson et al. (2010) challenges this perspective, stating that the call within *Valuing People Now* for people with an IDD and those that support them to 'believe work is a genuine possibility' (DH, 2009, para 3.45) is 'flimsy' rhetoric (Johnson et al., 2010, p.102). However, while agreeing that this rhetoric may be aspirational, the collaborators' narratives provide examples where the belief of a family member or employer was crucial to the person gaining or sustaining employment.

In drawing out the narrative frame 'finding both friend and foe', what emerged from the narrative was an observation that people were either *for* or *against* people with IDD in relation to work. Furthermore, unlike the activities such as self-care and leisure that can occur (although obviously not exclusively) in a private sphere, work by its very nature predominantly requires interaction with people and the social environment. 'Action', as Arendt (1958) defined it subsequently, becomes an essential part of engagement in this sphere. Home working is an option for many, but no evidence has been found in the literature that that people with IDD are engaging in home working. The construct of 'foe' in the narrative frame emerged not only as the presence of malevolent behaviour, such as Ruth being stalked in one work setting, but also the negative impact of latent human factors, such as ineffective or unsupportive people in the work environment or support services. These experiences were exemplified in work programmes without effective outcomes.

Although the direct report of people with IDD in the literature is limited, the findings from my collaborative research resonate with extracts taken from self-reports in related literature in relation to negative experiences of the social environment or lack of inclusion in the workplace (Li., 2004; Jahoda et al., 2008;

Akkerman et al., 2014). Li (2004), through her interviews with seventeen individuals with IDD in Hong Kong, noted that alongside the positive experience of meeting family expectations was the negative experience of people with IDD having poor relationships with co-workers or managers and getting admonished in the workplace. Similarly, Jahoda et al. (2008) detailed positive outcomes regarding levels of autonomy and wellbeing but equally identified the participants' experiences of a lack of social acceptance in the workplace. These positive and negative experiences of the human or relational working environment were equally echoed in the findings of Akkerman et al. (2014), in their details of 'job demands', described in part as abuse and prejudice. This mixed relational experience in the working environment resonates with the findings within the collaborators' stories in this research and exemplifies the clear experience of having both friend and foe. That is to say that even the collaborators who communicated a sense of a poor fit in their employment setting shared positive experiences of engaging with people at work alongside the negative, demonstrating the multi-faceted nature of the social environment. However, it was notable that none of the research collaborators discussed or included images of other people in their working environment in the visual component of their work stories. This was observed as relevant, as the impact of the social environment was significantly represented in their work story narratives.

Within the discussion above, the positive influence of familial support was highlighted. Evident in the work stories was the experience that on occasion family influence could also lead to increased pressure on the research collaborators. Examples of this included Tabitha stating she was part of a competitive family and Jennifer, when she identified that her mother in law wanted her to be in paid work and interfered with her attempts to find work. Additionally, Kenneth stated that his family had put pressure on him to work when he was clinically depressed.

The demographic focus of the literature discussed above focused on families and their sons and daughters with IDD and employment relating largely to transition age adults. While literature was sought that addressed the influence of families upon people with an IDD in adulthood, only one article could be found (Gilson, 2018). In this respect, the influence of family members and family cultures on adult life outcomes, such as paid work, is unexamined for adults with IDD. This results in family support being rendered invisible and its influence unknown, so

alongside limited understanding of the role of employers and peers in the workplace, the full impact of the social environment remains unexplored in work-related research. Furthermore, the emergence of family influence in the work stories shows the need for further research in this area, to illuminate sensitively the healthy and unhealthy support for people with IDD within their families.

## **7.5 Summary**

This research is the first to illuminate first person narratives of a small number of people with an IDD in paid employment. The collaborators' work stories constitute a unique contribution to knowledge and have been discussed in this chapter in the context of wider literature.

In the first section 'Understand me', focus was given to identity and how it emerged within the collaborators' work stories relating to self-identification, the disabled identity and the identity of being able to work and be a worker. The collaborators' narratives demonstrate that the personal is political and that while negative labelling and negative experiences relating to having an IDD in work exist, self-identification is also present, together with examples of empowerment, including being in employment. Nevertheless, although work was observed to have brought benefits to the research collaborators, this was not to the extent that policy aspirations had proposed, particularly in relation to low earnings and career development. The application of this new knowledge could involve encouraging workers, including occupational therapists, to embrace partnership working with the people they support, and to place the political as an essential component of working with people with IDD, in order to support them towards 'action' in the public sphere where work exists. This 'action' also requires the redefining of work and citizenship, so that it is not dependent on people with IDD being positioned as equals with non-disabled peers in the current labour market.

In the second section of this chapter 'belonging versus stress and striving', the collaborators' lived experience of being in employment was discussed in relation to the importance of doing and finding a good or poor fit in work. Identifying and contextualising the importance of 'doing' within the findings, the chapter highlighted specific learning for occupational therapists and other support workers, proposing a recalibration of their paradigm so that it is occupation

focused, pluralistic, participatory, individually and crucially structurally focused, with the political experience of the person at the centre. Within a new paradigm, the learning that emerged from the collaborators' narratives relating to a good and poor fit can be applied. This includes that those with a good fit were found to experience inclusion, wellbeing, synthesis in the role relating to their occupational competence, positive identity and a supportive environment.

Conversely, those who were identified as having a poor fit in their work setting, or lack of work in Jennifer's case, revealed variable support in their environment, a lack of synthesis between their job and their occupational capability and evidence of reduced wellbeing. However, within all the collaborators' stories, the importance of resilience was consistently evident, both in relation to the individual and the ecological.

'Re-devising work and employment support' outlined the research findings relating to the paradox inherent in the occupational narratives, where ineffective employment support contributed to the barriers surrounding employment of people with IDD. This included the identification of the protracted and extended journey experienced by the research collaborators, which had not been identified in literature previously. While identifying that good individualised support had been valuable to the research collaborators, the deficit of knowledge surrounding the workplace, working environment and guidance on best practice in supporting people with IDD was equally asserted. Central to the workplace and discussed in the last section of this chapter was the role of the social environment. The importance of family, employers, peers and workers, being supportive and 'for' the person with IDD in and around the workplace was identified as enabling the workplace to be a positive environment. Moreover, the negative impact of the social environment in the family and at work was emphasised. However, it was also acknowledged that it remains unexplored in the literature.

In the final chapter the implications of this research will be expanded in relation to people with IDD, occupational therapists, employment support workers, families, employers and policy makers seeking to support people with IDD in employment. Additionally, an assessment tool, 'My Work Plan', currently devised in draft, will be described and its potential role in supporting the consultancy work of occupational therapists explained. Furthermore, the limitations associated with the research will summarised and the contribution of the creative collaborative partnership to inclusive research methods outlined.

## **Chapter 8. Conclusion**

### **8.1 Introduction**

This thesis has addressed the specific aim of illuminating the lived experiences of six collaborators with IDD in paid work. Additionally, it has identified knowledge contained in the work stories and five narrative frames for application by people with IDD, their families, employers and workers supporting people with IDD into employment, including occupational therapists. The preceding chapters having outlined the collaborators' and my research journey: doing research inclusively using the creative collaborative partnership method, executed within a hermeneutic phenomenological methodology.

Chapter 7 discussed the research findings and situated them in the broader literature on work for people with IDD and occupational therapy. In this concluding chapter, the contribution of the findings will be expanded upon. First, it will consider what has been learnt from the work stories that can support people with IDDs employment needs, and then it will consider the implications for occupational therapists. This includes a draft assessment tool I devised, My Work Plan, that is in the early stage of development and evolved through the application of the research findings. This tool supports the paradigm shift that is required in practice to work in partnership with people with IDD in this area. Finally, the research contribution to policy and service redesign will be summarised, including workers' roles in employment services.

There will then be an overview of the contribution of the creative collaborative partnership to inclusive research methods and finally, the research limitations will be outlined. As in the preceding chapter, the interpretivist position is applied throughout and my position communicated explicitly within the sections.

### **8.2 The contribution of the collaborators' work stories**

Central to the research has been the desire to hear the voice of people with an IDD regarding their lived experience of paid employment, as this was limited or absent within the work-related literature. The primary contribution of this research is the work stories of the research collaborators, as they communicate their work

journeys situated within their broader lives (detailed in Chapter 5). The combined visual and narrative stories of Jo, Ruth, Mark, Tabitha, Jennifer and Kenneth illuminate the experience of seeking, gaining and being in employment. The thesis asserts that the personal is political and the insights drawn collectively from the collaborators through the narrative frames ('the quest to do', 'finding a good fit', 'navigating bureaucratic seas', 'finding both friend and foe' and 'the forging of identity') represent a political challenge about the need for social change, as well as showing the barriers and opportunities experienced by people with IDD.

The 'personal is political' (Hanisch, 1970) resonated greatly with me during the research process due to its inclusive premise. Within feminism, it has articulated the political potential of all women, as it acknowledges that irrespective of direct political opinion, they interact with and can be negatively affected by the political when living their lives. In this respect I have seen, as others have, the potential broader application of this phrase, for example in relation to disability discourse (Shakespeare, 2014; 2019), geography and the impact of austerity (Hall, 2018) and in counselling and psychotherapy practice (Winter, 2019).

The personal is political as applied in this thesis is twofold: it describes a framework from which to approach a person with IDD around work, and equally asks for the worker, or in my case, the occupational therapist, to adopt a position of situatedness within the story of the person they support. The therapist's position will be discussed in the next section. It acknowledges that within the work stories the research collaborators were interacting and facing barriers within the social, cultural and political environment. In this respect their personal experience was political. However, while the collaborators might have described themselves as apolitical if asked, what became clear to me was that in sharing their story, initially with me, then later with each other and in a public space through the exhibition, the political became actively engaged. In this regard, I was aware of the working out in the research of Arendt's (1958) definition of 'action', namely the activity that takes place between people. She suggested that it could not be separated from speech and that it took place in the presence of others. While I would replace 'speech' with 'communication' to reflect the broader range of ways through which understanding and interaction are gained, during the process of this research, the importance of being part of the public sphere and communicating their story and their place in society was established.

It is this central premise that has resulted in my continued support of employment as an opportunity for people with an IDD, while equally recognising the challenges this poses on many levels. I don't hold, for example, with a perspective that has normalisation at its core, namely a lack of acknowledgement of difference, nor do I believe, as Johnson et al., (2013) also assert, that work should be the badge of citizenship or in the policy that work is for all. However, within a capitalist western narrative that shows no sign of lessening in its dominance, engaging with these challenges appears to me to be the only way to bring about change in relation to the redefining of work and support of people with IDD in the public sphere.

Interacting in the public sphere and all the risks and benefits this entails is an essential component of work in a way that other aspects of our life, such as self-care and leisure, don't have to include. Equally, many of the narrative frames would not naturally be associated with other forms of activity, such as the forging of identity', 'finding a good fit' and 'navigating bureaucratic seas'. Work brings everyone directly into contact with the social and physical environment in a way that can push, affirm, develop, restrict, challenge and grow us as people.

This process, encapsulated in the narrative frame the forging of identity, emerged within the narratives relating to the conceptualising of identity, in relation to the collaborators' IDD, their worker role and in being more than any label. In the time spent with the collaborators, I was always aware of this as a complex dynamic element of our discussion, either directly spoken about or as a feature remaining unsaid. In the narratives terminology was discussed, stigmatisation described, labels communicated, self-identification with terms provided, pride in being a worker described and pride in being more than a worker asserted. This complex dynamic dialogue surrounding identity is always there whether it is acknowledged in an interaction with someone with IDD or not. This indicates the importance of asking about how someone views or wants to define their disability to allow their experiences, injustices and needs to be heard and recognised. The importance of offering the opportunity for self-definition is recommended alongside a focus on the person, on asking them what they find hard or need support with, while also acknowledging their impairments.

The knowledge gained from the collaborators' stories has also illuminated the fact that people with an IDD can have a good experience of work, 'a good fit',

and similarly, that they can have a poor experience or ‘poor fit’. The collaborators communicated that a good fit in employment was evident by features such as empowerment in the work role, a positive sense of wellbeing and inclusion and occupational adaptation. Occupational adaptation will be expanded on further in the next section looking at the research’s implications for occupational therapy practice. However, within the working experience of the collaborators who experienced a good fit, important characteristics were described, such as a synergy between the person’s ability and the job they were doing (including for most collaborators, the number of hours they were working) and a supportive social environment in line with their needs. These features, though sharing many commonalities, were different for every person and required personalised support to identify and remove barriers and create opportunities to enable the fit to occur.

In contrast, the collaborators who were identified as experiencing a ‘poor fit’ described the outcomes of working as negatively impacting their wellbeing, and an ongoing underlying stress that they were still searching for a job with a good fit. The features that were identified from the collaborators’ experiences as indicating a ‘poor fit’ included a lack of synthesis between the person’s ability and their role. This meant that their work was demanding, not in a way that led to overcoming problems and gaining fulfilment but rather that it had the potential to be overwhelming and impact their self-esteem. Again, the factors relating to the person’s abilities and job role were different for each person, including the impact of an unsupportive physical or social environment or occupational identity, namely that the job was menial and not what they hoped for, or the level of occupational competence, that is, the job was too hard.

The primacy of the social environment for positive work outcomes is a key conclusion of this thesis. If the social environment, comprising ESPs, employers and peers, is unsupportive, findings indicate that work will not result in bringing its positive potential to the person. As exemplified in Tabitha’s narrative, an imperfect job can be tolerated if the people are supportive. However, an imperfect job becomes intolerable if the social environment is negative, equally communicated in Tabitha’s description of her first job as a school catering assistant where the team were unsupportive, so she left. This is similarly reflected in the collaborators’ experience of family support. In most cases, the families of the research collaborators played a vital role in supporting them to find

work and in navigating the protracted journey and associated barriers they experienced. However, on occasion, they also appear to have contributed to the pressures experienced, although this impact is not fully understood and requires further exploration. Finally, in considering the impact of the social environment, the workers that supported people with IDD in employment were identified as acting as friend or foe within the work stories. It was effectively often the workers within government structures such as job centres, together with ESPs, that directed the protracted journey experienced by all the collaborators in relation to employment. This will be explored further in the section, ‘The contribution to policy and service redesign’.

Irrespective of whether the collaborators described an experience of a good or poor fit, they all communicated a continued reliance on benefits despite being in paid work. The experiences were of earning low wages and financial betterment, as promised in policy, was not evident. Should the collaborators have been working full time, it is unlikely that their pay would have been adequate to meet all their financial needs, so, as articulated in the previous chapter, there is an imperative to ‘re-think’ work (Johnson et al., 2013). This consideration is two-fold, firstly in terms of the incompatibility of placing people with IDD in direct comparison to their non-disabled colleagues in the labour market and secondly, in terms of reviewing the pay and quality of work for all as indicated but not fully expanded on by Taylor in his review of *Good Work* (2017b). Furthermore, while issues with pay and the quality of work for all have been highlighted by Taylor (2017a) the experience of different people within the labour market remain relatively unexamined. In this regard how the research collaborators’ experience compares with people with other impairments or non-disabled people within the labour market has been difficult to ascertain. However, what is clear is the barriers the research collaborators have described are not exclusively experienced by people with IDD (as outlined in Chapter 7) but are shared by people with impairments that result in them requiring increased support to gain and retain work. What does appear to be unique to people with an IDD, as described in the research collaborators work stories, is the extensive number of barriers experienced. Although the comparative nature of people’s experience in work with and without an IDD was not a focus of my collaborative research, the identification of the excessive barriers faced by people with IDD may contribute to an understanding of why the number of people with IDD in paid work remains so low.

Without exception, all the collaborators communicated a pride in their work irrespective of whether they experienced a good fit. Consequently, pride alone should not be identified as an indicator of a positive work outcome but rather a feature of individual resilience and the sense of citizenship that work provides in our culture. Findings of both individual and ecological resilience were identified as important features of the collaborator's stories, which provide valuable insights into the experience of what it takes to find and maintain work for other people with IDD. Further consideration of resilience and its relationship with policy will be expanded on when addressing the implications for policy and service redesign.

In conclusion, the collaborators' work stories embody the position that the 'personal is political' and that acknowledgement of the political through explicit discussion about the experience of having an IDD in work is of vital importance to identifying experiences of injustices, strengths and needs. This research, although composed of too small a number of participants to generalise findings, indicates that people with an IDD can have a 'good fit' in work as well as a 'poor fit' and it illuminates factors related to these experiences. Furthermore, it suggests that a hierarchy may be present in the factors that support people with an IDD in work, with a supportive social environment being of greatest importance to ensure that the protracted journey to employment highlighted by the collaborators can be reduced. Finally, work operates largely in the public sphere, unlike many activities, and this can be a supportive and challenging environment where considerations of individual and ecological resilience form an essential part of supporting and forging identities.

### **Recommendations for people with IDD and those supporting them in work**

- People with IDD have important stories to tell, which reflect that the personal is political in relation to the injustices, multiple barriers and positive experiences they face in seeking and gaining employment. Sharing these stories would be beneficial to any person with IDD looking for work and any review of policy or employment support services.
- People with an IDD would benefit from support workers in relation to employment helping them to talk about their IDD, the injustices and barriers they face and the impact of these and their abilities on their life and work.

- People with an IDD and the workers supporting them would benefit from consideration of the five narrative frames and characteristics of ‘a good fit’ and ‘poor fit’ at work (see My Work Plan, described in the next section).
- People with an IDD and workers supporting them in employment should prioritise establishing a supportive social environment when seeking and gaining employment. Furthermore, people with IDD would benefit from a skilled work consultant to provide personalised support in partnership.

### **8.3 The contribution to occupational therapy practice**

The second aim of this research was to gain new knowledge to inform staff, such as occupational therapists, in supporting people with an IDD towards and in employment. Building on the insights discussed above, the contribution to knowledge represented by these findings will be discussed in terms of their relevance to occupational therapists. However, these implications are equally valid for all workers supporting people with IDD in work.

This section will initially address how the research findings develop the occupational therapy approach in working with people with an IDD, outlining the need for occupational therapists to increase their emphasis on the political and structural impacts on a person alongside applying a participatory partnership approach to intervention. To support this approach in practice, I devised an OT assessment tool which has been informed by the research findings. The My Work Plan, that is in its early stage of development, builds on the framework of the ‘job story map’, integrating the paradigmatic implications for occupational therapy and the narrative frames within the occupational adaptation model from the MOHO (Taylor, 2017a) and Pentland et al.’s (2018) model of occupational therapy as a complex dynamic process. Finally, a summary of recommendations will close the section.

Chapter 7 described changes to the occupational therapy paradigm over recent decades, highlighting how it had moved away from an individualised reductionist approach which was impairment-focused and moved towards an occupation-focused paradigm that embraces the structural (Molineux, 2011; Fisher, 2013; Jansson and Wagman, 2017). The move towards an occupation-focused

paradigm is embraced by occupational science and is observed in the research findings relating to the ‘quest to do’ and the centrality of occupation to the collaborator’s lives. However, this shift in the paradigm towards an occupational focus is still in progress (Molineux, 2011; Fisher, 2013; Di Tommaso, 2016) and the factors that surround the ‘doing’ and how therapists address them require further attention. This relates firstly to the prominence and impact of the environment and identity in the occupational therapy paradigm and secondly to the situatedness of the therapist in partnership with people with IDD.

Within the occupational therapy literature associated with occupational science and occupational therapy practice, the importance of the structural (or environmental) is seen as inseparable from activity, as all actions take place within an environment (Wilcock and Hocking, 2015; Jansson and Wagman 2017; Taylor, 2017a; Pentland et al., 2018). However, within occupational therapy practice, individualised impairment-based perspectives can still dominate, resulting in individuals’ capabilities often being the central concern of the therapist. In this regard, the structural features may not be given equal consideration. Similarly, from a reductionist perspective occupational identity, (including the political and self-identification of the person with IDD) may not hold equal consideration, for example, to that of an individual’s cognitive or motor skills. In this respect, I believe that increased guidance is required to support occupational therapists situate their work with people with IDD in the context of disability studies and work-related literature, which focuses on occupational identity and the impact of the environment. This includes building on Shakespeare’s model of disability (2014) and expanding the understanding of the individual to address their identity from a political perspective. This acknowledges the therapist’s situatedness with the person in addressing the injustices, barriers and opportunities associated with occupational injustice and deprivation. Utilising a definition from counselling and psychotherapy, it is suggested that the occupational therapist adopts a different position:

...it is an acknowledgment that the work we do occurs in a socio-political context which it cannot be easily disconnected from (and therefore that things like power, discrimination and oppression are important) and that this work can have political implications. (Winter, 2019, p180)

The impairment-based approach continues to be supported by a reductionist medical model in the healthcare environment (Molineux, 2011; Fisher, 2013; Di Tommaso, 2016). This has understandably supported a pervasive individualistic perspective in policy where the ‘responsible individual’ perspective is highlighted in relation to resilience (Hart et al., 2017, p.1) and the focus on individual action in work-related policy (Johnson et al., 2013) risks, perhaps, therapists and other employment support workers holding the same position. Therefore, to support the therapist in practice with embedding a more expansive paradigm, I have returned to the MOHO construct of occupational adaptation (Illustration 22) and the complex dynamic process model outlined by Pentland et al. (2018, Illustration 23) when considering the construction of the assessment tool in the next section.

In commencing my collaborative research, a question was raised about the role of occupational therapists in supporting the work-related needs of people with IDD, as it is supported employment providers that are, on the whole, commissioned to provide work-related support to them, and they are not occupational therapists. Although this research has not sought to address this question, I have come to the conclusion that occupational therapists can have a valuable role in, as Lillywhite and Haines (2010) suggested, providing consultancy support to individuals and services for those with an IDD and the most complex needs. However, due to the pressures and strains on resources surrounding the health care environment, this consultancy intervention needs to be efficient and effective. This research proposes that the work stories shared by the collaborators illuminate the occupational experience of people with an IDD, and therefore form a valuable resource for therapists supporting people with complex needs who are seeking employment. Furthermore, My Work Plan, detailed below, has been devised as a tool which aims to promote the effectiveness of the therapist’s consultancy role to people working in employment support providers.

### **8.3.1 My Work Plan: an assessment tool in draft**

My Work Plan is an assessment tool (Illustration 24) in its early stage of development that I created to support the therapist in practice in conducting an assessment jointly with the person with IDD. Consequently, it has the potential to

be co-constructed with the person on their own, or in conjunction with a family member, carer or ESP, at the point of identifying employment as a goal.

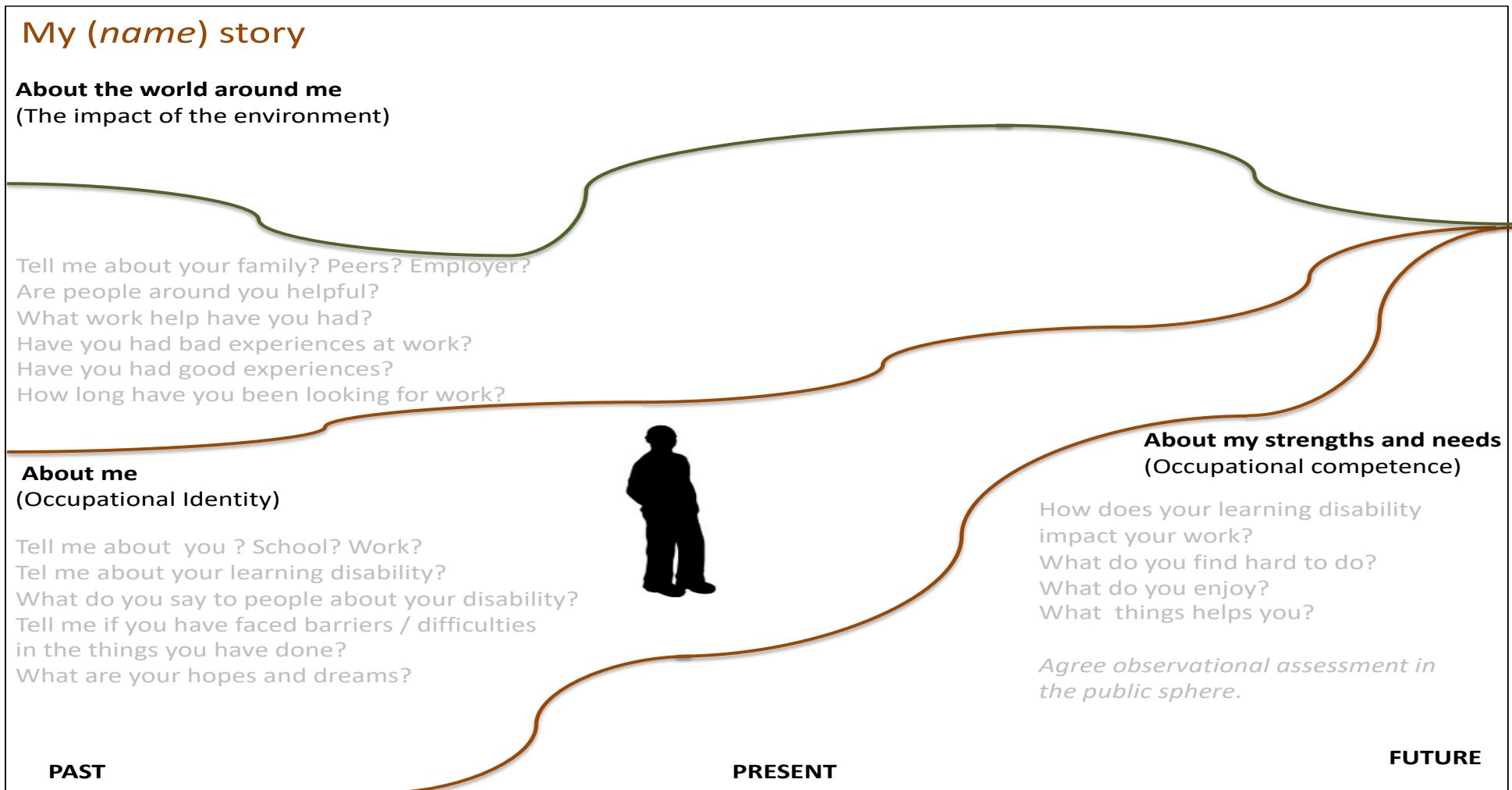
The assessment tool is underpinned with Taylor's (2017a) expanded description of the interrelated elements of occupational adaptation, as outlined in the 5<sup>th</sup> edition of Kielhofner's MOHO, and Pentland et al.'s (2018) complex dynamic process model of occupational therapy practice (Illustration 22 and Illustration 23). Occupational adaptation is defined by Taylor (2017a) as the positive outcome in the interaction between occupational identity and competence over time within the environment. This definition of occupational adaptation resonates with me as it contains characteristics of 'finding a good fit' in work as outlined above and, along with the three interacting elements that have supported the devising of My Work Plan, it builds on a strong history of evidence-based practice embodied in Kielhofner's model. Similarly, Pentland et al.'s (2018) complex dynamic process model expands on Kielhofner's perspective to situate the therapist within the broader micro and macro context where intervention takes place. It is felt that these models are compatible with one another and with the broader concepts involving disability, resilience and occupational science studies respectively.

Taylor (2017a) cited Christiansen (1999) when defining occupational identity as referring to the self, and being inclusive of values, roles, relationships, personal desires, goals and self-concepts, which he argues are created by participation in occupation. Similarly, this definition of occupational identity as interrelating with the environment resonates for me with the features identified in 'the forging of identity'. Taylor (2017a) goes on to state that if occupational identity is the subjective life of an individual, then competence is putting that internal world into action. In concrete terms this includes fulfilling the expectations of one's roles, maintaining a routine, participating in a range of occupations and pursuing occupational goals (Taylor, 2017a). These two elements then interact directly with the environment to form the environmental impact. Taylor (2017a) defines the environment as being made up of the physical, social, economic, cultural and political characteristics.

In the construction of My Work Plan (Illustration 24) the framework of occupational adaptation as defined in the MOHO (Taylor, 2017a) is used to underpin and contain the specific learning gained from the collaborators'

narratives and the narrative frames. Building on the occupational identity definition, for example, the expertise of the person themselves and their experiences (the political) are explicitly addressed. Similarly, the expanded perspective of the environment encapsulated in ‘navigating bureaucratic seas’ is built into its structure, to ensure equal value is given to each domain. Furthermore, efforts have been made in its construction to enable the person’s experience to be held alongside the therapist’s knowledge, in relation to the needs identified and barriers faced.

**Illustration 24 – My Work Plan: an assessment tool in draft (Original in colour)**



## My (name) work plan - Summary and goals

### About me (occupational identity)

*Social situation, self identification, hopes etc.*

### Personal strengths

### Challenges to self

### About the world around me (The impact of the environment)

*People, family, culture, support systems around employment, physical space, access, risks and vulnerabilities and objects...*

### Environmental strengths

### Environmental demands

### My strengths and needs (Occupational competence )

*Activity observed - motor, cognitive, communication skills*

#### **Strengths**

#### **Needs**

#### **The job demand -**

### My work goals and therapist actions

1.

2.

3.

4.

5.

## My work plan - guidance

### How to use the plan

1. Interview the person filling in the '**my story**' (A3) together writing or drawing.  
*'Can we talk about you? This is a path ... use questions in grey as prompts to talk about their story.'*
2. Observe the person in an **activity** which engages with the public sphere (in their work, shopping or community leisure activity)
3. Write the **my work plan** apart from the goals. Discuss and agree the plan with the person and write goals and actions together

### The impact of the environment

#### Social – Finding friend or foe

The social environment is the most important contributor to success for someone in work. People can tolerate a poor job with good support but not with poor support from peers, managers etc. Family can be a vital source of support practically and emotionally for people around work, though sometimes they can exert pressure. Paid work consultants with IDD knowledge are very the best form of 1-2-1 support into work.

#### Occupational Adaptation

##### What does a good fit look like ?

Synergy between job, capabilities and hopes

##### Evidence this is achieved?

Confidence in the work setting, belonging evident in joking, ability to criticize.

Supportive social environment – reciprocity

The job is neither boring or too challenging, it is just right

#### Occupational Competence, Identity and environment are inter-dependent

MOHO – With reference to Occupational Adaptation (Taylor, 2017)

### Occupational Identity

#### Being - Forging of identity

The personal is political, the persons Experience will have shaped their identity. Asking about their experience of their IDD is really important to recognise self-identification / stigmatisation and . Supporting them to work is for them to act in the public sphere, it requires individual resilience but not exclusively – see environment, ecological resilience

### Occupational Identity

#### Doing – the quest to do

Many people show a great deal of motivation to engage in work both voluntary or paid, the 'doing' may be as important as what they do. As humans we are occupational beings and having opportunities 'to do' is of great importance. Sometimes, hopes and aspirations don't' meet with people's reality and they may continue to seek (the quest) of another job, this can lead to disquiet for them.

### The impact of the environment

#### Cultural – Navigating bureaucratic seas

People with IDD can spend months or years Going through the system (Job centre Programs, training options etc.) without getting the support they need. Seeking specialist support and recognising the need to help remove the obstacles to getting the right support . Supportive systems and social environments are part of ecological resilience.

### The impact of the environment

#### Physical – environment and objects

Creative consideration is required when Thinking about the physical environment I.e.: Access to work money to support the Use of taxi for someone who could not Travel independently, flexible or reduced hours to manage a demanding working Environment.; break out spaces for someone who struggles with the Social environment.

### A Challenge to Occupational Adaptation

#### What does a poor fit look like?

Disquiet, reduced well being, not where the person want to be.

#### Evidence of this?

Work or a job feels hard and too stretching,

Dissatisfaction in current role

Limited or no reciprocity with others or over dependence. Unsupportive social environment

Constructed over three pages, page 1 of the My Work Plan worksheet sets out the person's story and experience of life in connection to work. As it is in the very early stages of development it has not been piloted or subject to scrutiny by occupational therapists, people with IDD, family members or workers supporting people with IDD into employment. Therefore, further development and validation is considered to be vital in establishing its effectiveness as a tool and is proposed to be the focus of my post-doctoral research activity.

In its current early draft, it is proposed that therapists, use the questions in grey to form a semi-structured interview, the therapists are encouraged to populate the worksheet in partnership with the person. This would include asking the person about their identity, what they like, value, how they identify in terms of their IDD, etc. This would be followed by questions relating to the environment and how they have experienced this and then by questions relating to their thoughts about their strengths and needs.

A second meeting would then be recommended where a functional assessment relating to occupational competence could be carried out, with the therapist observing the person doing an activity of their choosing in the public sphere. This might include, if they are in work, observation in the work setting, or if not, taking part in a leisure activity or going to the shops. The therapist would then collate the assessment findings on page 2 to share with the person in a third meeting, when goals and actions to remove barriers are agreed. Page 3 of My Work Plan comprises guidance on each area, allowing the learning from the research to prompt therapists' thinking and action.

### **Recommendations - occupational therapy**

- The collaborators' work stories can illuminate the understanding of occupational therapists and other individuals that work with people with IDD about the employment experience of people they support.
- Occupational therapists working in IDD are encouraged to reflect on the paradigm they employ. It is recommended that alongside being occupationally focused occupational identity, including the individual (political) experience, occupational competence and the impact of the environment, have equal consideration in their practice.

- The draft of the My Work Plan is to be subject to consultation and validation as part of post-doctoral research in conjunction with people with IDD, occupational therapists, families and people working to support the employment needs of people with IDD.

## **8.4 The contribution to policy and service redesign**

Past and present policy pertaining to the employment of people with IDD continues to articulate that an injustice is evident in the low numbers of people accessing paid employment. As discussed extensively in the previous chapters, policy has failed in its aims to improve employment opportunities for people with IDD. While the impact of the most recent policy *Work, Health and Disability Green Paper: Improving Lives* (DWP and DH, 2017) remains unknown at this time, within the content of this policy there is little, or no scrutiny of why previous policies have not prospered. There is a crucial deficit of knowledge regarding what good support, good employers, good working peers and good working environments look like for people with an IDD. This deficit exists perhaps because the focus of policy and research has been on the individual, asking them to change, from a normalisation perspective, and fit into the labour market as it stands. Therefore the systemic structural change required in either the labour market or legislation relating to good employment is at risk of being overlooked. This risk is not only experienced for people with IDD but for all those who are unemployed and requiring additional support to enter the labour market as highlighted by Jordon (2018). Furthermore, policy and practice has too great an emphasis on individual forms of resilience and not enough on ecological factors that are influenced by larger mechanistic change.

Crucially, another factor that continues to reverberate in current policy is ‘work for all’ as a principle (DWP and DH, 2017). Although this research has not addressed this question directly, the findings inherently challenge this aspiration. The collaborators in this research were not representative of the diverse needs of people with an intellectual and developmental disability in that it is likely that they would all have had a mild intellectual impairment as defined by WHO (2019). It appears, therefore, that although the sample was very small, it is only people with IDD who have the ability, with the appropriate support and adjustments, to fit

into the existing labour market, who can access work as it stands. Additionally, as evident in the research findings, the three collaborators who had found ‘a good fit’ in their job had multiple experiences of not being successful in a workplace and role, where the right synergy between working environment, role and capabilities had not been possible. Nevertheless, it is important to acknowledge that jobs as they exist in an open labour market are not devised for people with an IDD, namely, the adaptations and reasonable adjustments required to the role can only be sought once a job has been secured. Therefore, I would agree with Johnson et al. (2013) and Wilson (2003), that a ‘re-think’ is required in relation to the nature of work. This re-think would include the principles of normalisation being challenged within current policy, with people with IDD not being asked to do the same job as their non-disabled colleagues. Instead, it would focus on devising jobs for people with IDD and would emphasise a shift in the nature of ESPs, employer support and the working environments. The features involved in the changes suggested for ESPs are detailed below. However, more knowledge is required concerning what makes good employers and good working environments. Although change in this area is an ambitious aspiration, employer commitment to it might be of wider benefit if it is more fully understood and reflected in legislation. Potentially all people in employment might benefit, in acknowledgment of Shakespeare and Watson’s (2002) assertion that we all are impaired.

Inherent in the collaborators’ narratives was the protracted journey towards paid employment, which involved navigating complex systems of support, managing disappointment, rejection and multiple cyclical barriers. These negative experiences of the collaborators were not only associated with the labour market as a whole but paradoxically, services that were purported to be specialist often appeared to be ‘unsupportive’ or ineffective. Nevertheless, examples of positive personalised support were highlighted in the narratives, demonstrating that the right support is achievable. Features of this support included the importance of being ‘for’ the person, which is defined here as listening and responding creatively to the person rather than following a process. The examples of good personalised support in the findings revealed evidence of identifying and supporting the removal of barriers within the social, cultural and physical working environment. It meant adapting job roles, finding supportive employers and peers and knowing the person’s needs, in addition to providing ongoing support to the person in the work setting. Furthermore, evident in the narrative was the presence of positive

personal relationships between the person and worker, where good support had been provided. I acknowledge that good work support takes time and does not fit with a labour market that is often measured purely on numerical outcomes or funded through payment by results. However, it is clear that this is the nature of the support that is needed for people with IDD and that stopping short of this has the potential to lead to unnecessary failure in the workplace and to add to a negative employment cycle. Insight and learning gained from the processes applied in complex interventions research (Moore et al., 2015) may equally be of benefit for consideration in policy and service redesign.

### **Recommendations – policy and service redesign**

- Work for people with an IDD needs to be rethought in policy and the labour market. A model should be considered, potentially based on principles of complex intervention, which allows a re-think of jobs and workplaces so that they are supportive of people with an IDD and others who require additional support in recruitment and retention to the labour market.
- Current research and evaluation of services should address, through partnership working with people with IDD, the deficit of knowledge surrounding the quality of good employment support, good employers, and good working environments for people with IDD, in order to build ecological resilience.
- Providers of employment support services are encouraged to review their current provision of support, and where possible address their role in identifying and supporting the removal of barriers, building their skills and being ‘for’ the individual.

## **8.5 The contribution to inclusive research methods**

The creative collaborative partnership method was devised with the key aim of supporting the collaborators within the research process in telling and sharing their work stories with others. In Chapter 4, details were given of the application of this method and the process of engagement between the photographer, the collaborator and the researcher in telling the person's work story. The original contribution to knowledge of this method will be discussed primarily in relation to its role in supporting doing research inclusively, the role of the visual and narrative in the work stories and its application within a hermeneutic phenomenological methodology.

A central premise of inclusive research aims to change the dynamic between the researcher and subjects of research, towards a method of working *with, by or for* the person rather than *on* them (Nind, 2014, p.3). Within the creative collaborative partnership, the potential of the research collaborators to be involved and take control was increased in a number of ways. Firstly, the partnership supported the collaborators' communication. As a therapist, I recognised that written and verbal communication are not necessarily strengths for people with an IDD, that they are only one aspect of communication which also relies on the non-verbal and environmental cues where the interaction takes place. In this respect, including a mode of visual communication supported the person's potential to share a different aspect of their story and helped the researcher to gain an increased appreciation of their experience. This led, I believe, to an opportunity to share a perspective which may otherwise have remained hidden, in addition to highlighting what the collaborators felt was an important experience in their story. Moreover, it facilitated additional choices, decision-making and control in the research process through requiring consistent clarification to questions, for example, did they wish to be physically in the pictures? What did they want to photograph? Did they want to take the photographs themselves? Did they wish to take images in their workplace or not? Furthermore, the visual choices also served as a means for the photographer and I to confirm and clarify decisions in a tangible way but also to facilitate discussion. This discussion included topics such as levels of self-disclosure, checking for continued consent at each stage, e.g., making photos, exhibiting. In this way, having tangible objects to discuss and events to be included in supported the collaborators to exert control over the content and outcome of their participation. Furthermore, the partnership increased the amount

time available for the collaborators, photographer and me to build a rapport and share experiences that supported the partnership. The amount of time and number of meetings with each individual was dictated by that individual, therefore was variable as outlined in Chapter 5.

The method of the creative collaborative partnership also supported the research aim of giving ‘voice’ to the collaborators’ stories through supporting dissemination and having potential to influence social change. In the public exhibition of the work stories, which all collaborators chose to take part in, an audience was gained to hear and view their stories. In this respect the visuals, as experienced in the exhibition, acted as an invitation that drew people into the collaborators’ stories and encouraged them to stop and pay attention. This is perhaps of increasing relevance within a competitive public sphere, where it can be difficult to find the space to have your voice heard. However, the potential impact of the exhibition in influencing social change is debatable and will be discussed further below. Nevertheless, the exhibition offered the opportunity for the research to reach an audience beyond the academic and occupational therapy practice world.

A feature of this method that required consideration throughout the research process, but most significantly during the dissemination activity, was the fact that the narrative and visual features of the work stories were separate entities. Within phenomenology debates exist relating to the value ascribed to artistic versus scientific elements (Finlay, 2012). Central to the premise of the creative collaborative partnership in this research was the aim to create a work story with each research collaborator inclusive of both the visual images (or video in Tabitha’s case) and the person’s narrative. The two parts of the story as shared in Chapter 5 of this thesis and the exhibition and exhibition catalogue (Ramsey, 2018) were created to be viewed jointly. Nevertheless, during the exhibition and other dissemination activities there was an appreciation that the visuals would be viewed, at times, in isolation from the written narratives, even when they were both available. In considering this reflexively I was drawn to the conception of the image as part of the knowledge generated in the findings, and the interplay between the image and our experience of it visually, in addition to our discussion of it verbally (Pink, 2013). The visual component of the work story sought to elicit a different kind of information to the narrative, to expand the viewers’ appreciation of the story and the experience of the collaborator engaging in work as a phenomenon. In viewing the images separately to the narratives, the person’s experience of work is

still communicated, but crucially only in part. Although it is understood that research by its very nature is summarised throughout the dissemination process, whether this is during a short presentation, the creation of key findings or a peer reviewed article, it is anticipated that a distilling of the essential findings and their implications occurs. The challenge of sharing the visual component of the work stories alone was initially viewed as a limitation. The visual images were constructed not to distil the essence of the findings but as part of a whole in the context of the person's life and occupational narrative specifically. Nevertheless, during the dissemination process and in discussion with the research collaborators, the images were found to support inclusive dissemination creatively. This has occurred most significantly, for example, in sharing the research findings through presentations, where part or all of one person's narrative has been shared through recording an audio of the narrative or questions and answers about their journey and playing their images alongside it. In this respect it is my belief that the images and film have supported the audience to listen and engage in the research collaborators' experience of work as a phenomenon.

The creative collaborative partnership method was also found to be compatible with hermeneutic phenomenology as a methodology and critical realist assumptions. Hermeneutic phenomenology focuses on the interpreted lived experience of the individual and having increased time and creativity in communicating the lived experience enabled the person's work story to be fully told. Similarly, the acknowledgement of the intersubjective experience allowed mechanisms for supporting the three-way relationship between the collaborator, researcher and photographer. In this respect it contributed to a relational unfolding of knowledge and supported phenomenology's commitment to a multi-voiced perspective (Finlay, 2012).

As a central premise phenomenology is concerned with illuminating the aspects of the experience of work as a phenomenon. This method facilitated the capacity of the collaborators to be part of the unveiling of the hidden and enabled this to be witnessed by people engaging with the findings. Additionally, the visuals allowed a different way of communicating the complexity of the lived experience of work as a phenomenon and offered concrete references beyond the narrative, supporting critical realist assumptions in grounding the reality of the person's experience. Finally, the reflexive position I held and the adoption of the phenomenological attitude by the photographer and me helped in challenging our perceptions,

assumptions and biases. There were also limitations associated with applying this method and these will be discussed below.

## **Recommendations - inclusive research methods**

- The creative collaborative partnership method provides an original contribution to knowledge in working with a photographer to devise a visual component to the data gathering process when collaborating with people with IDD. It offers support in communicating and building a rapport with the research collaborator in addition to assisting with storytelling and dissemination.
- The creative collaborative partnership supports doing research inclusively with people with IDD through allowing increased opportunities for the research collaborators to exercise control, use visual means of communication and create tangible outcomes for discussion and dissemination.
- This creative collaborative partnership can support ethical considerations and transparency with research collaborators through ensuring ongoing consent, agreement on levels of disclosure and ownership.
- The creative collaborative partnership appears to be a good fit with a hermeneutic phenomenological methodology, as it aids the revealing of hidden features of the phenomena, the interpretivist position, opportunities for intersubjectivity and fusion of horizons to occur and it also supports both the art and science elements.

## **8.6 The limitations of the research**

In this section, the limitations of the study will be discussed in relation to the creative collaborative partnership, specifically addressing issues relating to the role of the researcher, collaborator diversity and inclusive research principles. Firstly, in terms of collaborator diversity, the individuals who consented to take

part in the research included only those people with a mild ID or DD, therefore no one took part in the study who had significant physical impairments or a moderate to severe ID. During the recruitment process I asked the work consultants to approach people with higher levels of need, but it was unclear whether they had approached people who refused participation or whether the ESP only saw people with lower support needs, in keeping with the findings of the literature discussed previously.

A principal limitation in applying the creative collaborative partnership involved the time and funding required to support this method. Within this project a grant was secured which paid for the photographer's time and the collaborators' and researcher's expenses, as well as the exhibition and catalogue costs. This limitation might be addressed in many ways: costs could be reduced through exploring potential partnership with art students or seeking online platforms for dissemination of research findings rather than exhibiting the work stories. However, it is anticipated that even if these adjustments were made, some costs would be incurred in supporting the data gathering process with the collaborators, researcher and photographer. Similarly, the degree of time investment required by the collaborators, photographer and researcher was substantial, for example, Mark's request for photographs in all his work settings led to six meetings taking place in addition to the group meeting, all of which involved lengthy travel time. As this research sought to adhere to inclusive research principles, an expectation of increased time investment was anticipated (Nind, 2014) and deemed as vital to the collaborative research process. However as a researcher, I was very aware of the cost in time for the collaborators to engage in the research and the fact that they did not receive payment while the photographer did. Consideration was given to paying participants beyond the voucher, but this was not applied due to the complexity implicit in the careful financial balance between the participants' pay and receipt of benefit.

When considering the limitations of the creative collaborative partnership in relation to the broader study, the influence of the researcher and photographer requires consideration. I was aware of the power implicit in my position as a health professional alongside my role as a student. I was also aware of the power influence from the photographer being there and the risk of their involvement potentially undermining the collaborator's voice. Furthermore, I was aware of the potential influence of a three-way relationship, where the

collaborator was literally outnumbered in person during the meetings. This was consciously acknowledged throughout the process and explicitly explored in Chapter 4 and when establishing ethical approval for the project. Features that addressed this limitation were primarily linked to the reflexive position and phenomenological attitude applied by both the researcher and photographer. These were to hold a position of enquiry as well as being 'for' the collaborators in telling their story, in line with the inclusive research principles. It was of crucial importance that the photographer adopt these positions, not only in supporting the research goal of seeking the collaborator's voice, but also in avoiding the artwork being a literal representation of the person in their work setting. The photographer was able to support the interpretivist position and was equally open to reflexively reflecting in discussions about their own potential bias, i.e., the nature of collaborative co-creation versus solo creation in terms of ownership of the image. A question that was consistently raised in my reflexive diary related to my desire to hear the voice of the collaborators. I wondered how much we (the photographer and I) were influencing the voice being heard? I was obviously aware of holding an interpretivist perspective and through the reflexive process I owned the fact that I had influenced the collaborators' stories, in that even with the same questions someone else would, to some extent, have elicited a different story. However, a question that consistently stayed with me, particularly in working with the collaborators whose verbal and written skills were limited, was the extent of the influence, despite the safeguards of reflexivity and consistency in the application of the method. In this respect, I acknowledge the fact that any knowledge co-produced in this research is 'contingent, proportional, emergent and subject to alternative interpretations' (Finlay, 2012, p.32).

Discussion pertaining to the ownership of the work stories also occurred with the collaborators. The collaborators were aware that they directed and owned their work stories, but I as researcher owned the PhD thesis. Comprehensive consideration was required in dialogue with the photographer about her role and ownership as the image maker. Even in Jo's case, although he took the images, the photographer through discussion with him created a visual image of the multiple images representing 'a day in my working life'. In discussion with each collaborator separately, we agreed that while the photographer would be named as taking the image / video / creating the image physically, they would own the image; therefore, as they owned the image, only they could give permission for its use.

A key feature of inclusive research includes the premise that the collaborators are involved in all parts of the research process. A challenge within this study was enabling the facilitation of group meetings. Firstly, the intended initial group meeting was cancelled due to differences in the timing of the collaborators who had come forward to engage in the research. I did not wish to delay commencement of the research with individuals once consent was gained. Similarly, the facilitation of the group meeting at the end of data collection to share the stories and discuss the exhibition and the narrative frames was a challenge to facilitate. This was due to the diverse timings of everyone's work, including that of the photographer and researcher, the diverse geography of their living and workplaces, their levels of independence in travelling to a venue and their confidence in meeting with others. In the single group meeting, all collaborators were able to attend which, as discussed, was positive and valuable in gaining feedback relating to all the areas specified above. Notwithstanding the geographical and practical issues involved in establishing group meetings, I believe the research would have benefitted from further opportunities to meet as a group to discuss the collective findings and recommendations further, including reviewing the easy read findings and commencing consultation on the My Work Plan. However, the focus of the research was on individual collaboration and recruitment to the research was conducted with individuals, including collaborators, being offered the option not to share their stories beyond the researcher etc. In this respect, if the wish had been to gain a fully engaged collective voice beyond the joint exhibition and discussion of the narrative frames, a redesign of the research method would have been required.

Many researchers struggle to resolve the tension that exists between research which is rigorous, acceptable to funding organisations and publishable, and research which is of use to the people who are subject to it, which is relevant to their needs and can inform and promote needed social change. A resolution of this tension is probably not possible. Rather it is met anew with each study and involves a continual process of balancing and compromise. It is a 'big ask' to be both reputable and helpful – and it is not enough. (Walmsley and Johnson, 2003, p.9)

A final limitation or challenge contained in the quotation above and highlighted in the introduction to this research, is balancing the requirements of publishable research alongside the needs and aims of people with IDD in research. A primary

aim of this study was to establish the voice of the collaborator in their experience of paid work, which was achieved through the collaborators' work stories in Chapter 5. However, moving beyond the collaborators' stories to the narrative frames and recommendations, I've been aware that in summarising them there is a risk of losing the 'voice' of the research collaborators. Consequently, a consistent effort has been made to ensure the inclusion of each collaborator's whole story, principally through the public exhibition and exhibition catalogue (Ramsey, 2018). This has additionally been addressed through the easy read summary (Appendix 13) and through collaborators being collectively directly involved, although not outside of the exhibition, in dissemination activity (Appendix 4). Nevertheless, I acknowledge the research's limited influence as a PhD study on delivering social change.

## 8.7 Summary

This research has addressed a gap identified in the literature relating to hearing the experiences of people with an IDD in paid employment. The collaboration with Jo, Ruth, Mark, Tabitha, Jennifer and Kenneth and their individual work stories illuminate their experience of finding and being in paid employment. Furthermore, the five narrative frames that emerged from the collective consideration of the work stories further contributes to the knowledge base relating to the experience of work for people with IDD, including 'the quest to do', 'finding a good fit', 'navigating bureaucratic seas', 'finding both friend and foe' and 'forging of identity'.

Within this concluding chapter, the unique contribution of this research has been outlined in relation to the learning held in the collaborators' work stories and narrative frames for people with IDD, policy and service redesign, occupational therapists and other people working to support people with IDD in employment. Furthermore, the contribution of the creative collaborative partnership method was discussed alongside the limitations of the research.

In summary, the research findings have promoted the importance of the first-person occupational narrative in illuminating the experience of people with IDD in paid employment. Central to the recommendations is that these stories, and those of the people with IDD going to employment services, are heard by people devising policy and services, as well as by individuals paid to support people with

IDD, including occupational therapists. As well as hearing the person, the worker supporting them is recommended to work in partnership, providing personalised support that recognises and addresses the barriers they face. This thesis highlights the polarised focus on the individual with IDD in the research and policy surrounding work and the deficit of knowledge relating to the quality of good policy, good employment support, good employers, and good working environments for people with IDD. This needs to be addressed to support the building of mechanisms that promote ecological resilience and greater attention should be given to these features in future work-related research.

The learning held within the work stories and narrative frames recommends that acknowledgement is given to the individuals story as political and the barriers they face, supporting the person to have the chance to ‘act’ in the public sphere. It outlines what constitutes a good and poor fit in work and suggests that anyone supporting the person with IDD into employment seeks to establish a supportive social working environment as a priority. Finally, I encourage occupational therapists to reflect on the paradigm they employ in their practice in working with people with an IDD. I recommend they ensure that alongside being occupationally focused, occupational identity, including the political, occupational competence and the impact of the environment, have equal consideration in their work. The My Work Plan once subject to consultation and validation may support occupational therapists to apply this learning in practice and in partnership with the person with IDD, their network and ESP, where work is an identified goal.

## References

Andrews. M., Squire, C. and Tamboukou, M. (2013) 'Introduction, what is narrative research' in Andrews. M, Squire, C. and Tamboukou, M. (ed.) *Doing narrative research*. 2<sup>nd</sup> Edition, London: Sage, pp.1-26.

Angus, J. E. (2011) 'Using critical realism in nursing and health research: promise and challenges', *Nursing Inquiry*, 19, pp. 1-3.

Akkerman, A., Janssen, C. G. C., Kef, S. and Meininger, H. P. (2014) 'Perspectives of employees with intellectual disabilities on themes relevant to their job satisfaction. An explorative study using photovoice', *Journal of Applied Research in Intellectual Disabilities*, 27, pp. 542-554.

Akkerman, A., Janssen, C. G. C., Kef, S. and Meininger, H. P. (2016) 'Job satisfaction of people with intellectual disabilities in integrated and sheltered employment: an exploration of the literature', *Journal of Policy and Practice in Intellectual Disabilities*, 13, pp. 205-216.

Allen, H. and Fuller, E. (2016) 'Beyond the feeble mind: foregrounding the personhood of inmates with significant intellectual disabilities in the era of institutionalisation', *Disability Studies Quarterly*, 36(2). Available at: <http://dsq-sds.org/article/view/5227/4301> (Accessed July 2018).

Arendt, H. (1958) *The human condition*. New York: Doubleday.

Atkinson, D., Williams, F. and the Open University (1990) *Know me as I am: an anthology of prose, poetry and art by people with learning difficulties*. London, Hodder and Stoughton in association with the Open University.

Atkinson, D. and Walmsley, J. (2010) 'History from the inside: towards an inclusive history of intellectual disability', *Scandinavian Journal of Disability Research*, 12(4), p.273-286.

Banks, P., Jahoda, A., Dagnan, D., Kemp, J. and Williams, V. (2010) 'Supported

employment for people with intellectual disability: the effects of job breakdown on psychological well-being', *Journal of Applied Research in Intellectual Disabilities*, 23, pp. 344-354.

Bambura, C. (2011) *Work, worklessness, and the political economy of health*. Oxford: Oxford University Press.

Bates, K., Goodley, D. and Runswick-Cole, K. (2017) 'Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity', *Disability and Society*, 32, pp. 160-175.

Beyer, S., Brown, T., Akandi, R. and Rapley, M. (2010) 'A comparison of quality of life outcomes for people with intellectual disabilities in supported employment, day services and employment enterprises', *Journal of Applied Research in Intellectual Disabilities*, 23, pp. 290-295.

Bhaskar, R. (1997) *A realist theory of science*, London: Verso.

Bigby, C., Wilson, N. J., Balandin, S. and Stancliffe, R. J. (2011) 'Disconnected expectations: staff, family, and supported employee perspectives about retirement', *Journal of Intellectual Developmental Disabilities*, 36, pp. 167-74.

Bjornsdottir, K. and Svensdottir, A. S. (2008) 'Gambling for capital: learning disability, inclusive research and collaborative life histories', *British Journal of Learning Disabilities*, 36, p. 263-270.

Blustein, C. L., Carter, E. W. and McMillan, E. D. (2016) 'The voices of parents: post-high school expectations, priorities, and concerns for children with intellectual and developmental disabilities', *The Journal of Special Education*, 50(3), pp. 164-177.

Booth, A., Sutton, A. and Papaioannou., D. (2016) *Systematic approaches to a successful literature review*. 2<sup>nd</sup> edition. London: Sage.

Booth, T. and Booth, W. (2003) 'In the Frame: Photovoice and mothers with earning difficulties', *Disability and Society*, 18(4), pp. 431-442.

Boyce, M., Secker, J., Johnson, R., Floyd, M., Grove, B., Schneider, J. and Slade, J. (2008) 'Mental health service users' experiences of returning to paid employment', *Disability and Society*, 23(1), pp. 77-88.

Bush, K. L. and Tasse, M. J. (2017) 'Employment and choice-making for adults with intellectual disability, autism and down syndrome', *Research in Developmental Disabilities*, 65, p. 23-34.

Butterworth, J., Migliore, A., Nord, D and Gelb, A. (2012) 'Improving the Employment Outcomes of Job Seekers with Intellectual and Developmental Disabilities: A Training and Mentoring Intervention for Employment Consultants', *Journal of Rehabilitation*, 78(2), pp. 20-29.

Caelli, K. (2001) 'Engaging with phenomenology: is it more of a challenge than it needs to be?', *Qualitative Health Research*, 11, pp. 273–281.

Cameron, J. and Hart, A. (2007) 'Ethical issues in obtaining informed consent for research from those recovering from acute mental health problems', *Research Ethics Review*, 3(4) pp. 127-129.

Cameron, J., Walker, C., Hart, A., Sadlo, G. and Haslam, I. (2012) 'Supporting workers with mental health problems to retain employment: users experience of a UK job retention project', *Work*, 42(4), pp. 461-471.

Cameron, J., Sadlo, G., Hart, A. and Walker, C. (2016) 'Return to work support for employees with mental health problems: identifying and responding to key challenges of sick leave', *British Journal of Occupational Therapy*, 59(5), p. 275-283.

Catalani, C. and Minkler, M. (2010) *Photovoice: A review of the literature in health and public health*. Los Angeles, CA: SAGE Publications.

Cluley, V. (2017) 'Using Photovoice to include people with profound and multiple learning disabilities in inclusive research', *British Journal of Learning Disabilities*, 45, pp. 39-46.

Coakley, K. and Bryze, K. (2018) 'The distinct value of occupational therapy in supported employment of adults with intellectual disabilities', *The Open Journal of Occupational Therapy*, 6(2), pp. 1-16. doi.org/10.15453/2168-6408.1424

College of Occupational Therapy (2007) *Work matters: vocational navigation for occupational therapy staff*. Great Britain. College of Occupational Therapy.

Conroy, J. W., Ferris, C. S. and Irvine, R. (2010) 'Microenterprise options for people with intellectual and developmental disabilities: an outcome evaluation', *Journal of Policy and Practice in Intellectual Disabilities*, 7, pp. 269-277.

Cooper, C. L. and Lu, L. (2019) 'Excessive availability for work: good or bad? Charting underlying motivations and searching for game-changers', *Human Resources Management Review*, 29, pp. 1-13. Available at: <https://doi.org/10.1016/j.hrmr.2019.01.003>. (Accessed: 1 September 2019)

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. and Petticrew, M. (2008) 'Developing and evaluating complex interventions: the new Medical Research Council guidance', *British Medical Journal*, 337, pp. 1-6 Available at: <https://www-bmj-com.ezproxy.brighton.ac.uk/content/bmj/337/bmj.a1655.full.pdf> (Accessed: 1 September 2019)

Craig, D. and Bigby, C. (2015) 'Critical realism in social work research: examining participation of people with intellectual disability', *Australian Social Work*, 68(3), pp. 309-323.

Crow, L. (2014) 'Scroungers and superhumans: Images of disability from the summer of 2012: a visual inquiry', *Journal of Visual Culture*, 13, pp. 168-181.

Crowther, S., Ironside, P., Spence, D. and Smythe, L. (2017) 'Crafting stories in hermeneutic phenomenology research: a methodological device', *Qualitative Health Research*, 27, pp. 826-835.

Danermark, B., Ekstrom, M., Jackobsen, L. and Karlsson, J. C. (2002) *Explaining*  
255

society: critical realism in the social sciences. Abingdon: Routledge.

Denzin, N. K. (2014) *Interpretive autoethnography*. London. Sage.

Deacon, J. (1974) *Joey, an unforgettable story of human courage*. London.

Charles Scribner's Sons.

De Botton, A. (2009) *The pleasures and sorrows of work*. London: Penguin books Ltd.

Dempsey, I. and Ford, J. (2008) 'Employment for people with intellectual disability in Australia and the United Kingdom', *Journal of Disability Policy Studies*, 19, pp. 233-243.

*Mental Capacity Act 2005 code of practice*. (2007) Department of Constitutional Affairs. London: TSO. [L  
SEP]

Department of Health (2001) *Valuing people: a new strategy for learning disability for the 21st Century*.

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/250877/5086.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf). (Accessed: 5 January 2016).

Department of Health (2009a) *Valuing people now: the delivery plan. 'Making it happen for everyone'*; London: H M Government.

[https://webarchive.nationalarchives.gov.uk/20130105063552/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093377](https://webarchive.nationalarchives.gov.uk/20130105063552/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377) (Accessed: 5 January 2016).

Department of Health (2009b) *Valuing employment now: real jobs for people with learning disabilities*. London. H M Government.

[https://www.legislation.gov.uk/ukia/2009/179/pdfs/ukia\\_20090179\\_en.pdf](https://www.legislation.gov.uk/ukia/2009/179/pdfs/ukia_20090179_en.pdf)  
(Accessed: 5 January 2016).

Department of Health (2018) *Adult Social Care Outcomes Framework*. London. H M Government. [L  
digital. <https://digital.nhs.uk/data-and>

information/publications/clinical-indicators/adult-social-care-outcomes-framework-  
ascof/current (Accessed: 1 June 19).

Department of Health (2012b) *Transforming care: a national response to Winterbourne View Hospital*. Department of Health review: final report. London. H M Government.

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf) (Accessed: 5 January 2016).

Department of Health (2015) *Transforming care for people with learning disabilities – next steps*. London. H M Government. <https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf> (Accessed: 5 January 2016).

Department of Work and Pensions and Department of Health (2017) *Improving lives – the future of work, health and disability*. London: DWP and DH. Available at:

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/663399/improving-lives-the-future-of-work-health-and-disability.PDF](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/663399/improving-lives-the-future-of-work-health-and-disability.PDF). (Accessed: 4 January 2018)

Disability Discrimination Act. (1995) London: HMSO.

Di Tommaso, A., Isbel, S., Scarvell, J. and Wicks, A. (2016) 'Occupational therapists' perceptions of occupation in practice: an exploratory study', *Australian Occupational Therapy Journal*, 63(3), pp. 206–213.

Edgerton, R. B. (1967) *The cloak of competence, stigma in lives of people with learning disabilities*. Berkeley: University of California Press.

Ellenkamp, J. J., Brouwers, E. P., Embregts, P. J., Joosen, M. C. and Van Weeghel, J. (2016) 'Work environment-related factors in obtaining and maintaining work in a competitive employment setting for employees with intellectual disabilities: a systematic review', *Journal of Occupational Rehabilitation*, 26, pp. 56-69.

Equality Act (2010) London: HMSO.

Finlay, L and Gough, B. (2003) *Reflexivity: a practical guide to researchers in health and social sciences*. Oxford: Blackwell Science.

Finlay, L. (2006) 'Going exploring': The nature of qualitative research', in Finlay, L. and Ballinger, C. (ed.) *Qualitative research for allied health professionals: challenging choices*. Chichester: John Wiley, pp. 3-8.

Finley, L. (2012) 'Debating phenomenological research methods', in Friesen, N, Henriksson, C, and Saevi, T. (ed.) *Hermeneutic phenomenology in education, method and practice*. Sense Publisher, pp.17-39. Available at: <https://www.sensepublishers.com/media/1552-hermeneutic-phenomenology-in-education.pdf>. (Accessed: 30 August 2019).

Finlay, L. (2011) *Phenomenology for therapists: researching the lived world*. Chichester: Wiley-Blackwell.

Fletcher, A. J. (2017) 'Applying critical realism in qualitative research: methodology meets method', *International Journal of Social Research Methodology*, 20(2), pp. 181-194.

Flores, N., Jenaro, C., Begona Orgaz, M. and Victoria Martin, M. (2011) 'Understanding quality of working life of workers with intellectual disabilities', *Journal of Applied Research in Intellectual Disabilities*, 24, pp. 133-141.

Flynn, R. J. and Lemay, R. A. (1999) *A quarter-century of normalization and social role valorization: evolution and impact*. Prescott-Russell Children's Aid Society, University of Ottawa Press. Available at: <https://www-jstor-org.ezproxy.brighton.ac.uk/stable/j.ctt1cn6s45?pq-origsite=summon>. (Accessed: 30 August 2019)

Forrester-Jones, R., Jones, S., Heason, S. and Di'terlizzi, M. (2004) 'Supported employment: a route to social networks', *Journal of Applied Research in Intellectual Disabilities*, 17, pp. 199-208.

Gadamer, H. G. (1975) *Truth and method*. London: Sheed and Ward. (Second  
258

revised edition originally published in German in 1965).

Gilson, C. B., Carter, E. W., Bumble, J. L. and McMillan E, D. (2018) 'Family perspectives on integrated employment for adults with intellectual and developmental disabilities', *Research and Practice for Persons with Severe Disabilities*, 43(1), pp. 20-37.

Giorgi, A. (1994) 'A phenomenological perspective on certain qualitative research methods', *Journal of Phenomenological Psychology*, 25, pp. 190-220.

Goodley, D. (2005) 'Empowerment, self-advocacy and resilience', *Journal of Intellectual Disabilities*, 9(4), pp. 333-343.

Goodson, I. (2006) 'The rise of the life narrative', *Teacher Education Quarterly*, 33(4), pp. 7-21.

Hall, S. M. (2018) *The personal is political – feminist geographies of/in austerity. Geoforum*. Available at: <https://doi.org/10.1016/j.geoforum.2018.04.010> (Accessed: 20 September 2019).

Hanisch, C. (1970) 'The personal is political', in: Firestone, S., Koedt, A (ed.), *Notes for the Second Year*. New York: Radical Feminism, pp. 76-78.

Hannes K. (2011) 'Critical appraisal of qualitative research', in: Noyes, J., Booth, A., Hannes, K., Harden, A., Harris, J., Lewin, S. and Lockwood C. (ed.) *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions*. Version 1 (updated August 2011). Cochrane Collaboration Qualitative Methods Group. Available at: <http://cqrmg.cochrane.org/supplemental-handbook-guidance> (Accessed: 2 February 2016).

Hart, A., Gagnon, E., Eryigit-Madzwamuse, S., Cameron, J., Aranda, K., Rathbone, A. and Heaver, B. (2016) 'Uniting resilience research and practice with an inequalities approach', *SAGE Open*, 6 (4), pp. 1-15.

Hart, A., Heaver, B., Brunnberg, E., Sandberg, A., Macpherson, H., Coombe, S. and Kourkoutas, E. (2014) 'Resilience-building with disabled children and young

people: a review and critique of the academic evidence base', *International Journal of Child, Youth and Family Studies*, 5(3), pp. 394-422.

Harper, D. (2002) 'Talking about pictures: a case for photo-elicitation', *Visual studies*, 17(1), pp. 13-26.

Heidegger, M. (1962) *Being and time*. Translated by J. Macquarrie and E. Robinson. Oxford: Blackwell Publishing. (Original work published 1927).

Herd, D., Mitchell, A. and Lightman, E. (2005) 'Rituals of degradation: administration as policy in the Ontario Works Programme', *Social Policy and Administration*, 39(1), pp. 65–79.

Heslop, P., Blair, P. S., Fleming, P. J., Hoghton, M. A., Marriott, A. M. and Russ, L. S. (2013) *Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD): final report*. Norah Fry Research Centre. Bristol.

Hocking, C. (2017) 'Occupational justice as social justice: The moral claim for inclusion', *Journal of Occupational Science*, 24(1), pp. 29-42.

Holloway, I. and Galvin, K. (2017) *Qualitative Research in Nursing and Healthcare*. 4<sup>th</sup> edition. Chichester: Wiley Blackwell.

Holwerda, A., Van Der Klink, J. J., De Boer, M. R., Groothoff, J. W. and Brouwer, S. (2013) 'Predictors of work participation of young adults with mild intellectual disabilities', *Research in Developmental Disabilities*, 34, pp.1982-90.

Humber, L. A. (2014) 'Social inclusion through employment: the marketisation of employment support for people with learning disabilities in the United Kingdom', *Disability and Society*, 29, pp. 275-289.

Husserl, E. (1970) *Logical Investigations*, (2 vols.) Translated by J. N. Findlay. New York: Humanities Press.

Inclusion London (2013) *UK Disabled People's Manifesto: Reclaiming our futures. London.* <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UK-Disabled-People-s-Manifesto-Reclaiming-Our-Futures.pdf> (Accessed: 9 June 2014).

Ineson, R. (2015) 'Exploring paid employment options with a person with severe learning disabilities and high support needs: an exploratory case study', *The British Journal of Occupational Therapy*, 78(1), pp. 58–65<sup>[11]</sup>

Ison, N., Cusick, A. and Bye, R. A. (2014) 'Techniques to tell the real story, narrative enquiry in health services research', *BMC, Health Services Research*. 14(22), pp. 22.

Iriarte, G E., O'Brien, P., McConkey, R., Wolfe, M. and O'Doherty, S. (2014) 'Identifying the key concerns of Irish persons with intellectual disability', *Journal of Applied Research in Intellectual Disabilities*, 27, pp. 564-575.

Jahoda, A., Kemp, J., Riddell, S. and Banks, P. (2008) 'Feelings about work: a review of the socio- emotional impact of supported employment on people with intellectual disabilities', *Journal of Applied Research in Intellectual Disabilities*, 21, pp. 1-18.

Jansson, I. and Wagman, P. (2017) 'Hannah Arendt's Vita Activa: A valuable contribution to occupational science', *Journal of Occupational Science*, 24(3), pp. 1-12.

Johnson, R. L., Floyd, M., Pilling, D., Boyce, M. J., Grove, B., Secker, J., Schneider, J. and Slade, J. (2009) 'Service users' perceptions of the effective ingredients in supported employment', *Journal of Mental Health*, 18(2), pp. 121-128.

Johnson, K., Walmsley, J. and Wolfe, M. (2010) *People with intellectual disabilities, towards a good life?* Bristol: The Policy Press.

Jurkowski, J. M. (2008) 'Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development', *Intellectual and developmental disabilities*, 46, pp. 1-11.

Kahlin, I. and Haglund, L. (2009) 'Psychosocial strengths and challenges related to work among persons with intellectual disabilities', *Occupational Therapy in Mental Health*, 25, pp. 151–163.

Kang, Y., Nye-Lengerman, K. K. and Nord, D. (2019) 'Weekly wage exploration of vocational rehabilitation service recipients: a quantile regression approach', *Journal of Rehabilitation*, 85(1), p. 4-14.

Kennedy-Jones, M., Cooper, J. and Fossey, E. (2005) 'Developing a worker role: stories of four people with mental illness', *Australian Occupational Therapy Journal*, 52, p. 116-126.

Kober, R. and Eggleton, I. R. C. (2005) 'The effect of different types of employment on quality of life', *Journal of Intellectual Disability Research*, 49, p. 756-760.

Koch, T. and Kralik, D. (2006) *Participatory action research in healthcare*. Oxford, Blackwell.

Li, E. P. Y. (2004) 'Self-perceived equal opportunities for people with intellectual disability', *International Journal of Rehabilitation Research*, 27, p. 241-245.

Lillywhite, A., Haines, D. and the College of Occupational Therapy (2010) *Occupational therapy and people with learning disabilities: findings from a research study*. London: College of Occupational Therapy.

Lindstrom, L., Hirano, K. A., McCarthy, C. and Alverson, C. Y. (2014) 'Just having a job: career advancement for low-wage workers with intellectual and developmental disabilities', *Career Development for Exceptional Individuals*, 37, pp. 40-49.

Lopez, K. A. and Willis, D. G. (2004) 'Descriptive versus interpretive phenomenology: their contributions to nursing knowledge', *Qualitative Health Research*, 14, pp. 726-735.

Lund, S. K. and Light, J. (2006) 'Long-term outcomes for individuals who use

augmentative and alternative communication: Part I - what is a "good" outcome?", *Augmentative and Alternative Communication*, 22, pp. 284-299.

Lysaght, R., Šiska, J. and Koenig, O. (2015) 'International employment statistics for people with intellectual disability—the case for common metrics', *Journal of Policy and Practice in Intellectual Disabilities*, 12, pp. 112-119.

Lysaght, R., Cobigo, V. and Hamilton, K. (2012a) 'Inclusion as a focus of employment-related research in intellectual disability from 2000 to 2010: a scoping review', *Disability Rehabilitation*, 34, pp. 1339-50.

Lysaght, R., Ouellette-Kuntz, H. and Lin, C. J. (2012b) 'Untapped potential: perspectives on the employment of people with intellectual disability', *Work*, 41, pp. 409-22.

Machingura, T. and Lloyd, C. (2016) 'Mental health occupational therapy and supported employment', *Irish Journal of Occupational Therapy*, 45(1), pp. 52-57.

Macken, J. (2019) 'Work stress among older employees in Germany: Effects on health and retirement age', *PLoS One*. 12(4), pp. 1-13. Available at: <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0211487> (Accessed: 1 September 2019).

Mactaggart, I., Banks, L. M., Kuper, H., Murthy, G. V. S., Sagar, J. and Oye, J. (2018) 'Livelihood opportunities amongst adults with and without disabilities in Cameroon and India: a case control study', *PLoS ONE*, 13(4). Available at: e0194105. <https://doi.org/10.1371/journal.pone.0194105> (Accessed: 5 January 2019)

Martorell, A., Gutierrez-Recacha, P., Pereda, A. and Ayuso-Mateosa, J. L. (2008) 'Identification of personal factors that determine work outcome for adults with intellectual disability', *Journal of Intellectual Disability Research*, 52, pp. 1091-101.

McGlinchey, E., McCallion, P., Burke, E., Carroll, R. and McCarron, M. (2013) 'Exploring the Issue of Employment for Adults with an Intellectual Disability in Ireland', *Journal of Applied Research in Intellectual Disabilities*, 26, pp. 335-343.

Medical Research Council (2000). A framework for the development and evaluation of RCTs for complex interventions to improve health. London: MRC.

MENCAP (2007) *Death by Indifference*. London: Mencap. Available at: <https://www.mencap.org.uk/deathbyindifference> (Accessed: 11 January 2018).

MENCAP (2017) *Here I am campaign - understand me*. Available at: <https://www.mencap.org.uk/get-involved/campaign-mencap/here-i-am> (Accessed: 11 November 2017).

Melling, K. (2015) 'Is policy having an impact? Commentary on "A summary of government initiatives relating to employment for people with learning disabilities in England" ', *Tizard Learning Disability Review*, 20, pp. 166-169.

Melling, K., Beyer, S. and Kilsby, M. (2011) 'Supported employment for people with learning disabilities in the UK: the last 15 years', *Tizard Learning Disability Review*, 16, pp. 23-32.

Merleau-Ponty, M. (1995) *Phenomenology of perception*. Translated by C. Smith. London: Routledge and Kegan Paul.

Michael, J. (2008) *Healthcare for all: independent inquiry into access to healthcare for people with learning disabilities*. London: Aldrick Press.

Mitchell, C. (2011) *Doing visual research*. London, UK: Sage Publications.

Molineux, M. (2004) 'Occupation in occupational therapy: a labour in vain?', in Molineux, M. (ed.) *Occupation for occupational therapists*. Oxford: Blackwell Publishing, pp. 1–13.

Molineux, M. (2011) 'Standing firm on shifting sands', *New Zealand Journal of Occupational Therapy*, 58(1), pp. 21–28.

Monteleone, R. and Forrester-Jones, R. (2017) 'Disability means, um dysfunctioning people': a qualitative analysis of the meaning and experience of disability among adults with intellectual disabilities, *Journal of Applied Research in*

*Intellectual Disabilities*, 30, pp. 301-315.

Moore, C. L., Alston, R. J. and Feist-Price, S. (2002) 'Competitive employment and mental retardation: interplay among gender, race, secondary psychiatric disability, and rehabilitation services', *The Journal of Rehabilitation*, 68, p. 14.

Moore, G. F., Audrey, S., Barker, M., Bond, L., Bonnell, C., Hardeman, W., Moore, L., O'Cathain, A., Tinati, T., Wight, D. and Baird, J. (2015) 'Process evaluation of complex interventions. Medical Research Council guidance', *British Medical Journal*, 350, pp. 1-7. Available at: <https://doi-org.ezproxy.brighton.ac.uk/10.1136/bmj.h1258> (Accessed: 1 September 2019).

Moran, D. (2000) *Introduction to phenomenology*. New York and London: Routledge.

Moran, R. R., McDermott, S. and Butkus, S. (2001) 'Getting a job, sustaining a job and losing a job for individuals with mental retardation', *Journal of Vocational Rehabilitation*, 16, pp. 237-244.

Moustakas, C. (1994) *Phenomenological research methods*, Thousand Oaks, Calif and London: Sage.

Murphy, N. A. and Wibberley, C. (2017) 'Development of an academic identity through PhD supervision – an issue for debate', *Nurse Education in Practice*, 22, pp. 63-65.

Nord, D., Hamre, K., Pettingell, S. and Magiera, L. (2018) 'Employment goals and settings: effects of individual and systemic factors', *Research and Practice for Persons with Severe Disabilities*, 43(3), pp. 194-206.

Northway, R. (2018) 'Reflections on labelling and counting', *Journal of Intellectual Disabilities*, 22, pp. 3-4.

Nind, M. and Vinha, H. (2012) 'Doing research inclusively: bridges to multiple possibilities in inclusive research', *British Journal of Learning Disability*, 42, pp.102-109.

Nind, M. (2014) *Inclusive research*. London: Bloomsbury Academic.

O'Connor, N. and J. Tizard. (1956) *The social problem of mental deficiency*. London: Pergamon Press.

Oliver, M. and Barnes, C. (2012) *The new politics of disablement*. Basingstoke: Palgrave Macmillan.

Oliver, M. (2013) 'The social model of disability: thirty years on', *Disability and Society*, 28, pp. 1024-1026.

Overmars-Marx, T., Thomese, F. and Moonen, X. (2017) 'Photovoice in research involving people with intellectual disabilities: A guided photovoice approach as an alternative', *Journal of Applied Research in Intellectual Disabilities*, 31(1), pp. 1-13.

Peelo, M, T. (2010) *Understanding supervision and the PhD*. London: Continuum International publishing group.

People First, a voice for people with learning difficulties. Our values. (2017) Available at: <http://peoplefirstltd.com/about-us/> (Accessed: 1 November 2017).

Pentland, D., Clausen, M. G., Kantartzzi, S., Witemyre, K. and Royal College of Occupational Therapists (2018) *Occupational Therapy and Complexity: defining and describing practice*. London: Royal College of Occupational Therapists.

Petner-Arrey, J., Howell-Moneta, A. and Lysaght, R. (2016) 'Facilitating employment opportunities for adults with intellectual and developmental disability through parents and social networks', *Disability and Rehabilitation*, 38(8), pp. 789-795.

Pink, S. (2013) *Doing visual ethnography*. London, SAGE.

Polkinghorne, D. E. (2007) 'Validity issues in narrative research', *Qualitative Inquiry*, 13(4), pp. 471-486.

Povee, K., Bishop, B. J. and Roberts, L. D. (2014) 'The use of photovoice with people with intellectual disabilities: reflections, challenges and opportunities', *Disability and Society*, 29, pp. 893-907.

Priest, B. and Bones, K. (2012) 'Occupational therapy and supported employment: is there any added value?', *Mental Health and Social Inclusion*, 16(4), pp. 194-200.

Qian, X., Johnson, D. R., Smith, F. A. and Payay, C. K. (2018) 'Predictors associated with paid employment status of community and technical college students with an intellectual disability', *American Journal of Intellectual and Developmental Disabilities*, 123(4), pp. 329-343.

Quiroga. V.A. M. (1995) *Occupational therapy: the first 30 years, 1900 to 1930*. United States of America: The American Occupational Therapy Association Inc.

Raghavan, R., Pawson, N. and Small, N. (2013) 'Family carer's perspectives on post-school transition of young people with intellectual disabilities with special reference to ethnicity', *Journal of Intellectual Disability Research*, 57, pp. 936-946.

Ramsey, D. (2018) *Work[able] - Working with a learning impairment*. Brighton library, November 2018 [Exhibition catalogue]. Available in the RCOT library.

Redley, M. (2009) 'Understanding the social exclusion and stalled welfare of citizens with learning disabilities', *Disability and Society*, 24(4), pp. 489-501.

Riessman, C. K. (2008) *Narrative methods for the human sciences*. London: Sage Publications. [SEP]

Rossetti, Z., Lehr, D., Pelerin, D., Huang, S. and Lederer, L. (2016) 'Parent involvement in meaningful post-school experiences for young adults with IDD and pervasive support needs', *Intellectual and Developmental Disabilities*, 54(4), pp. 260-272.

Rose, J., Saunders, K., Hensel, E. and Kroese, B. S. (2005) 'Factors affecting the likelihood that people with intellectual disabilities will gain employment', *Journal of Intellectual Disabilities*, 9, pp. 9-23.

Rusch, F. R. and Dattilo, J. (2012) 'Employment and self-management: a meta-evaluation of seven literature reviews', *Intellectual Developmental Disabilities*, 50, 69-75.

Sartre, J. P. (1995) *Being and nothingness. An essay on phenomenological ontology*. Translated by Hazels Barnes. London: Routledge.

Saloviita, T. and Pirttimaa, R. (2007) 'Surveying Supported Employment in Finland: A Follow- up', *Journal of Policy and Practice in Intellectual Disabilities*, 4, pp. 229-234.

Sannicandro, T., Parish, S. L., Fournier, S., Mitra, M. and Paiewonsky, M. (2018) 'Employment, income and SSI effects of postsecondary education for people with intellectual disabilities', *American Journal of Intellectual and Developmental Disabilities*, 123(4), pp. 412-425.

Schleien, S. J., Brake, L., Miller, K. D. and Walton, G. (2013) 'Using photovoice to listen to adults with intellectual disabilities on being part of the community', *Annals of Leisure Research*, 16, pp. 212-229.

Secker, J., Grove, B. and Seebohm, P. (2001) 'Challenging barriers to employment, training and education for mental health service users: the service user's perspective', *Journal of Mental Health*, 10(4), pp. 395-404.

Shakespeare, T. (2019) 'When the political becomes personal: reflecting on disability bioethics', *Bioethics*, 33(9), pp. 14–921. Available at: <https://doi.org/10.1111/bioe.12668> (Accessed: 10 September 2019).

Shakespeare, T. (2014) *Disability rights and wrongs revisited*. 2nd edtn. New York: Routledge.

Shakespeare, T. and Watson, N. (2002) 'The social model of disability: an outdated ideology?', *Research in Social Science and Disability*, 2, pp. 9-28.

and other developmental disabilities: predicting community employment outcomes', *Career Development and Transition for Exceptional Individuals*, 36, pp. 188-198.

Siporin, S. and Lysack, C. (2004) 'Quality of life and supported employment: a case study of three women with developmental disabilities', *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association*, 58, pp. 455-465.

Smith-Chandler, N. and Swart, E. (2014) 'In their own voices: methodological considerations in narrative disability research', *Qualitative Health Research*, 24(3), pp. 420-430.

Smith, A., Petty, M., Oughton, I and Alexander, R. T. (2010) 'Establishing a work-based learning programme: vocational rehabilitation in a forensic learning disability setting', *The British Journal of Occupational Therapy*, 73, pp. 431-436.

Smith, J. A., Larkin, M. H. and Flowers, P. (2009) *Interpretative phenomenological analysis: theory, method and research*. London: Sage.

Southward, J. D. and Kyzar, K. (2017) 'Predictors of competitive employment for students with intellectual and/or developmental disabilities', *Education and Training in Autism and Developmental Disabilities*, 52, pp. 26-37.

Spence, D. G. (2017) 'Supervising for robust hermeneutic phenomenology: reflexive engagement with horizons of understanding', *Qualitative Health Research*, 27, pp. 836-842.

Stanley, M. (2006) 'Grounded Theory of the Wellbeing of Older People', in Finlay, L., Ballinger, C. (ed.) *Qualitative research for allied health professionals: challenging choices*. Chichester: John Wiley, pp. 63-78.

Taylor, J., Williams, V., Johnson, R., Hiscutt, I. and Brennan, M. (2007) '*We're not stupid*', Shaping people's lives and people first. Lambeth. London.

Taylor, R. R. (2017a) *Kielhofner's model of human occupation*. China: Wolters

Kluwer. Fifth edtn.

Taylor, M. (2017b) *Good work – the Taylor review of modern working practices*.

Available at:

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/627671/good-work-taylor-review-modern-working-practices-rg.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/627671/good-work-taylor-review-modern-working-practices-rg.pdf).

(Accessed: 1 December 2018).

TUC (2018) *TUC response to the Taylor review consultation*. TUC. Available from:

<https://www.tuc.org.uk/research-analysis/reports/tucs-response-taylor-review-consultations> (Accessed: 1 December 2018).

Timmons, J. C., Hall, A. C., Bose, J., Wolfe, A. and Winsor, J. (2011) 'Choosing employment: factors that impact employment decisions for individuals with intellectual disability', *Intellectual and Developmental Disabilities*, 49, p. 285.

Townsend, E. (2003) 'Reflections on power and justice in enabling occupation', *Canadian Journal of Occupational Therapy. Revue canadienne d'ergothérapie*, 70(2), pp. 74-87.

Townsend, E. and Wilcock, A. A. (2004) 'Occupational justice and client-centred practice: a dialogue in progress' *Canadian Journal of Occupational Therapy. Revue canadienne d'ergothérapie*, 71(2), pp. 71 -75.

United Nations (2006) *Conventions of the rights of the person with disabilities*.

Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>. [Accessed: 11 November 2017].

United Nations (2017) *The United Nations inquiry into the rights of persons with disabilities in the UK*. Available at:

<https://www.ohchr.org/en/hrbodies/crpd/pages/crpddindex.aspx> (Accessed: 1 April 2017).

Urlic, K. and Lentin, P. (2010) 'Exploration of the occupations of people with schizophrenia', *Australian Occupational Therapy Journal*, 57(5), pp. 310-317.

Van Manen, M. (2017) 'But Is It Phenomenology?', *Qualitative Health Research*,  
270

Van Manen, M. (2016) *Researching lived experience, human science for an action sensitive pedagogy*. 2<sup>nd</sup> edtn. Abingdon: Routledge.

Van Manen, M. (2002) *The heuristic reduction: wonder*. Available at: [www.phenomenologyonline.com/inquiry/11.html](http://www.phenomenologyonline.com/inquiry/11.html) (Accessed: 4 December 2017).

Vessey, D. (2009) 'Gadamer and the fusion of horizons', *International Journal of Philosophical Studies*, 17(4), pp. 531-542.

Verdugo, M. A., Urries, F. B. J. D., Jenaro, C., Caballo, C. and Crespo, M. (2006) 'Quality of life of workers with an intellectual disability in supported employment', *Journal of Applied Research in Intellectual Disabilities*, 19, pp. 309-316.

Walmsley, J. and Johnson, K. (2003) *Inclusive research with people with learning disabilities: past, present and futures*, London: Jessica Kingsley.

Walton, G., Schleien, S. J., Brake, L. R., Trovato, C. C. and Oakes, T. (2012) 'Photovoice: a collaborative methodology giving voice to underserved populations seeking community inclusion', *Therapeutic Recreation Journal*, 46, p. 168.

Wang, C. C. (1999) 'Photovoice: a participatory action research strategy applied to women's health', *Journal of Women's Health*, 8, pp. 185-192.

Wearing, G. (1992-3) 'Will Britain get through this recession?', '*I signed on but they would not give me nothing*', 'I want to care about people, not about my job'. *Signs that say what you want them to say and not signs that say what someone else wants you to say*. C-type print, dimensions variable © the artist. Courtesy Maureen Paley, London

Wehman, P., Chan, F., Ditchman, N. and Kang, H. J. (2014) 'Effect of supported employment on vocational rehabilitation outcomes of transition-age youth with intellectual and developmental disabilities: a case control study', *Intellectual Developmental Disability*, 52, pp. 296-310.

Wehmeyer, M. L. and Bolding, N. (2001) 'Enhanced self- determination of adults with intellectual disability as an outcome of moving to community- based work or living environments', *Journal of Intellectual Disability Research*, 45, pp. 371-383.

Whiteford, G (2000). 'Occupational deprivation: global challenge in the new millennium', *British Journal of Occupational Therapy*, 63(5), pp. 200-205.

Whiteford, G (2011) 'From occupational deprivation to social inclusion: retrospective insights', *British Journal of Occupational Therapy*, 74(12), p. 545.

WHO (2011) *World report on disability*. Malta: WHO press. Available at: [https://www.who.int/disabilities/world\\_report/2011/report.pdf](https://www.who.int/disabilities/world_report/2011/report.pdf) (Accessed: 8 January 2012).

WHO (2018) *Stress at the workplace*. Available at: [https://www.who.int/occupational\\_health/topics/stressatwp/en/](https://www.who.int/occupational_health/topics/stressatwp/en/) (Accessed: 1 November 2018).

WHO. (2019) *ICD-11 for mortality and morbidity statistics*. Available from: <https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f605267007> (Accessed: 18 September 2019).

Winter, A. L. (2019) 'Social justice and remembering "the personal is political" in counselling and psychotherapy: so, what can therapists do?', *Counselling and Psychotherapy Research*. Available at: <https://onlinelibrary-wiley-com.ezproxy.brighton.ac.uk/doi/abs/10.1002/capr.12215> (Accessed: 10 May 2019).

Williams, A. (2012) 'Employment – hope and reality', *Mental health and social inclusion*, 16(4), pp. 201-205.

Williams, L., Rycroft-Malone, J. and Burton, C. R. (2017) 'Bringing critical realism to nursing practice: Roy Bhaskar's contribution', *Nursing Philosophy*, 18, pp. 1-11.

Wilcock A. (1998) *An occupational perspective of health*. Thorofare, NJ: Slack.

Wilcock, A. A. and Hocking, C. (2015) *An occupational perspective of health*. Thorofare: SLACK, 3<sup>rd</sup> Edition.

Wilcock, A. A. (1999) 'Reflections on doing, being and becoming', *Australian Occupational Therapy Journal*. 46, pp. 1-11.

Wilson, A. (2003)' 'Real Jobs', 'Learning Difficulties' and Supported Employment', *Disability and Society*, 18(2), pp. 99-115.

Worrall, L., Cooper, C. L., and Chang, Y. Y. (2013) 'The effect of the recession on UK managers: the quality of working life 2007–2012', *Research in Applied Psychology*, 59, pp. 23–48.

## Appendix 1. Research letter of invitation

### Letter of invitation

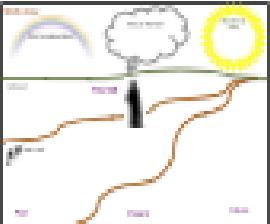
	Are you over 18 years?	<input checked="" type="checkbox"/> 
	Are you in a paid job?	<input checked="" type="checkbox"/> 
	Have you had help from Aldingbourne Trust WorkAid programme?	<input checked="" type="checkbox"/> 
	If you have answered YES to these questions would you like to talk to me about your job?	
	<p>My name is Diana Ramsey and I'm doing some research at Brighton University.</p> <p>I am asking how people with a learning disability find doing their job.</p>	
	<p>The work consultant has a fact sheet and consent form with more information.</p> <p>Do call me if you have any questions Tel: 07342 067583</p>	

## Appendix 2 – Research fact sheet

### Research Fact Sheet

#### What you need to know

	<p><b>Research Title:</b> How do people with a learning disability experience work?</p> <p><b>Invitation</b> My name is Diana Ramsey. I would like to invite you to be part of a research project that I am doing asking people with a learning disability what it is like to do their job.</p>
	<p><b>What is research?</b> Research is a word to describe a project trying to find out new things that can help make good changes for people.</p> <p>I am doing this research as part of a course at Brighton University.</p>
	<p><b>Why this research?</b> Questions have been asked about what helps people with a learning disability get and keep a job. But people with learning disabilities have not been asked what having a job is like for them.</p> <p>This research will ask that question.</p> <p>Knowing what people with a learning disability think can help people who support them.</p>

	<p><b>Why have I been invited?</b></p> <p>You are in paid work You are 18 years old or older You have been supported by WorkAid</p>
	<p><b>Do I have to take part?</b></p> <p>No, it is up to you if you want to take part.</p>
	<p><b>What will happen if I do take part?</b></p> <p><i>What to expect is numbered 1-6</i></p> <ol style="list-style-type: none"> <li>1. You will sign a consent form.</li> </ol>
	<ol style="list-style-type: none"> <li>2. You will be invited to 2 group meetings with other people taking part in the research. At the meeting you will: <ul style="list-style-type: none"> <li>• Find out more about the project, meet the photographer who is helping on the project</li> <li>• Have a chance to ask questions</li> <li>• Be asked to share your first name with the group.</li> </ul> <p>You do not have to come to the group. If you prefer, I will meet you on your own and give you a chance to ask questions.</p> </li> </ol>
	<ol style="list-style-type: none"> <li>3. I will meet with you two times and ask you about your job. You can choose where we meet. You can have a support person (family member, carer or key worker) with you if you like.</li> </ol>

	<p>In these meetings we will put your answers on a 'map' (which is like a person-centered plan) to tell your job story.</p>
	<p>4. You will meet with a photographer and me three more times.</p> <p>The photographer will talk with you and take pictures about your job story. You can choose to be in the pictures or not.</p> <p>You will choose which words and pictures you want to share about your job story.</p> <p>If you want to take a picture at work we will need to check its ok with your boss.</p>
	<p>5. You will have the chance to share your job story with other people if you like. This might be through:</p> <ul style="list-style-type: none"> <li>• An exhibition.</li> <li>• Going to a conference or university to tell your story to help staff who help people who have a learning disability get work.</li> <li>• Write about your story.</li> </ul> <p>You do not have to take part in these things if you don't want to.</p>

	<p><b>6. At the end of the research you will have a copy of your job story and the pictures for yourself.</b></p> <p>I will also have a copy as researcher and the story or pictures will be seen by people looking at the research.</p> <p>The photographer may want to show the photos again. You can choose if you want them to share the pictures.</p>
	<p><b>Will I be paid?</b></p> <p>There is no payment for taking part. However, a gift token of £50 will be available. Also, if you need to travel for meetings or have a drink when we meet this will be paid for.</p>
	<p><b>What might be difficult about taking part?</b></p> <p><i>What if I talk about things that upset me when we're talking?</i></p> <ul style="list-style-type: none"> <li>• If you are upset at any point we will stop and take a break. You can say when or if you want to continue.</li> <li>• If you want more support we will talk to your support person about how to get this.</li> </ul> <p><i>What if my employer isn't happy with what I say about my job and I get the sack?</i></p> <ul style="list-style-type: none"> <li>• What you say when we meet won't be shared with your employer.</li> </ul>

- We won't give details of your employer in your pictures if you do not want to.

*What if I don't want to answer a question?*

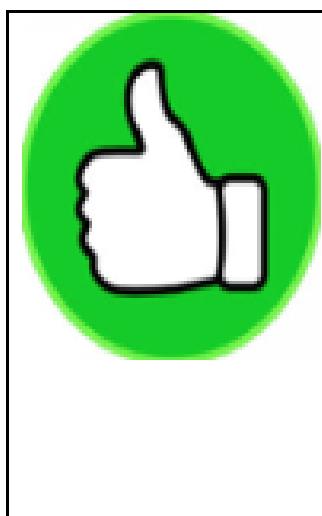
- You do not have to answer a question if you don't want to.
- I will check when we are talking that you are happy to continue or answer a question.

*What if I tell you that someone is hurting me when we are talking?*

- This is an important question. If you tell me that someone is hurting you I will need to tell the manager of WorkAid who will talk to the safeguarding team.
- It does not mean that people will take over. They will make sure you are part of everything that happens to keep you safe.

*What if I come across people when I'm doing the project that aren't nice?*

- In all the meetings you can have your support person with you if you like.
- I will be in every meeting (group meeting and with the artist) so you can tell me if you don't feel safe or if you're worried about someone and we will decide what to do about it together.



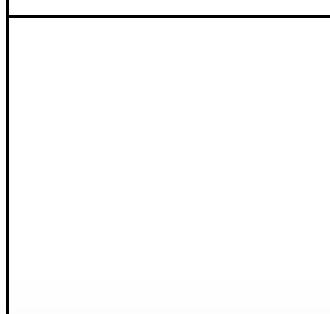
### **What is good about taking part?**

- You will have told people your story and have pictures about you in your job.
- Your job story may help other people with learning disabilities to get better help to work.
- If you like, you will have the chance to share your job story and tell people what you're proud of.



### **Will my taking part in the project be kept confidential?**

- Your full name, address, contact telephone number and that of your keyworker will be kept completely confidential.
- You can be part of the project and only share your story with the researcher and photographer.
- If you want to come to the group meetings you will need to share your first name and meet other people doing the research.
- If you want to share your story at an exhibition or conference you will be asked to share your first, full name or a pseudonym (you can decide which).



### **What if I want to stop taking part?**

You can stop being part of the research at any time. You do not have to give a reason for stopping.

	<p>If you have already taken part in interviews or meetings with the photographer and me. I will ask you if I can still use this information (without sharing your name). It will not be showed in an exhibition.</p>
	<p><b>What will happen with the research?</b>      Your work story may be shared at:</p> <ul style="list-style-type: none"> <li>• An exhibition (if you agree).</li> <li>• At a conference or university to tell your story to help staff that help people who have a learning disability find work.</li> </ul> <p>Things you've shared in your work story will be shared through:</p> <ul style="list-style-type: none"> <li>• An essay written by me for my course at Brighton University</li> <li>• An article for a magazine or journal.</li> <li>• At conference or university.</li> <li>• </li> </ul>
	<p><b>Who is paying for the research?</b>      I will be applying for some money for help do the research. This money will pay for:</p> <ul style="list-style-type: none"> <li>• Expenses like your vouchers, travel, teas and coffee's, group meeting venues.</li> <li>• The time of photographer and pictures.</li> <li>• The exhibition planning and venue.</li> </ul>

	<p><b>What if I'm worried about something?</b></p> <p>If you are worried about something or want to complain you can let me know:</p> <p>Diana Ramsey Tel: 07905 364622</p> <p>Rachel Smithers Tel: 01243 546035</p> <p>Josh Cameron: Tel: 01273 643648</p>
 University of Brighton	<p><b>Who has agreed this project?</b></p> <p>This project plan has been looked at and agreed by a group of people at Brighton Universities Research Ethics Committee</p> <p>Date: January 2017</p>

## Appendix 3. Research consent form

### Consent form

#### What I agree with

	I agree to take part in this research that asks me to tell the story of my Job.	Tick box if you agree <input checked="" type="checkbox"/>
	I have a copy of the research facts sheet dated January 2017	<input type="checkbox"/>
	I have had the research fact sheet explained to me.  I understand what is going to happen and the risks involved.	<input type="checkbox"/>
	I know I will be asked questions about my job.	<input type="checkbox"/>
	I agree to the photographer asking me questions and taking photographs about the story of my job.  I know I don't have to be in the pictures myself if I don't want to.	<input type="checkbox"/>

	<p>I know I may be asked to share the pictures and my job story in one or more of these ways.</p> <ul style="list-style-type: none"> <li>• With other people doing the research.</li> <li>• At an exhibition</li> <li>• At a conference.</li> <li>• In writing.</li> </ul> <p>I know that I don't have to share the photos or my story about my job.</p>	<input type="checkbox"/>
	<p>I know that if I go to two groups with the other people doing the research, they will know my first name.</p> <p>I know I do not have to go to the group or share my name.</p>	<input type="checkbox"/>
	<p>I know that my full name, address and telephone number (and that of my support person) will be kept safe by the researcher and not given to anyone else.</p>	<input type="checkbox"/>
	<p>I agree the researcher can record my voice when talking to me about my job.</p>	<input type="checkbox"/>

<b>" my words"</b>	I agree the researcher can use the things I say (my words) in the research.	<input type="checkbox"/>
	I know I can stop being part of this research at any time.	<input type="checkbox"/>
	Name:	
	Signature:	
	Today's date:	
	Address:	
	Telephone no:	
	Age:	
	Name and telephone no of support person:	<input type="checkbox"/>

## **Appendix 4. Dissemination activity**

### **Exhibitions**

- Work[able] - Working with an impairment - Public Exhibition - Brighton Library 19th - 25th November 2018.
- RAMSEY, D. 2018. Work[able] - Working with a Learning Impairment. Exhibition Catalogue. RCOT library. London.
- Participation in 'Show and Tell Exhibition - The image in research' - The University of Brighton, 29th April - 11th May.

### **Presentations**

- RCOT National Conference June 2018 – Belfast  
Title: The experience of paid employment for people with learning disabilities; an exploratory research design.
- Academic Session – Kent Community Health Foundation Trust
- WORK2019 – Real work in a virtual world – 14<sup>th</sup>-16th August – Helsinki  
Title: The experience of paid employment for people with intellectual and developmental disabilities.

### **Consultancy**

- Books beyond words – initial consultation on DWP funded four books on Work.
- Sussex Occupational Therapy support of DWP funded project to support people with IDD into employment.
- RCOT – Co-construction of course material relating to work related skill development.

### **Online**

- Exhibition advertised on Jubilee Library site and The University of Brighton site, Health sciences newsletter and main website.
- Key findings from the research shared on the RCOT website linked to grant funding received – circulated through RCOT SSPWLD network.

*(All activity has included the research collaborators as much as possible if not in person then by skype or through a recording or attending an exhibition)*

## Appendix 5. Literature review search strategy

The literature search sought peer reviewed qualitative primary research which related to the experience of work for people with an IDD. The selected papers were then critically appraised using guidance by Hannes, (2011), namely assessing for, credibility, transferability, dependability and confirmability.

Stage 1 – Table 1 – The initial literature search criteria included key concepts detailed below and published between 2000 – 2014

Stage 2 – Table 2 - This primary research search was then screened for studies that included direct involvement or self-report from people with an IDD. 5 papers selected that met these criteria were critically appraised.

*Table 1 – Initial search criteria*

Search term Group 1	AND	Search term Group 2	Databases searched included:
Intellectual Disability OR ID OR Learning Disability OR IDD		Work OR Paid work OR Employment OR Jobs OR Occupation	Allied and Contemporary Medicine (AMED); British Nursing Index (BNI); Business Source Premier (BSP); Cumulative Index to Nursing and Allied Health Literature (CINAHL); EBSCO E-journals; The International Bibliography of Social Sciences (IBSS); PsycARTICLES; PsycINFO.

Table 2 – Table of selected papers

Author and date	Title	Study design / Findings	Credibility	Transferability	Dependability	Confirmability
Akkerman, A, Janssen, C, G, C, Kif, S and Meininger, H, P. 2014	Perspectives of employees with intellectual Disabilities on themes relevant to their job satisfaction. An explorative study using Photovoice	<p>Photovoice – 9 participants Netherlands</p> <p><b>Findings</b> - 9 themes</p> <ul style="list-style-type: none"> <li>• The nature of work itself,</li> <li>• working conditions,</li> <li>• experienced job demands,</li> <li>• social relations at work,</li> <li>• received support,</li> <li>• Perceived autonomy,</li> <li>• opportunities for using competencies</li> <li>• Opportunities for growth and development</li> <li>• meaningfulness</li> </ul>	<p>The nine themes extracted from the empirical data provided, shows congruence with the participants narratives that were richly described in the breakdown of the thematic analysis.</p> <p>However, the recruitment to the project, appeared to be assisted strongly by staff in the work setting and by the researcher and there was an absence of detail in the literature about the researcher's background or presence of the reflexive.</p>	<p>The demographic information provided by the authors about the participants was clear and robust in relation to people with ID either mild or moderate.</p> <p>However, there was no effort to consider data separately between those with a mild and those with moderate ID, limiting its transferability.</p> <p>Also, the complexity of work settings i.e.: open and sheltered employment results being considered collectively means application to context was difficult to gauge, although the authors did suggest that the two-setting had similar themes.</p>	<p>The details provided relating to the implementation of the aspects of Photovoice in relation to the method were clearly articulated.</p> <p>There appeared to be a lack of fidelity to the methodology related to Photovoice action research appeared absent in the design.</p> <p>There were no attempts to draw the participants together to define the issues, look at the findings and agree recommendations in relation to social change.</p> <p>Recommendations in general were not explicit in the study.</p>	<p>The nine themes that were drawn from the research interview supported by Photovoice methods are well grounded in data.</p> <p>However, the remit of the study, appeared to go further than job satisfaction to a holistic look at factors effecting employment. Furthermore, perhaps as a result of translation, the theme headings did not best describe the content held in the broader description.</p>

Author and date	Title	Study design / Findings	Credibility	Transferability	Dependability	Confirmability
Timmons, J. C., Hall, A. C., Bose, J., Wolfe, A. and Winsor, J. 2011	Choosing employment: factors that impact employment decisions for individuals with intellectual disability.	<p>Participatory Action Research</p> <p>16 participants with IDD and 28 people interviewed in total including family and employment support staff of the 16 (In different rehabilitation provider settings).</p> <p>USA</p> <p><b>Findings – Factors that influenced employment decisions included:</b></p> <ul style="list-style-type: none"> <li>• Family in early life</li> <li>• School based staff and early employment experiences</li> <li>• The culture of the rehabilitation provider</li> <li>• The job developer</li> <li>• Personal preferences</li> </ul>	<p>The information held within the data provides a valuable insight into the context with family and workers supporting people with IDD of employment decision.</p> <p>However, the data relating to the 16 participants with an IDD is less full included with direct self-report being limited.</p>	<p>This research provides rich information surrounding access to employment and the impact on decision making.</p> <p>However, the transferability is impacted by a lack of information relating to the participant demographic relating to age, sex or level of IDD. Also, the specific pathway towards employment applied by these rehabilitation providers. This may reflect other services in the US but isn't replicated in the UK for example.</p>	<p>Action research applied were proposed and co-researcher with an IDD employed to support all aspects of the research, although details are not provided about this process.</p> <p>Furthermore, there was a lack of clarity in the approach underlying the semi-structured interviews, with thematic analysis applied using a software programme. No evidence of comprehensive action research methods were apparent.</p>	<p>This research provides through, thematic analysis, clarity relating to the factors shaping decision making for people with IDD in relation to employment. The factors highlighted area empirically rooted and recommendations given.</p> <p>The research, though referencing action research, did not communicate a robust methodology or details relating to the involvement of the co-researcher with IDD beyond the recruitment process. The researchers themselves and reflexivity was not evident in the study.</p>

Author and date	Title	Study design / Findings	Credibility	Transferability	Dependability	Confirmability
Li, E. P. Y. 2004	Self-perceived equal opportunities for people with intellectual disability	<p>In-depth interviews 18 individuals Hong Kong</p> <p><b>Findings</b> – 17 participants had positive and negative employment experiences, which were largely associated with the workplace, peers and employer attitudes. 8 employees may have experienced discrimination at work. Themes taken from the data included:</p> <ul style="list-style-type: none"> <li>• Work motivation</li> <li>• Employment experience</li> <li>• Ways to promote employment experiences</li> </ul>	<p>There is valuable self-report held in quotations within the research. Although it was included minimally in the article. This, and the choice of analysis, (which identified the prevalence of positive and negative experience) led to a suggestion that there was a great deal of qualitative data unexplored.</p>	<p>A robust summary was provided about the participants demographic details and a decision to only interview people who had a mild ID without a secondary diagnosis such as autism or down syndrome had been stipulated to support the recruitment of a 'relatively homogenous group'.</p> <p>The potential for this decision to increase transferability can be challenged as there remains a great deal of diversity within this group.</p>	<p>The research is described as a qualitative study applying content analysis and constant comparative method for data analysis.</p> <p>No methodology is communicated within the article although a reference is made to Glaser and Strauss. Additionally, although the only data source for the study was the 18 participants, data was collated from a single semi-structured interview of 50mins.</p>	<p>This was the only study found that had taken place in Asia within the broader literature review. It provides, grounded in the data, the incidence of positive and negative experiences of people with a mild ID in the work setting.</p> <p>The deficit in the application of a robust methodology and clarity of the researchers position reflexively limit the confirmability of the study.</p>

Author and date	Title	Study design / Findings	Credibility	Transferability	Dependability	Confirmability
Ineson, R. 2015	Exploring paid employment options with a person with severe learning disabilities and high support needs: An exploratory case study	<p>Case study design 1 participant with severe learning disability UK</p> <p><b>Findings</b> – The participant was unsuccessful at getting a job. Negotiating access to employers was a barrier for the occupational therapist supporting her.</p>	<p>This study provides good credibility as the data presented in all its forms holds true with the participant involved.</p> <p>In this respect the participant in the study is fully drawn within her context and balanced with other contributors.</p>	<p>A single case study design, the demographic information is clear and comprehensive relating to the persons severe ID.</p> <p>This alongside the detailed description of the activities taken and barriers faced demonstrate good transferability relating to issues that are likely to be faced by someone with a similar level of impairment in the UK.</p> <p>Evidently, the fact it is a single case and the specific needs to the individual will differ to other people with ID so is not fully transferrable.</p>	<p>Clarity was provided relating to the constructivist paradigm applied and case study design utilised.</p> <p>The data collection units were detailed in full and the researchers position outlined reflexively.</p> <p>The ethics though discussed in relation to the participants vulnerability related to her ID, do not explore the question of the ethics involved in intensively supporting someone towards a goal that was effectively not achieved.</p>	<p>Within this paper robust data is communicated from all parties involved in the research including the person with IDD, the family, care team and researcher.</p> <p>The complexity in relation to the themes gained from this experience are robustly explored and presented although a significant questioning of policy pertaining to work for all is not fully articulated by the researcher even though the policy gap is identified.</p>

Author and date	Title	Study design / Findings	Credibility	Transferability	Dependability	Confirmability
Siporin, S. and Lysack, C. 2004	Quality of life and supported employment: a case study of three women with developmental disabilities.	<p>Case Study 3 women (interviews also with a family member and job coach – 9 in total – job observations also took place with the women)</p> <p>USA</p> <p><b>Findings</b> – The suggested benefits of supported employment was not always realised for these three women whose quality of life outcomes were not always what the job coaches and families expected.</p>	<p>The representation of the data in this study reveals the experience of the three women involved, included in direct report and their observation in the workplace.</p> <p>However, within the case descriptions it was not always clear which party (person, family or job coach) provided the information.</p>	<p>This paper provides insight into the experience of three women in sheltered employment.</p> <p>No details were provided relating to the age or level of ID that the women experienced.</p> <p>However, the case descriptions provide insight into their experience which is likely to resonate and inform other people's experience of supported employment even with the differences associated with the construction of supported employment in the US.</p>	<p>A case study design was employed alongside a constant comparative method of analysis.</p> <p>The findings are presented in three rich case descriptions which include a significant amount of self-report from the participants. However, the researcher's reflexive position and approach being applied was not specified.</p>	<p>Within this research the research process is described, including a detailed method, supporting the confirmability of the findings in the data.</p> <p>A deficit of knowledge of the researcher outside of the ethical considerations and inclusion of the reflexive were evident.</p>

## Appendix 6. Ethics approval letter



**University of Brighton**

Tier 2 College Research Ethics Committee  
Research Office  
M24 Cockcroft Building  
Moulsecoomb  
Brighton  
BN2 4GJ

Diana Ramsey  
8 Cross Street  
Hove  
BN3 1AJ

LHPSCREC 16-08

19 January 2017

Dear Ms Ramsey

Thank you for your resubmission to the College Research Ethics Committee for the College of Life, Health and Physical Sciences at the University of Brighton.

The committee feel you have now addressed all the issues raised and are happy to offer a favourable ethical opinion for this study.

Favourable ethical opinion is given on the basis of a project end date of 31/07/19. If you need to request an extension, please contact the CREC secretary. Please note that the decisions of the committee are made on the basis of the information provided in your application. The CREC must be informed of any changes to the research process after a favourable ethical opinion has been given. Tier 2 research that is conducted without having been reviewed by the committee is not covered by the University research insurance cover. If you need to make changes to your proposal please complete and submit a change notification form in order that the CREC can determine whether the changes will necessitate any further ethical review. The form is available at:

<https://staff.brighton.ac.uk/ease/ro/Pages/ethics%20and%20governance/CREC-LHPS.aspx>

Once your research has been completed, please could you fill in a brief 'end of project report form' that can be found on the same website. Finally please could I ask that you flag up any unexpected ethical issues, and report immediately any serious adverse events that arise during the conduct of this study.

We wish you all the best with your research and hope that your research study is successful. If the CREC can be of further assistance with your study, please contact us again.

Best wishes

A handwritten signature in black ink, appearing to read "Lucy Redhead".

Lucy Redhead  
Chair  
Research Ethics Committee (Tier 2)  
Life, Health and Physical Sciences College

Copy: Josh Cameron by email: [J.Cameron@brighton.ac.uk](mailto:J.Cameron@brighton.ac.uk)

## Appendix 7. Research grant letter

UK Occupational Therapy  
Research Foundation

Building the evidence – creating the future

106–114 Borough High Street  
London SE1 1LB

t: 020 7450 2323

f: 020 7450 2349

e: researchfoundation@cot.co.uk

w: www.cot.org.uk/researchfoundation

Via email only.  
Ms Diana Ramsey  
8 Cross Street  
Hove  
BN3 1AJ

27 March 2017

Dear Diana

### UKOTRF Research Career Development Grant 2017

#### *How do people with intellectual disabilities (ID) experience work?*

Thank you very much for submitting a proposal to the 2017 round of funding opportunities from the UK Occupational Therapy Research Foundation (UKOTRF), in respect of the above project. I am delighted to formally confirm that you have been successful in your application.

The Advisory Group and reviewers commended you on a creative methodology to explore an under-researched area of occupational therapy. They welcomed the strong service user element of the research, and how these voices have already contributed to the design. They felt you had a firm grasp of the ethics involved and had a sound dissemination strategy. They noted your relevant experience and the appropriateness of the timing of the application in your research career pathway.

The Advisory Group and reviewers did suggest a few areas where the application could have been strengthened. They would have liked to see more discussion on the impact to occupational therapy practice. They also noted a more thorough proof-reading of the application would have been beneficial.

The next stage in the process is for COT to prepare a draft grant contract, and Lesley Gleaves (R&D Administrator) will be in touch with you about this shortly.

For your awareness, it is anticipated that details of the outcome of the 2017 UKOTRF funding round will be published in either May or June OTnews. This year's grant winners will also be invited to attend a special celebratory event in London on 20<sup>th</sup> September and you may like to note this date in your diary pending further information.



Very many congratulations on your success and all best wishes for your project activity.

Yours sincerely

A handwritten signature in black ink, appearing to read "Jo Watson".

Dr Jo Watson  
Assistant Director: Education and Research

## **Appendix 8. Semi-structured interview**

The interview will be structured as follows and include questions and follow up prompts as set out below. It will be used in conjunction with the job story map.

### **Beginning (Past)**

How did you spend your time before you got your job?  
What job did you want to do?  
What range of choices of jobs did you have available to you?  
What help did you have to get your job?  
Do you think having a learning disability made it hard to get a job?

### **Middle (Present)**

#### **(Habituation – Roles / Routine)**

Can you tell me about a typical day at work from beginning to end?  
What is the name of your job?  
Do you wear a uniform? (Anecdotally some people are very proud of their uniform and it's a key point of communication about their work)  
What hours do you work? Do you get a break?  
What are the important parts of your job?

#### **(Social environment)**

Tell me about the people you work with?  
Tell me about your boss?  
Tell me about the customers?  
What do your family/carers think of your job?  
Do you meet up with anyone you work with outside of work?

#### **(Physical environment / objects / physical, mental capacity)**

Tell me about the place where you work?  
Do you use any machinery / equipment?  
Are there things you find difficult in your job?  
Are some things about your job that are easy?  
What things about your learning disability affect how you do your job?

#### **(Volition – Self-determination)**

What are you most proud of in your job?  
What do you like best about your job?  
What do you do with the money you earn from your job?  
How do you know you've done a good job at work?  
Are you happy in your job?

### **End (Future)**

What hopes do you have for your future?  
Is your job important to those dreams?  
Would you like to work more hours?  
Do you want to stay in your job for a long time?

Would you prefer to do a different job?

Based on the narrative arc, person-centred planning concepts and the model of human occupation - Kielhofner (Taylor, 2017a)

Volition – personal causation (sense of competence, effectiveness), interests, values.

Habituation – Habits, Roles. Performance capacity – physical and mental components.

Environment – Social / physical / Objects.

## Appendix 9. Initial interview 1<sup>st</sup> edit – example

Interview 1 transcript – highlighted - anonymised changes and potential ‘story’ content

Key: I – interviewer and P – Participant

I – What were you doing before you got this current job or the help from ESP?

P – Um, well I was signing on at the job centre and .....

I – How long was that for?

P - 3-4 years

I - Was this after school, college?

P – Ah, no this was a bit after school. I did work for my dad and other people in a shop.

I - Ah, ok, what do you do there?

P – Tidying up, sweeping. Just generally tidying up.

I – Was that paid or was that just helping?

P – yeah, just helping

I – Was that just, was your dad like, now we should look at getting you work?

P – Well they had to let me go, because of, bit of trouble, they had to let me go and a few other people as well.

I – Ah, I see so they were financially going through it were they?

P – Yeah

I – So that’s when you signed on at the job centre?

P – Yeah, Yeah,

I – and you were signed on for how long?

P – 3 years?

I – That’s a long time, how did you find that?

P – Not too bad because, it was alright, (laugh).

I – yeah, yeah, from what other people have told me it’s very fixed, you got to apply for this many job, got to appear in person, make sure you fill in the forms, it’s almost a job in itself? Did you get any help?

P – My nan went with me. So, if there were any awkward questions they could ask her.

I – so she went with you and helped you?

P – Yeah.

I – So you say it's two years ago that you got connected with ESP?

P – yeah, yeah.

I – So tell me a little about that they just suggested did they?

P – They tried to find other things but couldn't think of anything at the time and the work consultant had a word with her work colleagues and had a chat and they sort of made up the job for me.

I – Great, and when did you start that?

P – End of March

I – and you've been doing all the holidays since that time? Great, tell me a bit about the job that they made up?

P – Well, It's a Cleaning job. Go round Cleaning toilets to make sure the bins have been emptied, to and there's a pick as well.

I – Ok, round the whole grounds, the perfect job. And that's how many hours?

P – Between 4 and 5 hours?

I – And that's every day during the holidays? So, you don't' come here on those days (day service)?

P – Not unless I've got a day off.

I – okay, okay, So I'm going to go back a bit to some questions. What job did you want to do when you were going to the job centre and first going to ESP?

P – Not a specific one, apart from mainly probably gardening.

I – have you enjoyed that in the past?

P – Yeah, my Grandad used to be a gardener so sometimes I used to go out with him.

I – But there wasn't anything at the time because they do quite a lot of work like that (deletion)? Did you try any of those jobs when you started in the ESP?

P – No,

I – So you had thought about gardening were there any other jobs you had thought about?

P – Not really no (laugh).

I – Did you have a range of jobs that were on offer to you when you first sat down with the work consultant?

P – There were a few but it was like getting there and getting back.

I – So all the travel challenge bit.

P – yeah

I – So where were they?

P – Somewhere like (Names of two places) way.

I – Oh, and this felt like the best fit.

P – Yeah

I – So what help did you get. Was the work consultant helping you the whole way through?

P – Yeah,

I – And do you think having a learning disability made it hard for you to get a job?

P – Yes,

I – And in what way particularly with you?

P - Travel and maybe reading and writing.

I – So those two things you see as being the hardest things?

P – Yeah, yeah.

I – So tell me a bit more about your job now? When you're working what would the typical day look like?

P – First get there and sign in...

I – so you get there quite early, because you get a taxi in?

P – I usually start between half 10 and 11am and then sign in and then start.

I – and what do you have to do?

P – I go to my cupboard where everything is kept and go and get that.

I - Is it the same system every single time?

P – Yeah, it's the same routine

I – So they don't tell you to go and do this area today.

P – Not unless they've got a problem

I – How much stuff do you have to carry round?

P – Well I've got this thing with everything in.

I – Is it like a trolley?

P – Um, I've got a trolley and like this little box thing.

I – Oh yeah, great.

P – Well I start with the toilets, and then check the bins, and then do the pick and then back to the toilets again.

I – Ok, so you'll rotate round? So, you'll start, maybe do the whole thing twice?

P - Maybe more than that.

I – oh really, do you feel like you're quite quick?

P - Yeah

I - And what's the name of the job?

P – I don't know what they call it now.

I – That's alright, there's all sorts of names that they things. Do you wear a uniform?

P – Yes,

I – How do you find wearing a uniform?

P – Yeah, ok.

I – I can imagine when you're doing a job like that it's quite nice not to have to wear your own clothes.

P – Yeah, it's only a shirt, you have to wear your own jeans.

I – So do they recommend you wear black trousers or is it your choice?

P – Your choice and you wear a T-shirt.

I – So your hours are?

P – four or five hours, 10 or half 9 until 3pm

I – and do you get a break?

P – Not usually, I just work through.

I – And what are the important parts of your job would you say?

P – Making sure the toilets are clean.

I – Do you get feedback from the customers?

P – Sometimes.

I – and I expect you get feedback if they're not clean. Tell me about the people you work with, do you tend to get to connect with them at all?

P – They're nice people.

I - And are you they all doing different parts of cleaning?

P - I'm the only one that's got cleaning, I mean they all clean. um yeah.

I - And how many people do you work with that you might have a chat with every time you go in?

P - It's usually people from reception

I - Oh, ok, yeah. Because you know what you're doing you just go in and talk to them. Do you talk to anyone else?

P – Sometimes

I – yeah, do you talk much to the customers?

P – Not an awful lot.

I – I guess there's not tonnes of opportunity. Tell me about your boss?

P – Um, I don't see her actually.

I – do you not? did you literally see her when you first started and then....

P – Yeah, sometimes I see her walking round the grounds and sometimes if I'm walking past, I'd say hello. We've never really had a proper conversation.

I - So if you've had a question about your job would you go back to the work consultant? rather than..

P – Maybe, and if she's not around then I'd maybe go to reception and there is another person that I know as well that my family know quite well so I'd go and see her as well.

I – that's very good. And what do your family think of your job?

P – Yeah, yeah, they like it.

I – Pleased for you?

P – yeah

I – do you meet up with anyone that you work with outside of work?

P – Um

I – Do they do sociable things?

P – They do from here,

I - but not from work?

P – No

I - Did they do anything at Christmas?

P – I think they usually do but I didn't go to the one last year. That would have been my first one.

I – And did you not want to

P – I think I was busy at the time. So

I – is that something you would like to build friendships at work to do socially or are you happy to keep work separate?

P – Yeah, Yeah.

I – So thinking about the physical environment, tell me a bit about the place you work. So, you cover the whole site?

P – It goes up to the farm but not through the farm.

I – So quite a bit area. And do you use any machinery, do you use the hoover?

P – No, No.

I – So all the things you use, you've got your clothes,

P – And all different trays.

I – and are they for different things

P – Yeah, Wipes

I – and is one of the things learning what to use when?

P – Yeah, Yeah that's it.

I – Is there some parts of the job you find difficult at all?

P – No everything seems to be ok.

I – Do you find some things almost too easy?

P – Apart from, there is one thing that we have a dispenser toilet roll holder thing.

Sometimes I have trouble opening it. but apart from that.

I – Is that because their locks thing is tricky.

P – No that bits alright but its' actually putting the toilet role in, it's alright putting it in, but it has to get through a slit bit and down that's a bit tricky.

I – And that has to go a certain way in order to come out a certain way?

P – If not it all ties up inside.

I – I can imagine. Do you find all the physical side of it fine? Lifting rubbish?

P – Yeah, That's fine.

I – you mentioned what things about your LD that affect getting a job. Do you find these things Reading and Writing and getting there affect doing the job at the moment?

P – No

I – It feels in your capacity to do it? Do you think it stretches you enough?

P – Maybe I could do different things as well.

I - Yeah, do you sometimes get involved in the café work?

P – Yeah, I do that as well

I - How do you find that, it's a bit more social?

P - Yeah, I love that

I - Do you, do you prefer it to the cleaning bit?

P - Yeah, I do, I mean I do like the cleaning, but I prefer the café bit.

I - Do you help on the food preparation and those things?

P – A little but not a lot.

I - Largely cleaning the tables

P – Cleaning tables, taking food out and bringing back, unloading and loading up the dishwasher.

I – Yeah, I imagine time flies doing that as it's constant

P - Yeah, yeah.

I – During the summer when they have a busy time do they say you're working in the café today or do you always have to do your cleaning first?

P – Usually I'm always doing cleaning and they're a bit behind and really really busy, then.

I – that's interesting, what are you most proud of in your job?

P – All of it really. That I've done a good job.

I – Yeah, having your contribution to working? And what do you like best about your job?

P – Out in the fresh air

I – Do you really like the fresh air? So even if the café is busy, is it still nicer to do the pick and things?

P – Yeah.

I – I imagine if it's pouring with rain it's not so great!

P – No

I – do you have a good waterproof and stuff?

P – Yeah but if it's usually that bad I'll come into the café instead.

I – If I asked you what thing about your job got you out of bed in the morning what would that be?

P – Going to work, talking to everyone

I – And how important is it for you to earn money?

P – Yeap

I – Is that a key motivator too?

P – Yeah definitely,

I – Have you noticed the difference since you've had work in terms of having a bit more money.

P – Yes, a little bit.

I – What do you spend it on, are you saving up for a holiday?

P – Yeah, I'm going on holiday in October

I - Lovely where are you going to go

P - I'm going to France.

I – Great. And how do you know you've done a good job at work?

P – It looks clean and sparkles.

I – Good, completely different from when you walk in I expect?

P – The customers are pretty good; they do keep it pretty clean

I – So it's isn't hideous. And are you happy in your job?

P – Yeah

I – and how much of the time do you think, even when you're fiddling with the toilet roll holder?

P – Yeah, all the time.

I – That's great, really great. So, this bit now is thinking about the future? Pause, Is that a hard question?

P – Yeah, Maybe a bit more work?

I – Is this one only holiday, rather than all the time, would you prefer it to be all the time.

P – More often, Yeah

I – And what would your ideal be if I said you could have anything you wanted in terms of work, hours?

P – I haven't' really got one.

I – So just more of it really?

P – Yeah.

I – When I say what do you want for the future, bigger picture, do you have things you really want to do outside of work?

P – (Pause) not really

I – You're happy? So, some people say they want to live alone, drive, so those sorts of things aren't on your mind?

P – Not at the moment?

I – you have a good support around you, (describes living situation with family) around the corner and your happy with that as it is?

P – Yeah

I – Do you want to stay in your job for a long time.

P – Maybe

I – Is it a bit like if there was something else on offer, you'd look into it. And what about the type of work, you mentioned gardening and working in the café, do you think you'd like to build your skills to work in another area?

P – Yeah

I – and how important is the social aspect of work, it sounds like the café is more sociable than cleaning. Would one be more important to you?

P – No

I – So you don't mind if you're working on your own or with people?

P – No, I'm easy going so.

I – And would you prefer to be doing a different job?

P – If it came around, yeah, well depending

I – What it was, so in the future you might be thinking about perhaps looking at something that builds on what you're doing at the moment?

P – Yeah,

I – And is there anything I've missed when talking about your job?

P – No

I – Do you find it ok when you've finished your hours, are you tired?

P – Sometimes a little tired. But its sometimes mentally.

I – Does it take a lot of concentration sometimes?

P – Not really, Sometimes, when it's weather like this (Sunny)

I – Yeah, you don't want to stay in. And when you were learning the job did you start your job did you have a prompt sheet to help, with pictures to say have you done these things or did you learn it on the job?

P – Just learned it really. There was someone with me at the start till I got used to it, the first couple of weeks then I was alright.

I – I know you find reading hard do you find following the sprays and know what's what or have you got used to it?

P – It was at the beginning, but I've got used to it and realised what the different ones were.

I – How do you find, if you find reading difficult do you find numbers difficult too, do you find budgeting and money management difficult to?

P – Yeah, Not too bad

I – Do you ever use the till at work?

P – No, I never go anywhere near that.

I – Is that a bit scary is it? A couple of people I've asked how they feel about the term learning disability? Do you have any strong feelings about it?

P – Yeah, Yeah, how we talk about it.

I – You're fine with learning disability as a phase?

P – Yeah

I - Do you sometimes feel that people understand when they meet you or do you have to tell them you find these things difficult.

P – Sometimes

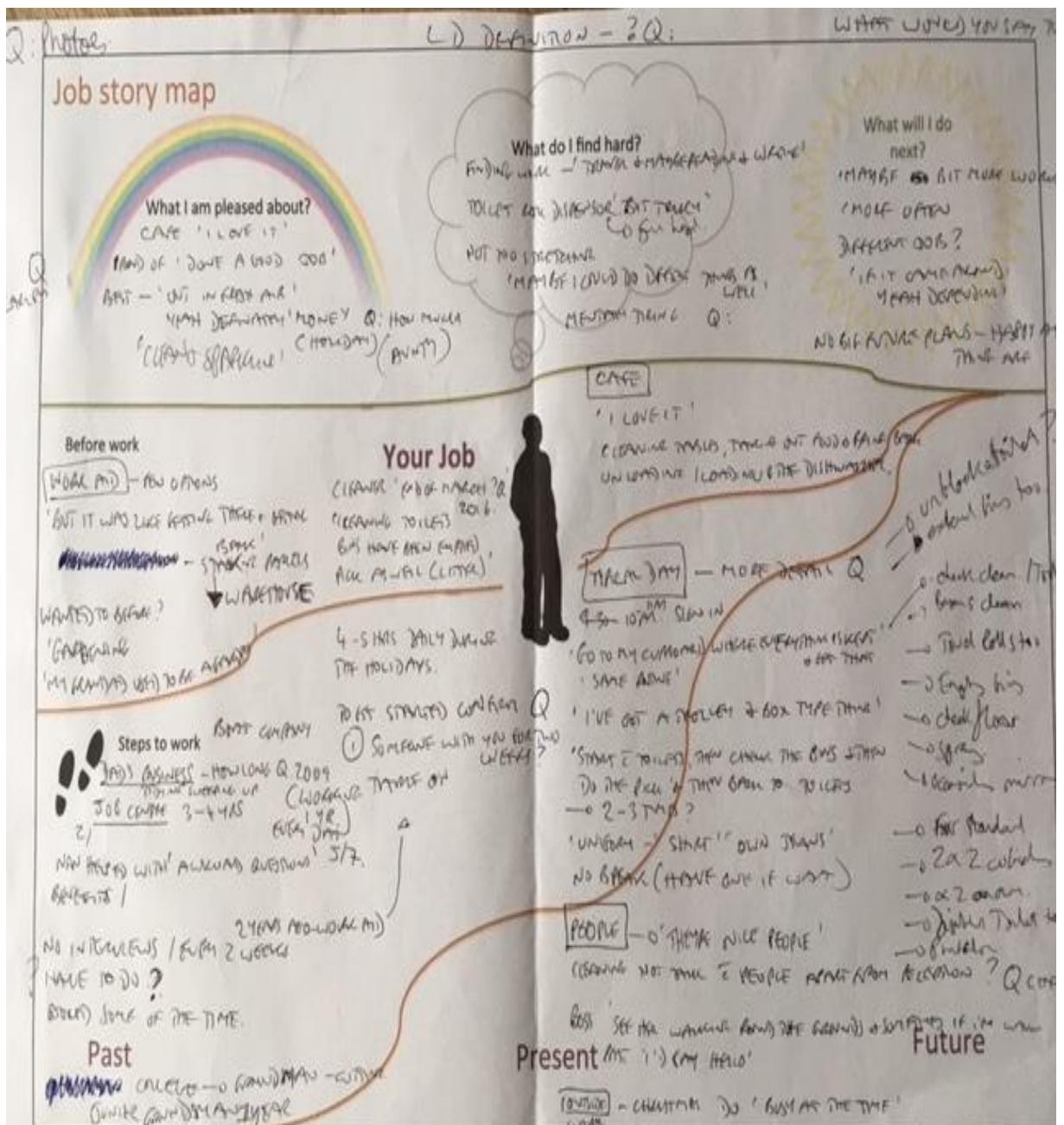
I – When you were going to at the job centre did they know it?

P – well I did have an advisor that specialised with people with LD, yeah so that helps.

Thanks, expressed and interview ended.

## Appendix 10. Job story map - example

Job story map constructed following the first interview to inform the second interview - 'Q' references the need for further information.



## Appendix 11. Crafted narrative with link words - example

(Words marked in green were added by myself as researcher – removal or changes of names / places of work also took place)

The last paid work I did was as a cleaner so obviously I had that experience to draw on and know that I could do it, by having done some cleaning before but that was back in 2009 so a long time without doing any paid work. I got dismissed from that job, I left unwilling. And the same went for the same kind of job I did in 2007, just two years before that and similarly I left again through no choice of my own.

It's no great secret to anybody and I'm not ashamed, my employer felt that I was spending too long to clean certain areas, because I have high standards. I've always believed in quality over quantity and I can't do both. I say to people I can't work quickly and competently its either one or the other with me and they want me to work both quickly and competently and I couldn't. It was much the same story with the other job too and eventually I enjoyed what I was doing and got satisfaction from doing and it was taken from me unfairly and it was unjust, and I couldn't challenge their decision.

Those two positions were the only paid work that I've had in some time as far as working to a contract that's the only paid work I've had in 19 years since I was diagnosed with depression and started taking medicine for it. So I've actually spent less than a year in paid employment in the last 19 years.

Quite a bit of my paid work has been in retail up until my diagnosis with depression in early 1999. It was quite timely that it came just after a very stressful time, which led to a nervous breakdown really, and a crisis following the only full time job I've ever had actually. It was as milkman of all things working for the same firm and same place as my dad, my dad was instrumental in getting me that job soon after I left working at Supermarket after a year part time at the end of 98.

My job as a milkman was full time and lasted about four months. I was sacked from this job. It was a very stressful it goes to show how little insight I had into my own mental health which was already deteriorating back then but I couldn't see it because it had quite a degree of responsibility put on me you know which I couldn't cope with.

I went very quickly into the job because I was put on Job Seekers Allowance and the pressure to find a replacement job as soon as possible and because the pressure from family as well at that time. I landed a job working in the kitchen of a restaurant here in the town, and that lasted as little as a week or two so I got quickly resigned from there.

If ever a job brought together everything that doesn't suit me it was this. Because the need to serve customers, the need to go out in all weathers, to start early in the morning, the need to drive, there was an unpredictable element of the job as well needing to deal with customers with their changing orders, you having to get money out of difficult customers sometimes of dealing with traffic on the roads all those sorts of things.

It was at a time where I hadn't long started driving anyway, I was only 21 when I got that job and I was kind of thrown in the deep end, I had another milkman who I shadowed for a couple of days but then I was left on my own with all these customers and this big round to cover. All that retail customer service, customer facing work I've done has gone a long way to contributing to a hatred of doing any sort of customer facing sort of work which I will now never do again. And it's fed my distrust because of this belief that the customer is always right, for me it's harder than the average person to summon any charm you know just to keep them on side. And those professions was where I had to work with some of the managers I had to work with some intimidating people, I was at the co-op before I was at a supermarket and I had a rather bullying manager to deal with there.

And all the while dealing with colleagues because you're out there working but then you come back to a depot where you've got to order produce for the next day and when you go into the staff room the necessary banter. Every place of work has a culture and often that is not touched on, people apply for work and it's not like, it's fine you've got the qualifications but for me it's the added dimension and worry about finding it hard to get on with colleagues or if you're in customer service too, maybe customers. That is a big ask, but for many years I found it hard to explain to my parents or brother those difficulties without coming across as work shy and a moaner.

You know, my family were very hostile to the idea of me becoming unemployed due to my mental health due to depression because following losing 3 jobs in quick succession between October 98 and March 99 you know they wanted me to go straight to work. Initially I kept it secret I was seeing a shrink and a community psychiatric nurse but they were initially hostile to the idea of me being unemployed and as they saw it doing myself a great disservice. But I needed to recover.

Since that time (and still now) I've been with a charity, except for a two-year break in the noughties, since 2005 and I've been with the charity shop down the road, for a year before, so I was doing two volunteering jobs. Additionally, once every 6 weeks with the talking news service locally. So, volunteering for 3 places but doing very little of it. The charity up until last September just a couple of hours a week once a week and 3 hours with the charity shop and 1hr once every six weeks to come in and read for the talking news in their studio. So yeah, up until 3 years ago that's all I was doing. There was a bit of both thinking really. I could be doing more to help myself and move forward.

I don't want to give the impression that support agencies weren't in anyway supportive because I managed to secure my first voluntary work I ever did with a charity shop through workability or it might have been the volunteer bureau again there's been a certain degree of cross over with some of these because I've seen so many people in supportive roles its as if they're all kind of intertwined and as a result. The feelings I have are always one of disappointment disillusionment of things not quite working out, me ending up feeling like I've not fully pulled my weight, and me feeling like the people, the job coaches, support workers, whatever you want to call them haven't pulled their weight. So I've done a drama course, which I now regret not taking any further and I've since done courses in IT through adult education. I pursued, a career, I did a photography course, two, after I left school, one a city and guilds and another which I think is a BTEC which I think was

more like an art course which I dropped out **after** just two terms in, so I didn't even complete a year.

I did start off working outdoors here doing some gardening really although as you can see there isn't much of a garden here. **This** opportunity arose through being referred to the employment support provider. **Starting with** the employment support provider I just wanted to get back and thought the time was right to do some paid work. And certainly the DWP were encouraging me, with the change to employment, I mean Employer Support Allowance, you know the key words were support and I was not getting any support. **Initially**, there was something appealing about working outdoors but I didn't really stop to consider that it would be problematic some times and it has been.

The weather is a big bugbear for me generally, with not knowing what to wear and through all the moaning I was doing with the managers here. It was sort of mutually agreed they wanted to retain me and I did think of quitting as I often do with jobs and other things and I reflected on it and I thought I don't really want to leave. The management have been very supportive and encouraging where as they're aware of my issues and are willing to be more accommodating than the average employer would. And so it was agreed **as** the previous cleaner left, would I like to take that on board along with another cleaner already doing some work here and I accepted, about 2 years now and also I managed to get more hours as well, increased to 6 from 3.

I'm here Tuesdays from about 11.30am, I aim to start between 11 and 11.30. They let me be flexible fortunately, but I always do my 3 hours. I start at 11 or 11.30am **and** finish at 2.30 or 3pm and the same on Friday, so that way there's an equal balance in the week.

I've now got a kind of schedule which I didn't have at the beginning, of areas to clean, and where I focus on and areas of priority which are the bathroom here and the W/C next to the office where hygiene are most considered. Also the stairways as well which are less of priority so I always aim to do one side of the building the stairways and the halls one week and the other side the following week so there's two week rotation. And the manager's office and also the office next door.

The most problematic thing **is** not the cleaning per say. Where I get a problem in every place of work, and here is no exception, are the peripheral things which I don't think people always take consideration off. There's always lots of talk about are you qualified for the job and yes but for me there's these extras and the biggest of them is people, like staff / colleagues, dealing with a particular place of work and this place hasn't always been good for my mental health.

In a place like this people are moving about, you've got staff you've got residents and some places call for me to work close to them, in the communal areas people come in and out of their flats in the office next door how contained it is, its quite a narrow space and I've had to work around other people occasionally and clean and there's been moments of difficulty where I've got into in peoples way and vice versa I've not been able to clean where I want to when I want to and I've then got upset and had to leave and if that happens it's then a question of where do I go. Because

sometimes I've come in with an idea of what to do and it's hindered by the unpredictability of finding that there are too many staff.

If the previous day I've seen the office is in need of a clean but the next day I can't' because there's lots of staff going in and out all the time. On another instance I came in and to my surprise there was someone from outside working in the corridors where I wanted to as well and with alarms going off and that sort of thing bothered me.

The job coach helped me a bit in that respect, just taking note of whenever I can't' clean in a certain place or its difficult and just moving on to something else and just avoid particular situations where conflict might occur.

It was only about 5 years that I received a diagnosis of Asperger's syndrome which kind of, at least it put my actions and stupid decisions and tom foolery into perspective, it gave an explanation. I would say I am neuro different with learning difficulties. If you've got a LD with much more obvious signs of need you will get more help and more tailored support than if you're in this vague middle ground area that I exist in and people like me. Why is it only the very old or the very young with mental health problems or the very disabled that end up getting the most support? why is it never those in a kind of nether world or who are approaching that middle age in that 30 something or 50 something bracket? It's like nothing exists for people like me, that's the way it feels, there's no support there. It's assumed that everybody has sorted themselves out, if they're not 'normal' for want of a better expression in my age group.

I often catch myself working in such a way or behaving in such a way, from what I've seen of other people working, how I work might be considered weird or unusual. I try and organize the way I work here and yet some how I still slip back into old habits or don't stick to my own routine. It's like I'm incapable of following my own or anybody else's instructions. Again it's not cleaning. I can never get done as much as I want to. This is a problem in countless jobs, I'm badly organized. I often finding myself spending too much time cleaning a sink for example or the bath or the shower or being rather too fussy cleaning the banisters. But that's a focus of people with Asperger's we can hyper focus and be consumed with detail. If I've ever asked for clarity on things, my thoughts are hard to get into words so that other people can understand them, so I don't' get the answers I need so I'm left with answers that don't' really help me.

The manager accepted, I've not really found the staff to be that friendly towards me, with one or two exceptions. They've probably been advised to say as little to me as possible for fear of upsetting me or keep me at arms length and I'm not a very chatty person anyway. Its funny with me because I'm not a very friendly person, I don't' like chatting to people much and yet I get upset whenever I feel ignored I get annoyed. I'm just contrary like that.

**Outside of work** the only time I went along to a Christmas party at the football club the first year I was here. And I felt so out of place not just because of my own not liking social events anyway but because everyone else felt so much more important than me and I'd only been here six months and just having started that summer I felt weirdly apart form anybody no body introduced me

hardly to anybody and if they did you had to launch into a big explanation of what I did what I'd done before, really low down in the pecking order really low down in terms of importance.

The same goes for the charity, if you're directly involved with the people the charity is set up to support like the support worker's you've probably met today then its almost as if, I feel, you don't matter, you're a peripheral person and because I have this difference, the Asperger's and mental health which now people know only too well about because of my behaviour here it's like, I think you just mentioned the word disconnect and that very much describes me disconnected.

There's no understanding of how people like me struggle with the world of work. But you know the government the DWP put great store into work and this whole belief that somehow work, its' a strongly engrained cultural thing where work is the one thing that gives people their reason for living. It's like if you don't work or you're doing a very menial level type of work for a very short length of time like I do that somehow you know, its one step up from being a complete lay about or scrounger.

People put rather too much, in my opinion, **on work** it's as if you're judged entirely on what they do for a living, if they work at all, and you know it's usually the first thing people want to ask. You know I was watching a programme this morning that was about the whole American dream; it's perhaps not the same as here. It's one of the first questions people ask if not how are you? What do you do, what do you do for a living? What do you do?

The government believe that work alone is the harbinger, or the bringer of self esteem, yes, self-improvement, it's a good thing, it brings self-confidence it makes a person, gives a person reason to.... But in my place and in my experience the world of work has been a harbinger of depression its bought precious little but misery to my life. It's somehow hyped up to be this great thing it's supposed to bring you self-esteem and a sense of purpose in life and yes it brings, but ultimately its just a means to an end so you can get paid to pay the bills but its not the be all and end **all** and it's certainly not given me much joy in my life in fact 80% of all the depression I've ever had has come from directly or indirectly from work.

I don't enjoy coming to this place. Half the time its with a sense of dread I come to this place I don't enjoy coming here for one moment I don't like this place I don't like half the people who work here and yet I've got to be proud of what I do and I feel trapped being here because if I weren't here what else would I do? where else would I work? and THAT other place of work would bring just as much misery probably.

The more people I have to interact with, in a place the worse it is. I could never work in one of these great multi-national companies or office blocks or god forbid anymore a large supermarket my mum works in with all the levels of management and the politics and back stabbing that goes on and all the rest of it. I hear all these horror stories from my mum about how she's been treated so badly over the years and she's a strong woman. How would I cope in a world like that? I wouldn't last five minutes and she agrees with me.

I think the world of work is all right if you're neuro-typical but if you're not. It's alright if you have a learning disability, they will get support because they've got a proper disability and look like they have and act like they've got a disability, for me, Like I said last week, existing in this 'no man's land', what am I to do? I need support but I don't look like I need support at the same time and it's a horrible confusing world to inhabit and it makes me really angry and it makes me annoyed in the way the world of work is so geared.

If I left here I might find myself in a position where the job coach said 'I don't want to support you anymore' and then I'd have to explain myself and the next time job centre plus want to get me in for one of their so called work focused interviews they'd want me to explain how I left my last bit of paid work and why and they'd pressure me to find paid work as soon as possible with one of their experts, one of their people. And somehow they think pressuring someone into finding work is the key to someone's salvation. Where as it would probably make my depression worse and their way of trying to help a person is counter productive. There you go rant of the day over.

I'm proud of the standard of my work. I mean I would take issue with anybody who says I don't do a good job. From all my modesty I always come away with a sense of achievement. And that the thing about the sort of work I do, cleaners, people who do low end jobs someone has to do it and if you've left a place looking better and more hygienic than when you arrived that's something to be proud of. I'm not all together sure, well the manager is pleased with what I do but I don't know about other staff.

What's best about the job is being able to work alone. So the time always goes by quickly because I'm always moving about and its keeping me fit at the same time when sport doesn't appeal to me and when other things I do to keep to fit like cycling and swimming can be a particular bind its like killing two birds with one stone sometimes, the satisfaction of doing the work itself with also the awareness that I'm keeping fit and active at the same time.

I know how much I earn an hour and that I'm entitled to amount of paid leave in line with how many hours and how much rate of pay I get. I've got an account that it's paid into along with my ESA which fortunately hasn't changed lately in line with what I'm earning here because it's under a particular threshold and it all goes into the same pot for bills and luxuries sometimes as well but I'm never in debt and if anything I'm rather too careful.

Right now on a percentage scale I would say I'm 50-60% happy. What might improve this level of happiness may be to clean a different type of place and buildings and layout and lighting and things like that and I would prefer not to have to come into contact with any of the residents here or see any of them some of whom annoy me and because right now I'm not very tolerant of people generally and sometimes that intolerance has spilled over into how I have talked to staff and people. What would tip it upwards would be seeing fewer people here staff and residents and cleaning in a different type of place.

I've been thinking a bit about long-term employment thinking only yesterday that I lack aspiration because it's easy for me to get stuck in a rut. But at the same time unless I make the effort which I

don't usually do, (I'm not in the habit of being a very proactive determined person) I could stay here doing this for the rest of my working life and I don't want that.

In the short term I'd like to be able to cope with some more hours and perhaps work somewhere differently or as well as here but in the longer term to do something that's more, would make me more proud, more satisfied.

It's frustrating and it doesn't help that in, my working history I've done so many types of voluntary things. I've been supported by so many different agencies and been on quite a few different programmes that it just feels like um, you know, like they all merge together after a while. Yes dates might be fine but it's what happened and why that's so hard to recall, I have no emotional memory. I'm not sure I've ever had any good help around work. Nothing I can think of right away. I've had lots of support; (named numerous employment support providers) but nothing sticks out.

**Getting a desired job** feels more like a dream at the moment such as working as an actor, or as an author or as writer, or taking up studying psychology for myself. They're all subjects I've got an aptitude for or an interest in. Even I have a desire to do something that's better than this in the long term. I think it's time to aim a bit higher and get out of the rut of doing menial work because that all I've ever done really menial work.

**My family**, they're aware of **my work** but I'm not sure what they think. I think they're pleased for me that I'm doing some paid work and making that progress towards being a bit more useful in society generally and not being as idle as I once was or as work shy. I think they're a bit more proud of me than they used to be.

**I would say to someone in a similar position to me** ask yourself, what you're skill set is and what it is that you'd really like to do, and if the two meet then go for it then look into that, look into paid work in those areas.

## **Appendix 12. Employer consent form**

**Research Project Title - How do people with a learning disability experience work?**

Please initial or tick box

I agree to consent to the identity of the employer being possibly identifiable from photographs taken in the work setting or related objects i.e.: uniform.

The researcher has explained to my satisfaction the purpose, principles and procedures of the study and the possible risks involved.

I have read the information sheet and I understand the principles, procedures and possible risks involved in the researcher and photographer being on the premises and taking photos and those photographs being shared.

---

I understand how the data collected will be used, and that the identity of this work setting may be identifiable in the data collected (photographs and interviews).

I understand that I am free to withdraw my consent to any image / interview detail that identifies this work setting being shared, at any time up to publication without giving a reason and without incurring consequences from doing so.

I agree that if the participant withdraws from the study, the data collected up to that point may be used by the researcher for the purposes described in the information sheet.

Name (please print) .....

Signed ..... Date .....

Please return this form in the pre-paid envelope provided to or hand to researcher:

Josh Cameron, PhD  
Principal Lecturer  
School of Health Sciences  
University of Brighton  
Robert Dodd Building  
49 Darley Rd  
Eastbourne  
BN20 7UR

Thank you for supporting this project – Diana Ramsey

## Appendix 13. Easy read findings summary

### WORK(ABLE) Working with a Learning Impairment



The government in England says that in recent years 5-6% of people with a learning impairment are in paid work.



Although lots of government policies have been written to try and increase this number, not much has changed.



We don't know much about the experience of those small number of people with a learning impairment in paid work.

# **WORK(ABLE)**

## **Working with a Learning Impairment**



6 people with a learning impairment took part in a research study with Diana Ramsey, an occupational therapist and a photographer to talk about their experiences.



They told their story about looking for and being in paid work with both words and pictures.



They all had important stories to share about their experiences.

## WORK(ABLE)

### Working with a Learning Impairment



They all said it was hard and took a long time to find paid work.



They said it was a demanding finding their way through bureaucracy around work.



Some said they had found a good fit in their job.



Some said they had a poor fit in their job and work was stressful.

# WORK(ABLE)

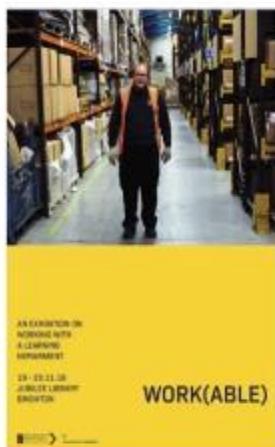
## Working with a Learning Impairment



They said in their experience they had met people who had helped them and people who had not helped them.



They said the experience of finding and being in work shaped who they were and their identify.



They shared their stories and pictures in an exhibition at Brighton Library (Ramsey, 2018)

# **WORK(ABLE)**

## **Recommendations**



If you are a person looking for work  
find a worker who knows about  
learning impairments.



It is important that workers helping you to  
get work listen to you about the barriers  
you face getting work and the things you  
find hard .



It is important that workers helping you  
to get work make sure the people in  
your work place are helpful and su-  
portive .

# WORK(ABLE)

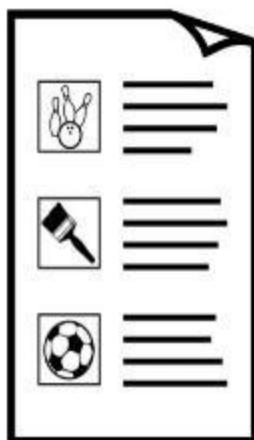
## Recommendations



Workers and occupational therapists can learn from listening to people with a learning impairment telling them about their work story.



Occupational therapists need to think more about the person's identity and the barriers they face trying to find work.



This research has made a 'my work plan' to help occupational therapists to support people around work better.

# WORK(ABLE)

## Recommendations



We need to think more about work and how to adapt jobs and employment to make it a better fit for people with a learning impairment .



We need work research and work services to look more at what makes a good services and good work place for people with a learning impairment



We need workers in employment services to be 'for' the person and help them take down barriers to getting work.

If you want to find out more or see the pictures from the research stories contact Diana at [diana.ramsey2@nhs.net](mailto:diana.ramsey2@nhs.net)

Ramsey, D. 2018. Work[able] - Working with a Learning Impairment. Exhibition Catalogue. Available in the RCOT library, London.