
OCCUPATIONAL THERAPY SUPPORTING
PEOPLE WITH
PROFOUND INTELLECTUAL
DISABILITIES
TO ENGAGE IN OCCUPATION AT HOME

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Abstract

This thesis explores the nature of engagement in occupation (meaningful activity) and the different levels at which people with profound intellectual and multiple disabilities may engage. Research suggests that many are poorly supported to do this meaningfully at home. When through circumstances beyond their control, people do very little, occupational injustice arguably results, impacting on physical and mental wellbeing and quality of life.

Research evidence and theory from occupational therapy, occupational science and active support underpins support for people to engage in occupations at home. Occupational therapists claim to support people to do this in complex situations, but exactly *how* they do it and whether it differs from other methods evidenced in the literature remains unclear. Better understanding is needed of how to support people to engage in ways that are authentic and meaningful.

Using a qualitative case study methodology from an interpretivist and social constructionist stance and multiple ethnographic methods (participant observation, interviews and document analysis), I explored over one year, a single purposively selected case. In this Esther, an occupational therapist, worked with Matt, Steve, Becky, Jane and Harold, five people with severe and profound intellectual disabilities and their support workers to increase their engagement in Cavendish House.

Data were analysed systematically using an emergent coding strategy, with NVivo qualitative data analysis software to manage the process. Various formal first and second cycle coding and categorising procedures were used, alongside more intuitive and affective analysis (e.g. concept mapping).

The case's story has two overarching themes: the impact of shifting support and leadership cultures on engagement and characteristics of occupational therapy, which: aimed to create and sustain cultural change; had a particular understanding of authentic occupational engagement; and sought to work with the staff team in a collaborative and empowering way. Three vignettes, constructed from field notes and interview transcripts, bring the case to life for the reader.

Unique contributions made include: (1) how creating stories using narrative reasoning can propel occupational therapy towards a hoped for ending; (2) that authentic engagement in occupation is possible for those with profound intellectual disabilities and essentially means engaging in co-occupations at a sensory level, without them necessarily *physically* doing anything; (3) how occupational therapy sought to address occupational injustices not only for those with profound intellectual disabilities, but also for those supporting them, for whom role ambiguity risked burnout; and (4) how occupational therapy sought to sustain a different way of supporting engagement by collaborating with and empowering the staff team.

Five "*petite generalisations*" (credibly transferable when contextualised to the case) are suggested: (1) organisational culture may impact on whether people are supported effectively to engage in occupation; (2) recognising the level at which people can engage in occupation seems necessary for support to engage authentically; (3) "independence", "choice" and "personalisation" are everyday words, but how they are meaningfully relevant to people may not be fully understood; (4) occupational therapists should focus on facilitating sustained cultural change in support of occupational engagement at home; (5) narrative reasoning seems to help propel occupational therapy interventions towards hoped for endings and may be facilitated by opportunities for reflection.

Implications are suggested for occupational therapists and others working with people with profound intellectual disabilities and others with high support needs and for occupational therapy education.

Key words

Occupational therapy, intellectual disability, activities of daily living, decision making, healthcare quality assurance, qualitative research, case study

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Abbreviations

COT	College of Occupational Therapists
IQ	Intelligence Quotient
MCA	Mental Capacity Act 2005
MOHO	Model of Human Occupation
NHS	National Health Service
PIMD	Profound Intellectual and Multiple Disabilities
UK	United Kingdom
WHO	World Health Organization

Key terms

Intellectual disabilities/ learning disabilities	“A significantly reduced ability to understand new or complex information and to learn new skills and a reduced ability to cope independently starting before adulthood, with a lasting effect on development” (Department of Health 2001, p.14).
Profound intellectual and multiple disabilities (generally referred to in this thesis as “profound intellectual disabilities”	Those who are among the most disabled and vulnerable and who have more than one disability, the most significant of which is a profound intellectual disability (intelligence quotient notionally estimated at under 20) with consequent severe impact on understanding and other cognitive skills (Mansell 2010, p.3)

Occupation	<p>"All that people need, want or are obliged to do; what it means to them; and its ever-present potential as an agent of change" (Wilcock 2006, p.343).</p> <p>"Activity that is both meaningful and purposeful to the person engaging in it" (Fisher 2003, p.2).</p>
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Cast of Characters

Esther	Occupational Therapist
Matt, Steve, Jane, Becky, Harold	People with severe/ profound intellectual disabilities living at Cavendish House
Mo	Person with moderate intellectual disabilities also living at Cavendish House
Sue	Manager of Cavendish House
Norma	Assistant Manager of Cavendish House
Jean, Doug, Olly, Tracy, Julie, Paula, Gemma, Robert, Dina, Ivan	Support Workers at Cavendish House
Adam	Community Intellectual Disability Nurse

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“Esther” and all participants at Cavendish House – it is your case as much as mine and I am very grateful for your time.

Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is my original work. 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

Dated

Chapter 1. INTRODUCTION

“People with profound intellectual and multiple disabilities are among the most disabled individuals in our community ... a relatively small, easily identified group of people with undeniable needs for care and support. Despite ... serious impairments, people ... can form relationships, make choices and enjoy activities [but they] have often not been provided with services to adequately [enable this].... New models of providing services in a person-centred way should make us raise our sights.” (Mansell 2010, p.3)

Research evidence, expert opinion (such as *Raising our Sights*, the document from which Professor Jim Mansell’s words are taken) and my own personal experience as a support worker and occupational therapist, all suggest that people with profound intellectual and multiple disabilities may not always be well-supported to engage in a rich variety of daily occupations. This is despite what we know (e.g. from Mansell and Beadle-Brown 2012) about effective ways of providing support. People’s rights are arguably infringed if they are prevented from leading meaningful occupational lives (Whiteford 2000).

Some occupational therapists work specifically with adults and children with intellectual disabilities and I explored the nature of their work in previous research commissioned by the College of Occupational Therapists (Lillywhite and Haines 2010). It was apparent that this work includes supporting people with profound intellectual and multiple disabilities to engage more fully in activities, including in their own self-care and domestic and leisure activities at home. With only limited research evidence, however, this role could be better understood, both in terms of what occupational therapists do and how that may differ from the ways others, such as support workers, foster engagement.

This thesis presents research exploring the ways that an occupational therapist, Esther, supported five people with severe and profound intellectual disabilities to engage in occupations in their home, Cavendish House. I used a qualitative case study methodology to investigate, over the course of a year, a single case of

Esther's work with Matt, Steve, Becky, Jane and Harold and the people supporting them.

I begin this chapter by explaining the rationale for the study before defining some key terms and making clear my aims. I then outline the structure of the thesis.

1.1 Rationale

I began working with adults with intellectual disabilities in 1993, initially employed by a voluntary organisation as a support worker in a number of small group homes. A major focus of my work then, before I had even heard of occupational therapy and its concern with meaningful occupation, was on how those we supported spent their time – what they *did* all day long. As a support worker, I loved involving people with severe and profound intellectual disabilities as fully as possible in cooking, cleaning, self-care and leisure activities in their homes, valuing even very partial participation in such ordinary activities.

Later from 2000, as an occupational therapist based in community teams for people with intellectual disabilities, I often worked with people who had far too little to do in their days and witnessed the consequences of this on physical and mental health, on level of skill and sometimes on behaviours which could become self-injurious, or otherwise challenging. Throughout my work I have believed passionately in the rights of people with intellectual disabilities to be fully part of society and to have full and meaningful lives. As both a support worker and occupational therapist, I gained great satisfaction from seeing people develop skills and engage in activity in however small a way, finding it a joy to see people surpass the expectations of others.

Over my time in this field, the philosophy underpinning service provision has evolved and people with intellectual disabilities have become notably more prominent in the Government policies of all four countries of the United Kingdom (for example Department of Health 2009 in England). In the service in which I worked in 1993, we spoke of “normalisation” and “social role valorisation” (Wolfensberger and National Institute on Mental Retardation 1972, Wolfensberger 1992). We evaluated the success of our service by the extent to which we enabled

individuals to achieve the “*Five Accomplishments*” (O'Brien 1992) of community presence, relationships, choice, competence and respect. Over time, these ideas have developed and four core values are now part of Government policy in England, within *Valuing People* (Department of Health 2001) and *Valuing People Now* (Department of Health 2009):

- Having the same human *rights* as everyone else.
- *Independent living* through choice and control over the support needed to go about daily life.
- Having involvement in and *control* of life decisions, with sufficient information and support to understand options, implications and consequences.
- *Inclusion*, through support to participate fully in the community.

There is a particular focus in *Valuing People Now* on “having a life” (including addressing needs related to health, housing, work, education and relationships); on personalisation of services; and on the relevance of these values to *all* people with intellectual disabilities. My own experience suggests, however, that we are nowhere near achieving this for everyone and that those with more complex needs may be at particular risk of experiencing deprivation of meaningful activity or marginalisation.

Occupational therapists work with people to promote health, prevent disability and develop or maintain abilities (College of Occupational Therapists 2015). Ensuring a beneficial match between individual abilities, the demands of activities and the environment, can maintain or improve function and provide opportunities for participation (Creek 2003). Current policy strongly favours mainstream rather than specialist services meeting health and social care needs wherever possible (Department of Health 2009, College of Occupational Therapists 2013b), therefore an occupational therapist based in *any* service may work with someone with an intellectual disability. Many needs are however necessarily met by specialist multi-disciplinary services, for example health and social care community teams and teams in special education settings. This research, relates particularly to the practice of occupational therapists based in such teams where they have wide

roles supporting engagement in occupation and promoting independence and community participation (College of Occupational Therapists 2013b).

My experience suggests that these occupational therapists do valuable work to enhance the quality of life of people with intellectual disabilities, but there is little research evidence documenting this. I will draw on key findings from my own research into the nature of occupational therapy with people with intellectual disabilities, including occupational therapists' suggestion that they have a particularly important role in enabling those with complex needs to engage in their occupations.

1.2 Definitions of terms

Before framing the issue to be explored, clarification of some of the terminology that I have already begun to use is necessary, in particular terms such as “intellectual disability” and “profound intellectual and multiple disabilities”.

1.2.1 Learning disabilities

Various constructs have been used over the years to label the people that this research concerns and there is debate about the appropriateness of different terms (see for example Wehmeyer et al. 2008). Many of these, for example, mentally retarded, educationally sub-normal, or ineducable, would be regarded as offensive, or at least of little utility today. Whichever term is currently in vogue, it remains a social construction, of questionable use in accurately identifying those it claims to represent, as I will go on to explain in 1.2.3.

I have always used the terms **learning disability** or **learning disabilities** and both are in common current usage in the United Kingdom, along the lines of the generally accepted definition in *Valuing People*, which refers to those adults who have:

- A “significantly reduced ability to understand new or complex information and to learn new skills”.
- A “reduced ability to cope independently”.
- Starting before adulthood, with a lasting effect on development (Department of Health 2001, page 14).

This is broadly consistent with the World Health Organization (WHO) definition (2001) of mental retardation: “a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities”. I have always preferred learning disabilities to the oft-used alternative term “learning difficulties”, even though it is one that some people with learning disabilities themselves may prefer to use (British Institute of Learning Disabilities 2011). Its potential confusion with the unrelated group of people with specific learning

difficulties such as dyslexia, where the difficulty is particular to an area or areas of learning such as reading and writing (Gillberg et al. 2006), means that this term can be unhelpful.

1.2.2 Intellectual disabilities

For reasons I will go on to explain, I intend, however, to adopt the alternative and synonymous term “intellectual disabilities” throughout this research, as it sits better with its social constructionist stance.

Wehmeyer et al. (2008) emphasised the distinction between operational definitions that define constructs in observable and measurable ways (to facilitate, for example, diagnosis and classification); and *constitutive* definitions that better facilitate understandings of the theoretical underpinnings of the construct. The above WHO definition of learning disabilities emphasises an internal condition, namely the deficits within the individual. It is operational in nature. A more useful construct is one that reflects an individual’s disability as the fit between their capacities (affected as they may be by cognitive impairment) and the context in which they function, which fits with bio-psycho-social and interactionist models of disability, such as the International Classification of Functioning, disability and health (WHO 2001). The term “**intellectual disabilities**” is increasingly being used internationally, as it is felt to be more accurate and less easily confused. The intellectual disability construct, whilst acknowledging the limitations in an individual’s functioning, better reflects the multi-dimensional nature of human functioning (Wehmeyer et al. 2008). The American Association on Intellectual and Developmental Disabilities Association definition (2010) refers not just to significant limitations in intellectual functioning and adaptive behaviour, but also to health, participation and context. Rather than merely a defect in the person, the disability resides in the fit between the person’s capacities and the context in which they function. It is less something that is fixed, but rather an individual status within the world, which is actively negotiated, albeit from an unequal position (Rapley 2004).

1.2.3 Social construction of intellectual disability

I explain the social constructionist approach I have taken in this research and the implications of this in 4.3.1.2. The way that the definitions of learning or intellectual disabilities cited in 1.2.1 and 1.2.2 are used in practice suggests that they are often regarded as discrete conditions that people can clearly be said to either have or not have, rather than, as Whitaker (2008) points out, constructs determined by a dividing line that has been placed at a particular point on a continuum: notably an intelligence quotient (IQ) of 70. Whitaker goes on to report high margins of error in the measurement of both IQ and adaptive functioning, meaning that conclusions reached (particularly in the severe – profound ranges of cognitive impairment) can be of questionable accuracy. He concludes that diagnosis of intellectual disability should be acknowledged as a matter of clinical judgement and suggests the following as an alternative definition:

“A person can be regarded as having [intellectual disabilities] if they are judged to be in need of community care or educational services due to a failure to cope with the intellectual demands of their environment and are suffering significant distress or are unable to take care of themselves or their dependents or unable to protect themselves or their dependents against significant harm or exploitation” (2008, p.7).

None of these definitions, however, give us real insight into how the world is experienced by diverse individuals with profound intellectual disabilities. Simmons and Watson (2014) reviewed the substantial literature in this field, much of which is informed by educational and behavioural psychology. They highlighted how a discourse of deficits and barriers has othered people, constructing their identity as bodies requiring treatment and leading to incomplete understanding of what they can do and be. Instead, “multi-situated understandings ... that move away from epistemological reductionism” (Simmons et al. 2008, p.734) are needed. Such understandings do not come from definitions, but may (at least partially) be gained from close relationships and intimate knowledge about individuals and their lives.

1.2.4 Complex needs

Individuals may have mild, moderate, severe or profound intellectual disabilities. Some have a range of multiple or additional needs, sometimes referred to as “**complex needs**” (Commission for Social Care Inspection 2009), a term which I occasionally use in this thesis to refer to people:

- Who have profound intellectual and multiple disabilities.
- Whose intellectual disability is moderate or severe, but who have additional physical or sensory disability, mental health or dementia.
- Whose behaviour presents a challenge to services, by threatening quality of life and/or physical safety of themselves or others and which risks restrictive or aversive responses (Royal College of Psychiatrists et al. 2007).

1.2.5 Profound intellectual and multiple disabilities

There seems not to be a single agreed definition of the term profound intellectual and multiple disabilities, resulting in inconsistent identification of individuals. This creates uncertainty, for example, as to whether different research using the same terminology refers to the same people (Nakken and Vlaskamp 2007). Those authors emphasised the importance of describing individuals clearly in publications using operational definitions and called for a clearer taxonomy.

In this research, I use the term **profound intellectual and multiple disabilities** (PIMD) as defined by PMLD Network (2009a) and Mansell (2010), though generally shortening it to **profound intellectual disabilities** to enhance readability. I prefer this term to “profound and multiple learning disabilities”, the expression used more commonly in the United Kingdom, concurring with others (Nakken and Vlaskamp 2007, Pawlyn and Carnaby 2009) that it is more accurate. This term refers to a heterogeneous group, described by Mansell (2010), as among the most disabled and vulnerable amongst us and who have more than one disability, the most significant of which is a profound intellectual disability. This means an intelligence quotient notionally estimated at under 20, which is estimated to be five standard deviations from the norm (Pawlyn and Carnaby 2013) with consequent severe impact on understanding and other cognitive skills.

Some definitions (see e.g. Vlaskamp and Nakken 1999) include a narrower focus only on those also with severe or profound *motor* disability. Such physical disability is at least very likely along with possible sensory, complex health and mental health needs. Mansell (2010) describes multiple disabilities, potentially including:

“Impairments of vision, hearing and movement as well as ... epilepsy and autism. Most people ... are unable to walk unaided and many people have complex health needs requiring extensive help. People with profound intellectual and multiple disabilities have great difficulty communicating; they typically have very limited understanding and express themselves through non-verbal means, or at most through using a few words or symbols. They often show limited evidence of intention.” (2010, p.3)

Communication may be limited to immediate needs and wants and understanding of cause and effect is likely to be partial (Imray and Hinchcliffe 2012). These additional needs (especially when combined with a lack of appropriate support) may also affect behaviour, for example self-injury and people require significant support in all aspects of daily life (Mansell 2010).

1.2.5.1 Prevalence

An understanding of the number of people with intellectual disabilities in England can be gained from estimates used to project adult needs and services (Institute of Public Care 2013) and research by Emerson et al. (2012). Figures are based both on numbers known to GP and other services along with projected numbers in the population. Although acknowledged to be estimates, these figures are sufficiently accurate for current illustrative purposes.

The English adult population was estimated in 2012 to be 41,542,200 (Institute of Public Care 2013). Emerson et al. (2012) then estimated that 236,000 children and 908,000 adults had “learning disabilities” and Institute of Public Care (2013) a slightly higher figure of 979,275 adults. These figures are suggestive of slightly over 2% of the population, a little lower than Matson et al.’s (2012) recent assertion that intellectual disability affects approximately 3% of the population worldwide. The Institute of Public Care (2013) estimated that 47,767 of these had

a “severe learning disability”, which would include those who have profound intellectual disabilities, estimated by Emerson (2009) to number 16,036 in 2008.

People with profound intellectual disabilities are therefore relatively small in number, estimated by King et al. (2009) to be about 2% of those with intellectual disabilities and by the American Psychiatric Association (2013) as about 1-2% of that population. Prevalence is, as always, difficult to establish as figures vary according to definitions adopted in different parts of the country and world. In the London Borough of Lambeth, for example, within an adult population of 202,800, 81 were identified as having PIMD (Mencap 2011). Essentially, therefore, this suggests that we are talking about 2% of the 2% with intellectual disabilities, which is to say about 0.04% of the overall population.

This number is however growing, with a sustained and accelerating increase of 37.41% predicted by Emerson and Hatton (2008) by 2026 (compared to a general population rise more like 11% over the same period). An interesting illustration of growing numbers in one particular city over the period 1998-2008 is provided by Parrott and Wolstenholme’s examination of the statistics in Sheffield (2008). Over that period, the total number of people with intellectual disabilities increased by 25% and those with severe or complex needs by an astonishing 70%. Emerson and Hatton (2008) argued that three factors are likely to lead to an increase in prevalence rates in England:

- An increased prevalence of more severe intellectual disability within some growing minority ethnic communities (the Sheffield study, for example, indicating an increase of 80% in the number of adults with intellectual disabilities within such communities over the ten-year period).
- Increased survival rates among babies and young people with severe and complex disabilities.
- Reduced mortality among older adults with intellectual disabilities.

1.2.6 Occupations and activities

The terms “occupation” and “activity” are used with specific meanings in this thesis. There are overlaps between these concepts, which are used in varying ways by different authors and it is inevitably challenging to be completely consistent in their use. Creek (2003, 2010) refers to a paradigm shift in occupational therapy, from a structuralist, hierarchical and perhaps reductionist way of organising knowledge, to one which has become more reflective of the complexity of the dynamic relationship between human beings, our occupations and our environment and the ways in which this impacts on our health. This shift to what she describes as a pragmatist epistemology, is I feel more accepting of uncertainty, recognising that such terms are mere social constructions and how it may be difficult and perhaps unnecessary to pin terms such as “occupation”, “activity” and “task” within a rigid taxonomy.

The dictionary definition of “**occupation**” is “1. The action, state, or period of occupying or being occupied. 2. A job or profession. 3. A way of spending time” (Soanes and Stevenson 2009). Four definitions from occupational therapy and occupational science are however more helpful in explaining the specific, though broad, way I use this word to mean:

- “All that people need, want or are obliged to do; what it means to them; and its ever-present potential as an agent of change” (Wilcock 2006, p.343).
- “The doing of work, play or activities of daily living within a temporal, physical and sociocultural context that characterises much of human life” (Kielhofner 2008, p.5).
- “A group of activities that has personal or sociocultural meaning, is named within a culture and supports participation in society. Occupations may be categorised as self-care, productivity and/ or leisure.” (Creek 2010, p.68).
- “Activity that is both meaningful and purposeful to the person engaging in it” (Fisher 2003, p.2).

Creek further explains (2003, 2010) that occupations are the most complex way in which humans function. An occupation has characteristics which come from the culture and context in which it is performed (its “**occupational form**”) but is not observable in itself. What may be observed is the doing of the occupational form, that is the *performance* of the occupation, or “**occupational performance**” (Hemmingsson and Jonsson 2005, Kielhofner 2008, Creek 2010).

“**Activities**” are “a structured series of actions or tasks that contribute to occupations” (Creek 2010, p.28). For me, despite at times using two terms interchangeably, the key difference between occupation and activity, as Fisher suggests, is that an occupation has meaning, significance or importance for the person performing it, either personally or socio-culturally. The idea of *meaningful* engagement in occupations will be explored further in 2.2.4 below.

1.3 Aims of this research

In chapters 2 and 3, I review the literature that resulted in me using this research to answer the question: “In what ways does an occupational therapist support people with profound intellectual and multiple disabilities to engage in occupation in ways they find meaningful at home?” My aims were:

- To investigate and provide a rich description and analysis of the practice of an occupational therapist interacting with and supporting people with profound intellectual disabilities to engage in their occupations.
- To establish similarities and differences between her approaches to supporting engagement and others described in the literature.
- To generate professional knowledge, understanding and theory which could inform practice, including occupational therapists’ consultancy role with those who support people with intellectual disabilities on a day to day basis.

As well as enabling occupational therapists better to describe their practice, thus promoting understanding of the profession, I hope that my findings can contribute to enhancing the quality of support for and everyday lives of those with profound

intellectual disabilities. It may thus contribute to the raising of sights envisaged by Mansell (2010) at the beginning of this chapter.

1.4 Thesis structure

In keeping with an interpretivist and social constructionist epistemology, this thesis is written in the first person (see further 4.3.4).

In Chapters 2 and 3, I review the literature relevant to this thesis, consciously dividing this discussion into two parts. **Chapter 2** contains an exploration of some of the contextual literature around engagement in occupation. I begin by exploring engagement in occupations and why as occupational therapists and occupational scientists we believe this is important. This then leads to what we know about the occupational engagement of people with intellectual disabilities, in particular those with profound intellectual disabilities. I argue that the extremely low level of engagement that they are often supported to achieve is an issue of occupational injustice.

Chapter 3 provides more in depth critical analysis of the evidence, central to this thesis, regarding how occupational therapists and others support people with intellectual disabilities to engage in occupations at home. I describe the strategy used to search the literature reviewed in this chapter and reach conclusions regarding what we know about how to support people with profound intellectual disabilities. I draw in particular on research evidence and theories from occupational therapy and occupational science, but also on evidence regarding active support and personalised residential supports. I highlight the gaps in our current knowledge and clarify my research question and aims.

Chapter 4 explains my methodological approach, justifying the choice of qualitative case study over other methodologies. I examine the theoretical perspectives and philosophical roots underpinning the research and in particular the kind of knowledge this interpretive and social constructionist qualitative study has produced and the assumptions it makes about the world. I conclude that chapter with a consideration of relevant conceptual and theoretical frameworks.

Chapter 5 explains the methods of data collection and analysis. I describe the purposive selection of an environment with potential to be an exemplar of practice and a case within it that seemed to offer most opportunity to learn. I gathered data about the case – the work of Esther, supporting five people with severe/profound intellectual disabilities to engage in occupations at home – throughout 2012, using participant observation, interviews and documentary and artefact analysis. In this chapter I also explain in detail how I addressed the ethical issues in this research.

Chapter 6 uses excerpts from field notes and interview transcripts to introduce the setting for the case and some of its key players, notably Matt, Steve, Jane, Becky and Harold.

This sets the scene for **Chapter 7**, in which I tell a story of the case that illuminates my research question, in other words, I present my findings. Throughout the chapter, I refer to three different vignettes, presented at the beginning of the chapter, which illustrate in detail how Esther sought to embed a different way of supporting those living at Cavendish House to engage in occupation.

The discussion in **Chapter 8** evaluates the ways in which this story sheds light on the research question, situating it within the wider literature in the fields of both occupational therapy and intellectual disabilities (including my own previous research). I use my theoretical framework to explain aspects of this story and develop a theory of the case itself, presenting the contribution to knowledge that it makes, discussing its implications for practice and making some recommendations. I also discuss the study's limitations and suggest ideas for further research.

Chapter 9 consists of a short overall conclusion and in the **Appendices**, the reader will find supplementary information, including participant information sheets and additional examples illustrating data analysis.

Chapter 2. LITERATURE REVIEW Part 1:

The context – engaging in occupations

2.1 Overview of Chapters 2 and 3

The aim of my literature review, as suggested by Oliver (2013), is to lay a foundation for my study by establishing the research areas and academic traditions relevant to the field. Following Boote and Biele's criteria (2005) of a good doctoral literature review, I:

- Outline the context, clearly identifying and justifying what is and is not within my study's scope, concentrating on aspects of literature of direct relevance to my research question.
- Situate existing literature in a broader scholarly and historical context.
- Critically examine the research methods used in previous studies so as better to understand whether the claims are warranted.
- Synthesise existing literature to provide a new perspective.

I begin my review in this chapter by exploring the nature of engagement in occupations, why occupational science (the academic discipline concerned with the study of occupation) suggests that this is important and the different levels of engagement that individuals may have in their occupations. I then move on to draw conclusions regarding what we know about how people with intellectual disabilities and complex needs (and particularly profound intellectual disabilities) engage in occupations and how both their primary disability and the quality of the support available in the social environment impacts on engagement. With levels of engagement in occupation generally found to be low, I consider whether this represents an occupational injustice.

In Chapter 3, I critically analyse in more depth the literature that is particularly central to this thesis regarding how occupational therapists and others support people with intellectual disabilities to engage in occupations.

2.2 Engagement in occupation

In 1.2.6, I outlined a number of definitions of the word “occupation”, clarifying that I am using the term to mean activity (or doing) that has meaning, significance or importance for the person performing it, either personally or socio-culturally.

The term ‘**engagement**’ is much used in literature within both occupational therapy and intellectual disabilities. It is sometimes used on its own, but more often reference is to “engagement in occupation(s)”, “occupational engagement”, “engagement in activities”, or “engagement with the environment and/or people”. I explore here the meaning of engagement in this context, clarifying use of this term. I consider how we may tell when someone is engaged and the varying levels of engagement possible. This is important because, as I argue in 2.3.4, an important way of gaining an understanding of people with profound intellectual disabilities’ engagement in occupation is through observation. I go on to explore ideas from within occupational science about why such engagement might be important for health and well-being.

2.2.1 Use of ‘engagement’ by occupational therapists

Creek concluded (2010) that a person might experience four different sensations or feelings when engaging in occupation:

- *A sense of involvement* (close concern, or emotional commitment to a person, place, or thing).
- Choice.
- *Positive meaning* (what one is doing is significant or important to oneself or others).
- *Commitment* (towards a person, activity or thing).

Kielhofner and Forsyth (2008) explain, using the Model of Human Occupation (MOHO), how occupational therapists’ reasoning involves them considering people’s “**occupational engagement**”. They define this as their “doing, thinking and feeling under certain environmental conditions” (2008, p.171) and explain how this engagement is shaped by individuals’ volition, habituation and performance capacities along with the environment. As with Creek’s definition,

the inclusion of volition again makes clear the importance of choice, motivation and meaning (see further 2.2.4). The Model of Human Occupation considers occupational engagement to be multi-dimensional. The complexity of engagement (and why people with intellectual disabilities might experience difficulties with it) – becomes more apparent when considering that it can be seen as having nine different dimensions, as illustrated in Figure 2.1 (Kielhofner and Forsyth 2008).

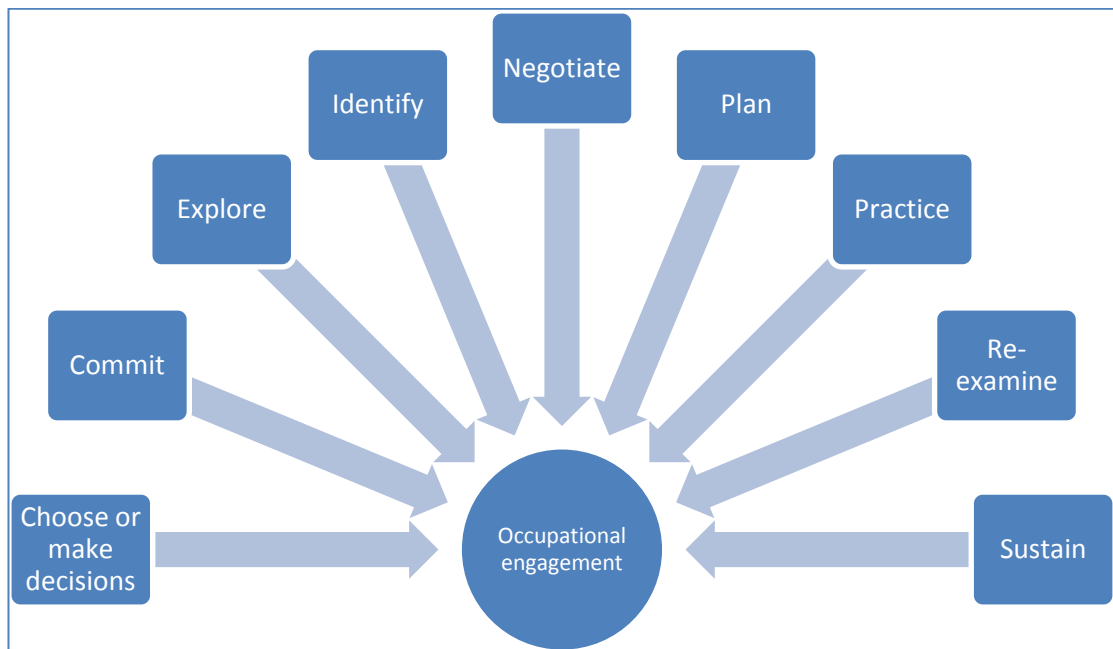


Figure 2.1 Dimensions of Occupational Engagement (Kielhofner and Forsyth 2008 p.172)

2.2.2 ‘Engagement’ and ‘participation’

Within the field of intellectual disabilities, the terms “engagement”, or “participation” in activity are commonly and sometimes interchangeably used. I do, however, see a distinction between these two terms, which I will first clarify before exploring what we can understand about the meaning of engagement from research measuring the extent to which people with intellectual disabilities engage in activity.

The terms “engagement” and “participation” in activity are sometimes used synonymously. The volume of discussion about the meaning of participation suggests however that there is still no consensus on this. The starting point for most researchers (Dijkers 2010) is the *International Classification of Functioning*,

Disability and Health (WHO 2001) definition of “involvement in a life situation”. This definition is, however, often extended by emphasising that participation involves relationships with others. For example, Creek’s definition of “involvement in life situations through activity within a social context” (2010 p.180) seems similar to the definition of community participation used by Dusseljee et al. (2010): performing activities while interacting with others. Eysen et al. (2011) also suggest that participation requires a social context, that is to say essentially involving other people.

My conclusion is that it is generally unhelpful to treat the terms “engagement” and “participation” as synonymous as engagement in occupation need not necessarily involve relationship with others. In the context of people with profound intellectual disabilities, however, this is perhaps, however, a moot point due to their relative inability to engage in occupation without the support of others, as we shall see in 2.3.

2.2.3 Engaging in occupations for health, quality of life and learning

The fields of occupational therapy and occupational science contribute to an understanding of the nature and importance of human engagement in occupation. Human life is seen as characterised by the doing of occupations (Kielhofner 2008) and in many ways what we do “defines” us. Wilcock’s theory of how humans have used occupation as a means of survival and to promote their own health and well-being throughout history (2006) suggests that we are “occupational beings” (Wilcock 2006), not just ‘doing’ for the sake of it, but because it is “wired” into us (Johnson and Yerxa 1989). This understanding is, I would argue, as relevant to those with profound intellectual disabilities as to anyone else.

2.2.3.1 Occupation as a source of health

The range and type of occupations in which an individual participates is perceived as being a determinant of their health (Townsend and Wilcock 2004), which can be “attained, maintained and improved... through doing” (Wilcock 2006, p.21) and in particular through active use of our personal capacities (Whiteford 2000). Rebeiro et al. (1999) for example explored in depth the meaning of engagement for eight women participating in an occupation-based mental health group. Their findings

provide some support for a conceptual model to describe the process of improving mental health through occupation, which they labelled “occupational spin-off” (1999, p.179).

2.2.3.2 Occupation and quality of life, choice and self-determination

Research into quality of life supports the argument regarding the importance of ‘doing’. Quality of life has been conceptualised and measured in many different ways, though a review of the different measures concludes that it is a multi-dimensional construct across core domains of physical, material, productive and emotional well-being, interpersonal relationships, personal development, self-determination, social inclusion and rights (Schalock et al. 2005). Drawing on these and other sources, a consensus panel of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) has developed an agreed set of dimensions (Mansell and Beadle-Brown 2012 pp.34-35). Subjective components of quality of life include in particular an individual’s personal set of values and their appraisal of their own happiness and satisfaction (Schalock and Felce 2004, Schalock et al. 2005).

Amongst quality of life outcomes frequently suggested by the literature (alongside developmental growth and access to the local community) is the extent of engagement in activity (Felce 1997, Perry and Felce 2003). Felce and Emerson (2004) reviewed research into engagement as an indicator of quality of life and concluded that it is this that underpins all the other quality of life outcomes. The IASSID consensus formulation of quality of life cited above explicitly refers to purposeful activity as one of its domains.

Clear relationships have been shown for example between the extent of engagement in meaningful activities and quality of life of people with a mental health diagnosis (Goldberg et al. 2002), and diminished quality of life noted amongst people with Alzheimer’s Disease where insufficient attention is paid to occupational needs (Wood et al. 2009). Research with people with intellectual disabilities in residential settings provides quite a large body of evidence for a relationship between engagement and behaviour, with increase in adaptive behaviour and reductions in levels of challenging behaviour associated with

observed levels of engagement in activity (for example Felce 1999, Hatton et al. 1996, Stancliffe et al. 2008b).

Opportunity to exercise choice in relation to engagement in occupation also seems, unsurprisingly, to be a key element in enhanced self-determination and thereby quality of life. A large Italian study in which professionals rated on standardised scales the self-determination and quality of life of 141 people with intellectual disabilities found self-determination to be conceptually and correlationally linked to more positive quality of life, with those with most severe intellectual disability showing the lowest levels of both self-determination and quality of life (Nota et al. 2007). This theme is taken up further in section 2.3 below.

2.2.3.3 Occupation and development/ learning

Occupational therapists have long-emphasised the potential for learning and development that comes from engaging in occupations (Creek 2010). Although the research evidence base for this could be further developed, emerging findings from neuroscience (for example Ilg et al. 2008) provide some support for this. Learning is by nature difficult for those with severe and profound intellectual disabilities (as we shall see in 2.3.2), which suggests a particular need for plentiful occupational opportunities if the suggested occupational right to develop through engagement in occupation is to be upheld (this is explored further in 2.3.5).

2.2.4 Levels of engagement – motivation, meaning and developmental level

Efforts made to measure the extent of engagement in activity or occupation are suggestive of the possibility of engaging at different levels or to different degrees. One way of looking at levels of engagement is to consider the degree to which an individual engages in a way that is *meaningful* to them, including how what is meaningful might link developmentally with their abilities. An individual's motivation to engage in a particular occupation is affected by the meaning, or the significance or importance (Creek 2003) it has to them. This suggests that supporting someone to engage in that occupation is unlikely to be successful without a good understanding of its subjective meaning to them and the level of engagement they are likely developmentally to be able to achieve. Criteria that

have been used to measure meaningfulness include whether an activity is congruous with an individual's values, whether it provides evidence of competence and mastery and its value in their social and cultural group (Goldberg et al. 2002). Egan and Delaat (1997) describe a meaningful activity as one which fulfils a purpose that is important to the person, or in their culture. What this may imply in the context of someone with profound intellectual disabilities is discussed in 2.3.

Bejerholm and Eklund (2006) identify limitations with any methods of recording engagement that do not attempt to uncover the person's own experience of the meaning of the occupations. Investigating the engagement in purposeful occupations of twenty people with schizophrenia using 24 hour "yesterday diaries" and interviews, they found three different levels of engagement. Each of these was characterised by different daily rhythms (the balance between different types of occupation and between activity and rest) and different amounts of *meaning* assigned to occupational performance (see Figure 2.2).

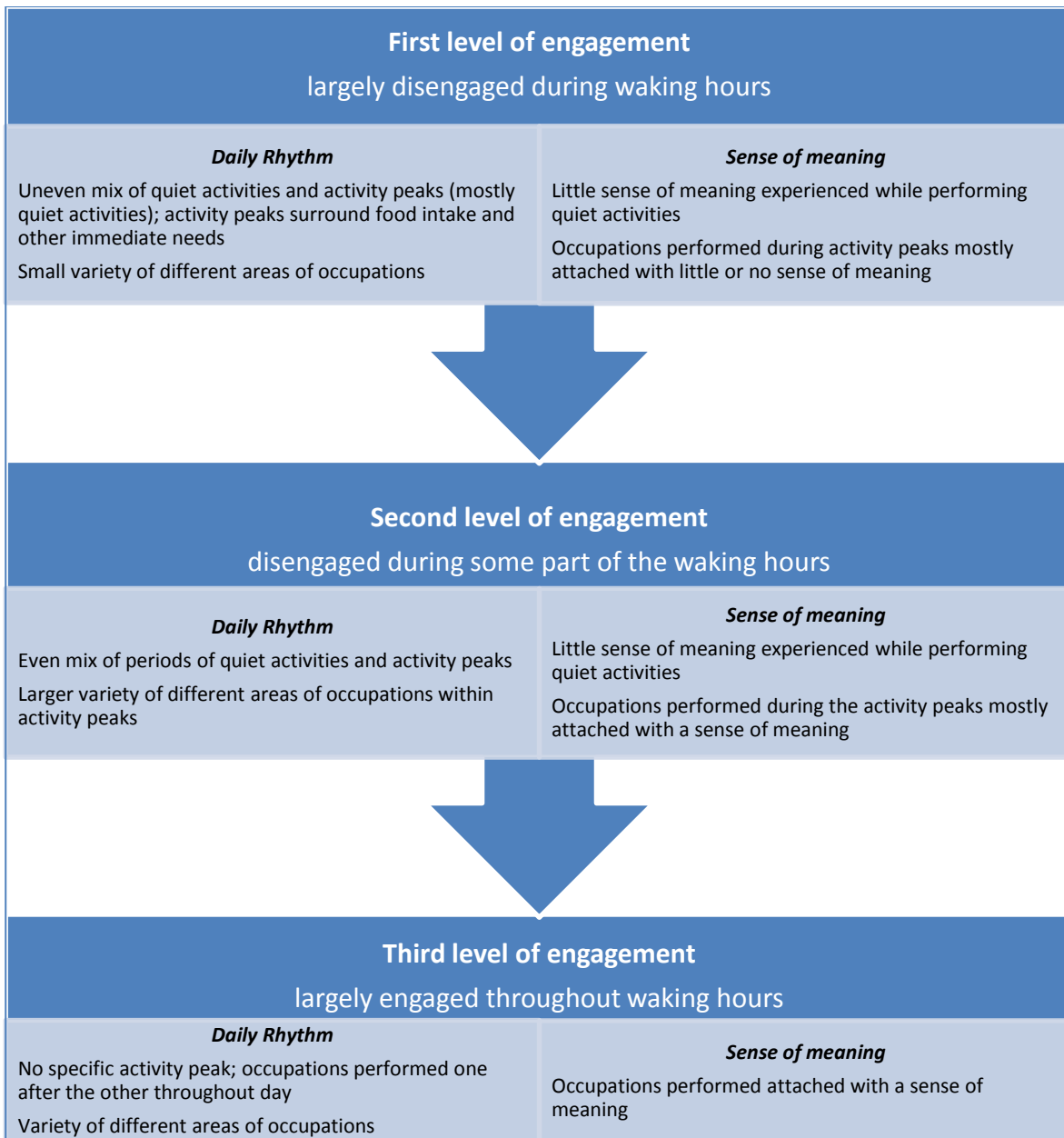


Figure 2.2 Three levels of engagement and their characteristics (from Bejerholm and Eklund 2006, p. 107)

The third level, where there is a general attribution of meaning to a relatively continuous flow or ongoing stream of activity, is contrasted with someone who is largely disengaged at level 1 and who engages in an uneven mix of activity usually in response to immediate needs.

Occupational therapists are highly interested in the meanings that people's occupations have for them and how this links to their motivation for occupation, or volition. This term is used by Creek (2010) to represent a skill of being able to

choose and decide action autonomously, but it is also used within occupational therapy in a wider sense representing the whole of an individual's motivation for occupation, including their personal causation (their belief in skills, whether they expect to succeed or fail and the extent to which they have an internal or external locus of control) along with their interests and values (Kielhofner 2008). A link is suggested between volition and occupational engagement and the MOHO "Re-motivation Process" (de las Heras et al. 2003) illustrates the difference between engaging at an exploratory level (initiating actions, or showing preferences), competent level (indicating goals or trying to solve problems), or achievement level (seeking challenges or taking on additional responsibilities).

In section 2.3.2, I reach conclusions about the levels at which people with profound intellectual disabilities might engage in and, in particular, experience meaning in occupation.

2.2.5 Conclusion

The above literature, from the fields of occupational science, occupational therapy and intellectual disabilities, suggests that occupations may be fundamental to human existence and that meaningful engagement in occupation may be a prerequisite of health, well-being and quality of life. If this is accepted, it is then I feel logical to propose two further points:

- That the *wrong* kind of doing can lead to a *lack* of well-being.
- That injustice may therefore occur when sections of the population for whom occupational engagement is more challenging, such as people with profound intellectual disabilities, are not supported to have occupational choices, opportunities or resources (Townsend and Wilcock 2004).

In 2.3.5 I explore the extent to which people with profound intellectual disabilities may experience such occupational injustices and then in Chapter 3 the ways we can support them to engage meaningfully or authentically in occupation at home.

2.3 Engagement in occupation by people with profound intellectual disabilities and others with complex needs

Having profound intellectual disabilities impacts on ability to engage in day-to-day occupations. This is due both to the direct impact of brain damage on performance capacities, but also, and importantly, to the inter-relationship between these capacities and the opportunities, resources, constraints and demands of the social environment, including, in particular, the quality of support (Mansell et al. 2003b).

In this section, I discuss how individuals with intellectual disabilities and particularly those with profound intellectual disabilities have been found to engage in occupations. New insight is gained from considering this using theory from occupational therapy and occupational science that has not otherwise been applied in the intellectual disabilities field – the Model of Human Occupation (Kielhofner 2008) and occupational justice (Townsend and Wilcock 2004).

2.3.1 Profound intellectual and multiple impairments – the primary disability

Intellectual disabilities are generally categorised as mild, moderate, severe, or profound levels of cognitive impairment (Belva and Matson 2013). People with profound intellectual disabilities are said to have multiple disabilities, the most significant of which is a profound intellectual disability (PMLD Network 2009a). This means a high level of cognitive impairment, though otherwise heterogeneous patterns of functioning (Nakken and Vlaskamp 2007, Axelsson et al. 2013). Each person is affected by their intellectual and other disabilities to different extents and in different ways dependent on the location and degree of damage to their brain (Pawlyn and Carnaby 2013). This has a unique impact on their performance capacities, with particular areas of strength and difficulty in motor, process and communication and interaction skills (Kielhofner 2008).

In the following sections, I explain further how intellectual disabilities and likely additional sensory, or physical disabilities, complex health and communication needs impact on engagement in occupation and occupational performance. The consequence is a need for high levels of skilled support with most aspects of daily

life, an absence of which reduces engagement and potentially leads to behaviour that can be found to be challenging.

2.3.1.1 Cognitive disabilities

Profound cognitive impairment results from significant brain damage before, during or immediately after birth (Pawlyn and Carnaby 2013). In a large study Belva and Matson (2013) collected data on the daily living skills of over two hundred adults with profound intellectual disabilities in the United States and described major deficits in adaptive behaviour. People with profound intellectual disabilities have a notional intelligence quotient of 20 or less, though complexity of need means that this is regarded as difficult to assess meaningfully (Pawlyn and Carnaby 2013).

Learning is possible, but is said to take place very slowly and adults will still have learning needs for skills more usually learnt at very early stages of development, such as cause and effect and turn taking (PMLD Network 2009a). Individuals may have low levels of alertness and difficulties with processing and retaining information, sustaining attention, problem solving and making connections between ideas, in other words process skills, a group of purposeful actions contributing to occupational performance (Kielhofner 2008).

2.3.1.2 Additional disabilities and complex health needs

Significant brain damage increases the likelihood of experiencing additional disabilities and health needs.

a. Physical needs

Although some people with profound intellectual disabilities are fully mobile, more commonly they experience severe physical disabilities including difficulties with gross and fine motor skills and in maintaining posture and balance (Pawlyn and Carnaby 2013). They often require specialised, perhaps bespoke, equipment to aid mobility, maintain functional posture and protect body shape and muscle tone (Vlaskamp and Nakken 1999, PMLD Network 2009a).

b. Complex health needs

People with profound intellectual disabilities may have a range of complex health needs and higher mortality rates than those with mild, moderate, or severe intellectual disabilities (Belva and Matson 2013). The literature suggests, for example, that more than half have seizure disorders and that an estimated 70% suffer from gastro-oesophageal reflux, with risk of dehydration, malnourishment and recurrent pneumonia or other chronic respiratory disorders (Pawlyn and Carnaby 2013). A number could be described as being 'technology dependent', perhaps needing gastrointestinal feeding tubes due to swallowing difficulties, oxygen, or suctioning equipment (Mencap 2011).

Skilled support is needed to maintain health, for example to ensure safe feeding and swallowing, and to recognise needs in someone who may not be able to communicate symptoms such as pain explicitly.

c. Sensory needs

Multiple disabilities are likely to include a degree of multi-sensory impairment and effective support is said to require a good understanding of sensory needs (Mencap 2010). Visual and hearing impairments are particularly common, with Zijlstra and Vlaskamp (2005b) concluding from reviewing the literature that at least 85% experience visual impairments, usually as a result of damage to the visual cortex in the occipital lobe. Evenhuis et al. (2001) estimated that in the Netherlands between 25 and 33% have auditory impairments, though acknowledging this as a potentially substantial under-estimate due to difficulties in diagnosis. People may additionally have impairments in the ability to detect touch, pressure, temperature and pain (WHO 2001, Zijlstra and Vlaskamp 2005b).

Sensory disabilities may lead to hypo- or hyper-sensitivity to particular stimuli leading to sensory seeking or sensory avoiding behaviours (Pawlyn and Carnaby 2013). This could take the form of, for example, hyper-sensitivity to touch, which can be problematic in someone who requires a lot of support with personal care. Some experience difficulties in integrating and modulating information from the various senses (Urwin and Ballinger 2005).

d. Mental health needs

Our understanding of the mental health needs of those with profound intellectual disabilities remains incomplete, largely because of difficulty with assessment and diagnosis, diagnostic overshadowing and uncertainty as to the relevance of generally used criteria (Pawlyn and Carnaby 2013). The causes of behaviour found to be challenging are not necessarily psychiatric in origin and Cooper et al. (2007) found that rates of identified mental health needs varied from 11.4% to 52.2% according to the criteria used. Overall however they concluded that both incidence and prevalence were higher than in both the wider intellectually disabled and general populations. Mencap (2011) regarded these needs as insufficiently considered.

e. Communication needs

Although some people with profound intellectual disabilities have formal communication using speech, symbols or signs, receptive and expressive communication abilities are likely to be at an early developmental level (WHO 2001) with little or no apparent understanding of verbal language (Zijlstra and Vlaskamp 2005b). Some may not have reached the stage of using intentional communication and needs, preferences and reactions to events and people may require interpretation through signals such as reflex responses, actions, sounds, body language, facial expressions and behaviour (WHO 2001, Mencap 2010, Mansell 2010). There may only be limited symbolic interaction with objects (Zijlstra and Vlaskamp 2005a).

f. Understanding behaviour

Belva and Matson (2013) found that behaviours such as physical aggression and self-injury are also common, but it is important not to see these behaviours as part of their disability (Matson et al. 2012). Rather they are likely, in the case of someone with a limited communication repertoire, to be a form of communication that attention has not been paid to other needs, including perhaps boredom, or pain.

2.3.2 Profound intellectual disabilities and engagement in occupation

Given the above, it is perhaps not surprising that people with profound intellectual disabilities are likely to struggle to engage in occupation and to require substantial support to achieve this (Mansell et al. 2003b). Understanding developmentally what engagement means for someone with this degree of disability and the level of engagement in occupation that they are likely to be able to achieve seems important if that support is to be effective. The challenge is that we cannot rely on people being able to understand and self-report on what is meaningful to them and this therefore needs to be interpreted from their behaviour.

Echoing my earlier discussion of occupational therapy terminology, the importance of activity having meaning to a person with profound intellectual disabilities is recognised by Mencap (2011). This does imply to me that meaningful and authentic engagement in occupation is possible. The literature suggests that such engagement may be characterised as follows:

- Meaningful activities are suggested to be ones that recognise and take into account that many people experience the world largely at a sensory level (Mencap 2011), with their awareness more likely to be of individual sensory stimuli within an activity than the activity as a whole (Pool 2012).
- The Pool Activity Levels (Pool 2012) illustrate the different degrees of ability someone with a cognitive impairment may have to engage in occupation. Pool describes four different “activity levels”, ranging from reflex to planned and suggests ways to support engagement at each of these levels. This theory has been found to have strong content, criterion, concurrent and construct validity (Wenborn et al. 2012) and is illustrated in Figure 2.3. Although devised to support the engagement in occupation of people with dementia, occupational therapists have found this theory a helpful way of explaining to others how best to support people with severe and profound intellectual disabilities to engage in occupation (Lillywhite and Haines 2010) and my own experience concurs with this.

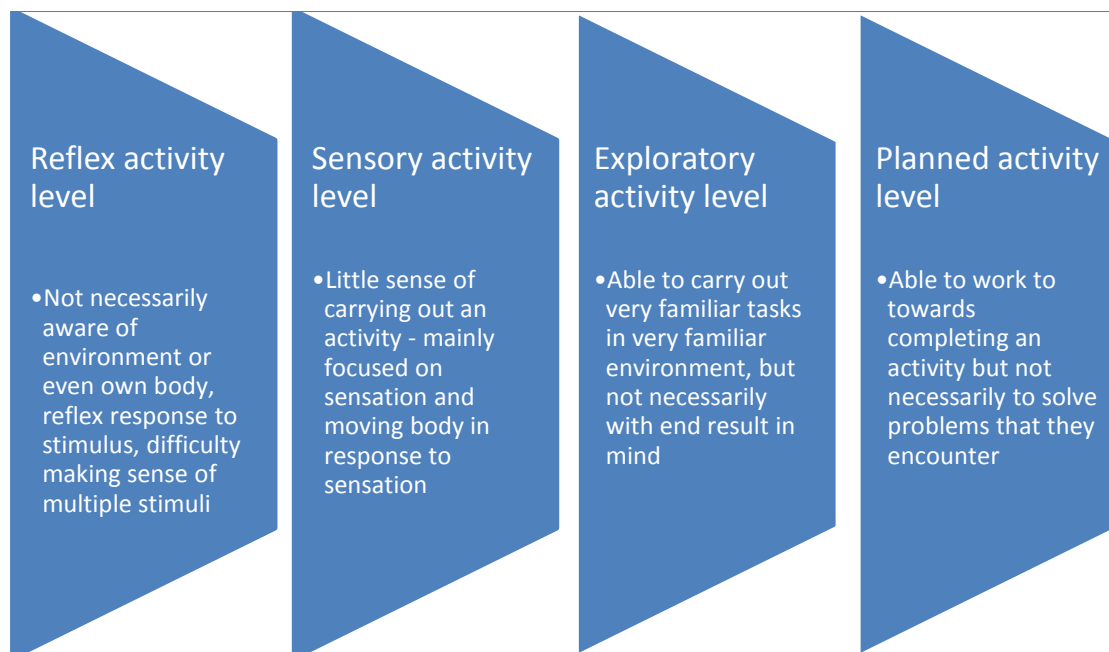


Figure 2.3 Pool activity levels (Pool 2012 pp54-5)

- Through interviews with support staff and participant observation, Mahoney and Roberts (2009) explored whether or not activities available to adults with moderate and severe developmental disabilities in a United States day centre were meaningful to them (and thus, they argued, occupations). They found that activities were meaningful for both parties when there was both engagement and reciprocal interaction, that is to say co-occupation occurred, with each person influencing the responses of the other. Whether any of the participants in this study with “severe developmental disabilities” had profound intellectual disabilities is, however, unclear.
- Bunning (1998) investigated the impact of an “individualised sensory environment” (p 387) on adults with severe and profound intellectual disabilities’ interactive behaviour outside of that environment. She used five categories (without specifying their theoretical basis) to describe participants’ interactive behaviours on a spectrum from passive or self-focused engagement, to engaging with another person and then engaging simultaneously with a person and object (see Figure 2.4). It seems to me likely that there is meaning for the individual when they are engaging

with a person, an object or both, but debatable whether this is the case when they are in self-active, or, in particular, self-neutral engagement.

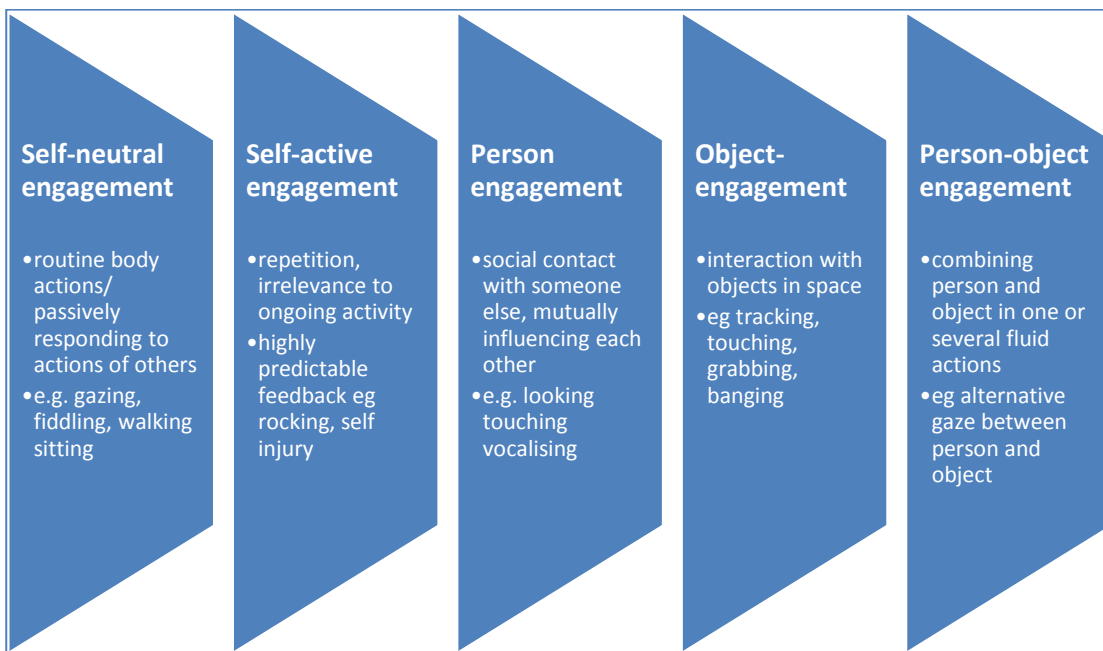


Figure 2.4 Levels and types of interactive behaviour (Bunning et al. 1998 p.388)

Although the above theory gives us some idea of what meaningful or authentic engagement might be for someone with profound intellectual disabilities, this could be more fully understood and illustrated.

2.3.3 Unmet high support needs – a secondary disability

Insight from the social model into how people are disabled by society rather than their bodies (Coles 2001) has provided an alternative to the traditional medical perspective view of disability. Rather than seeing these as dichotomous views, however, it can be helpful, particularly perhaps in the case of those with high levels of impairment, such as those with profound intellectual disabilities, to view disability as neither purely medical, nor purely social (WHO 2011). Interactionist and bio-psycho-social models such as the International Classification of Functioning, disability and health (WHO 2001) understand functioning and disability as dynamic interactions between the person and their environment. Drawing on such interactionist models, disability can importantly be seen not a fixed attribute of an individual, but rather as residing in the fit between them and their environment:

“Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (United Nations 2008, p2).

In order to maintain good health and to engage in a rich variety of meaningful occupations, people with profound intellectual disabilities are described as very likely to need a lot of support from others, remaining relatively unable to engage in activities of daily living without this (Mansell et al. 2003b, Vlaskamp and Nakken 1999). The Model of Human Occupation highlights the “intimate and reciprocal” relationship between people and their environment (Kielhofner 2008, p.111), with these individuals’ occupational engagement particularly dependent on the opportunities, resources, constraints and demands of their *social* environment. Essentially this equates to the opportunities available and the degree to which support received enables rather than acts as a barrier to engagement.

In the quotation at the beginning of Chapter 1, Mansell (2010) makes clear the possibilities – and rights – of people nonetheless to achieve their potential and to have what he refers to as “a good life”. This requires skilled day-to-day support that understands complex health needs and recognises individual means of

communication and effective interaction. This includes input from specialist professionals such as physiotherapists, speech and language and occupational therapists. Appropriate opportunities and the right support can facilitate engagement, including in domestic activities around the home and individuals' own self-care (Mansell and Beadle-Brown 2012) and even if this is very partial, it can nonetheless be meaningful. Donati, for example (2000) explored the occupational lives of two young people with severe intellectual disabilities who had skilled, individualised support, focusing on what was meaningful and purposeful to them and on developing their abilities. The website of Mencap gives examples of people with intellectual disabilities and complex needs who are well supported to participate in day to day occupations (Mencap 2014a, 2014b).

The link between good support and occupationally richer lives comes out strongly in the findings from Petry et al.'s (2007) interviews with 76 parents and support workers of people with profound intellectual disabilities. Mansell et al. (2003b) observed 343 adults with intellectual disabilities in 76 English residential homes measuring adaptive and problem behaviour and observing engagement in daily activities at home and support given. They reached a similar conclusion to Felce et al. (1999) that the only important predictor of engagement in meaningful activity other than an individual's skills or adaptive behaviour, is whether or not they are supported in a way that directly facilitates such engagement.



In conclusion, seen from the perspective of interactionist models of disability, there is a dual aspect to an individual's profound intellectual disability. There is the direct influence of the impairments of the primary disability, but potentially also a secondary disability if society offers poor quality support and limited opportunity to develop through occupational engagement. In 2.3.5, I describe low levels of engagement in occupation, indicative of many people with profound intellectual disabilities experiencing this secondary disability and argue that this is an occupational injustice.

2.3.4 People with intellectual disabilities – indicators of engagement

Research has often sought to understand or measure people with intellectual disabilities' engagement in activity, or the "direction and extent of [their] engagement with the physical and social environment" (Felce and Emerson 2004, p.354) as this can be seen as an indicator of the quality of their support. The problem, however, when exploring the extent of engagement and the meaning of occupations to people with severe cognitive impairment such as profound intellectual disabilities, is that they are unlikely to be able to self-report this. Felce and Emerson (2004) reviewed the findings and methods of investigation of research into people with intellectual disabilities' engagement in activities. They concluded that insight into the existence and degree of engagement has tended to come from observing and interpreting behaviour. Although finding the concept operationalised in different ways by different researchers, their suggested typical set of definitions is reproduced in Table 2.5.

Social engagement	Speech, sign, gesture, or other attempt to gain/ retain attention of another (except by challenging behaviour). Giving of attention, evidenced by eye contact or head orientation, to another who is reciprocally interacting
Non-social engagement – domestic/ personal/ leisure/ other	Getting ready for/ doing/ clearing away a household/ gardening/ self-help/ personal/ recreational/ educational/ other activity
Challenging behaviour	Self-injury, aggression towards other, damage to property, stereotypy, other inappropriate behaviours
Disengagement	All other behaviour, including no activity, passively holding materials, walking when not part of an engagement activity, and un-purposeful activity such as manipulating materials to no apparent purpose

Table 2.5 Typical set of behavioural observation definitions regarding 'engagement' (from Felce and Emerson 2004, p.356)

Time use studies are the most well-established methods of exploring the nature of people's occupations (Wilcock 2006). There are a number of examples that have involved the systematic direct observation of people with intellectual disabilities' engagement in activity, for example those reported by Engleman (1999), Klatt et al. (2000) and Jones et al. (1999). Subjective judgement on the part of the observer is involved and Ware (2004) cautions against the risk of merely substituting the

values and attitudes of the observer when seeking the views of the observed. Observation does seem to produce useful insight into engagement, as Ware herself acknowledges, where steps are taken to recognise and minimise subjectivity by knowing the person really well from a wide range of information (explored in more detail in 3.3.5). Vos et al.'s research (2012) also shows promising potential use of physiological measurements (respiration and heart rate variability in their study) to validate such behavioural observations.

There are various suggestions as to indicators of engagement. The Engagement Profile and Scale (Department for Education Specialist Schools and Academies Trust 2011), for example, developed as a pathway to meaningful and personalised learning for young people with complex learning difficulties and disabilities, encompasses seven indicators of engagement (see Figure 2.6). Its concepts seem relevant to measuring engagement (for example it is theoretically similar to the constructs in the MOHO taxonomy in Figure 2.1), which suggests face validity, though there is little information about its theoretical underpinnings.

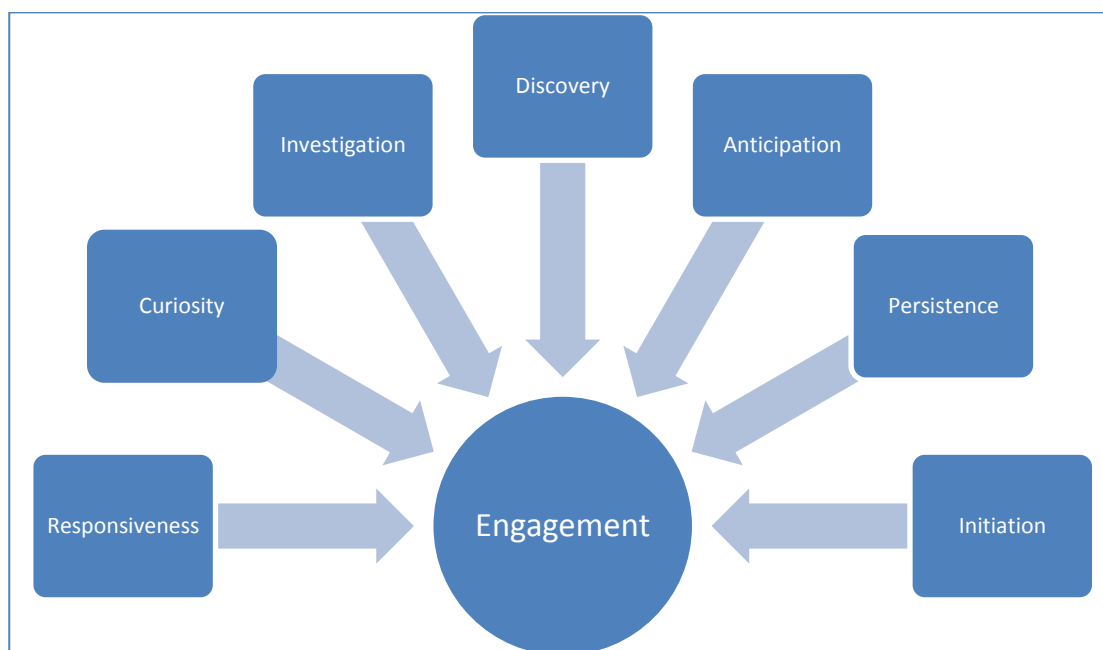


Figure 2.6 Engagement Profile and Scale (DfESSAT 2011, p.3)

In a study involving three adult men with intellectual disabilities, Klatt et al. (2000, p.496) defined engagement as “actively manipulating an item (activity) presented”. Although they interpreted this widely, their definition could be seen as rather

narrow, if engagement is merely a response to a stimulus presented by someone else. Many people with profound intellectual disabilities *do*, however, require opportunity for occupation to be presented to them (see 2.3.2).

Similarly recognising doing activity (or initiating action) as indicating engagement, Mahoney and Roberts (2009) suggested additional indicators of positive affect and focused attention. The level of interest and engagement in immediately available activities (in this case of people with Alzheimer's) was also judged by Wood et al. (2009) from degree of focused attention to people, things and events. People with profound intellectual disabilities may have low, or fluctuating, levels of alertness, which has been found most useful to view as "the level and functionality of an individual's interaction and engagement with their environment" (Munde et al. 2009, p.475). Alertness seems, therefore closely linked to occupational engagement and can perhaps be seen as a precursor to it.

A slightly different focus of Mansell et al. (2002) is on engagement (or participation) in meaningful activity as the extent to which an individual is involved in *directing or carrying out* their activities of daily living. This definition has merits, despite their suggested four-point rating scale of the nature of engagement being incompletely defined and limited explanation of exactly how it was used. It acknowledges that someone may very much be engaged in an activity in which they are not physically able to participate, if they are directing its completion. Along similar lines, Dijkers (2010, p.13) suggests an expansion to the "involvement in life situations" definition of participation, by adding "which includes being autonomous to some extent, or being able to control one's own life, even if one is not actually doing things [by one's self]". Certainly Arvidsson et al.'s review (2008) of studies exploring aspects of "participation" in young adults with mild intellectual disability suggested that a key aspect was self-determination, including autonomy, independence, self-empowerment and decision making.

2.3.5 Low levels of engagement in occupation – an occupational injustice?

Mansell and Beadle Brown (2012) summarised the findings from all available studies investigating the average amount of time people with intellectual

disabilities spend engaged meaningfully in activities. The findings varied considerably, but they concluded that compared with the general population as a whole who typically engage in meaningful activity and relationships over 90 per cent of the waking day, engagement levels for people with intellectual disabilities average 39%. This figure is somewhat crude, as it masks a wide range from 17-70% across all the studies. The lower end of this range however does imply that some people have extremely low levels of engagement. In this section, I explore some of this research over the last 25 years, both in the United Kingdom and further afield, consistently finding that people with intellectual disabilities (and those with complex needs in particular) have levels of engagement in activity notably lower than the typical engagement levels of the population as a whole.

It is pertinent to consider what research and policy tells us about the occupational lives of people with intellectual disabilities from an occupational science frame of reference (see for example Wilcock 2006), a perspective that my search of the literature suggests has thus far been ignored. The occupational science construct of occupational justice (Townsend and Wilcock 2004) expands on arguments for social justice. Drawing on this theory suggests that when the occupational lives of those with complex needs are short of their full potential, there is consequent risk to health and well-being and one or more of four overlapping occupational rights proposed by Townsend and Wilcock (2004) are infringed. These rights are set out in Figure 2.7 and infringement of them risks injustices of occupational deprivation, occupational alienation, occupational imbalance and occupational marginalisation.

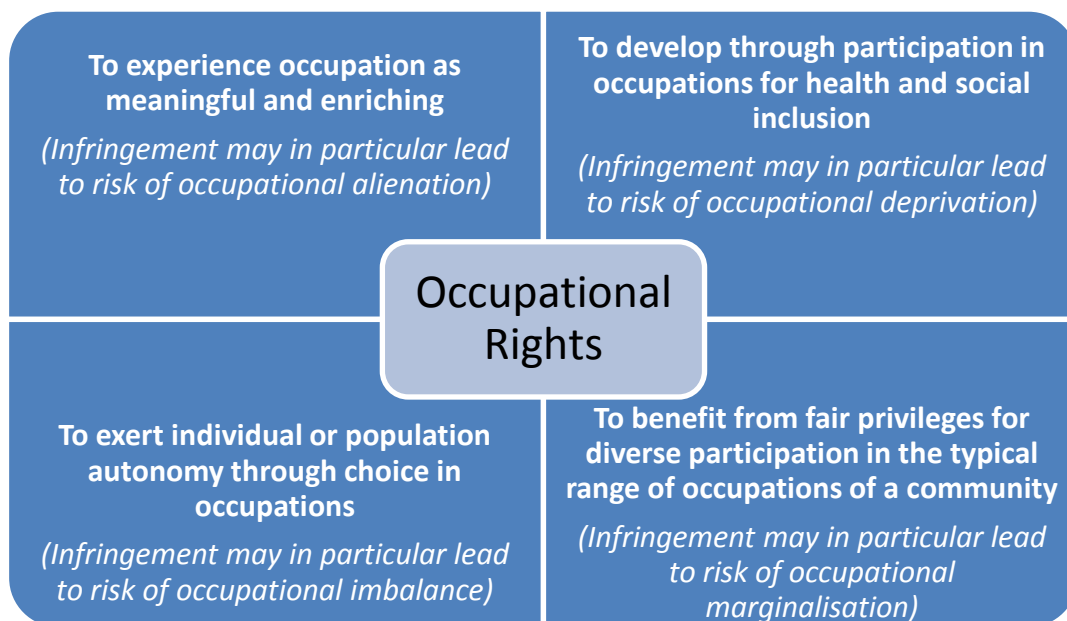


Figure 2.7. Four Occupational Rights, as proposed by Townsend and Wilcock (2004, p.80)

Townsend and Wilcock (2004) described this theory of occupational rights and risk factors as exploratory and 11 years later, this seems still to apply. It has been related to forensic mental health inpatients, (Farnworth et al. 2004, Whiteford 2000), and very old people in Sweden (Nilsson and Townsend 2010), but the only examples of specific use to consider the occupational lives of people with intellectual disabilities are by Mahoney (2009) and Mahoney and Roberts (2009). It is arguably implicit in some of the general and specific Articles of the Convention on the Rights of Disabled Persons (United Nations 2008), for example Articles 19, 23, 28, 29 and 30, but does not explicitly map to convention. My experience of working with people with intellectual disabilities over 20 years, mirrors the previously referred to conclusions of Mansell and Beadle Brown (2012) regarding their low levels of engagement in meaningful activity. This and the research evidence explored below strongly suggests to me that many people, and in particular those with complex needs, are at risk of occupationally deprived, occupationally alienated and occupationally marginalised lives.

2.3.5.1 Occupational deprivation

As previously stated, people with profound intellectual disabilities require support from others in order to engage to their full potential in occupations. Such support

can and should improve lives, but research often reveals people who are nonetheless often found to be inactive and lacking in meaningful occupation, bored and isolated.

By way of example, researchers from University of Groningen have undertaken a number of large studies providing interesting insight into the lives of people with profound intellectual and multiple disabilities in the Netherlands. Zijlstra and Vlaskamp (2005a), recording actual leisure provision for 160 people over a period of four weekends in seven residential facilities, found a total mean of only 3.8 hours of leisure activities each weekend. Although large variation between individuals means this figure should be interpreted cautiously, it is notable that within this limited time nearly half of the few leisure activities that did occur involved watching television or listening to music, with older people receiving significantly fewer opportunities. Overall, the study indicated severely restricted leisure provision, with “more empty hours than quality time” (2005a, p.446). In a second study, Vlaskamp et al. (2007) investigated how people passed the weekly average of 14.2 hours they spent in seven day activity centres. With 28.9% of this time spent on group activities and 13.0% on individual activities, they questioned not only the limited amount of time engaged, but also the extent to which those activities that did take place were purposeful, meaningful or productive.

In the 2005 study, Zijlstra and Vlaskamp suggested that one of the reasons for a low level of engagement in activities by those with complex needs may be a lack of advanced planning. Planning does not necessarily mean that activities will actually happen though, as an earlier study suggested that one third of activities planned for adults and children in five residential and non-residential centres (Vlaskamp and Nakken 1999) were cancelled, often with no alternative activity provided. This risks many unoccupied hours despite the availability of skilled support (Zijlstra and Vlaskamp 2005a). The findings from these studies echo earlier findings from Wales where Lowe et al. (1992) used interviews and direct observation to investigate the activity programme of over 200 people, including at least 33 with complex needs, attending two day centres. They noted discrepancies between planned activities on timetables and those that actually happened and a low level of engagement in those activities that did take place.

Low levels of staffing may partially explain this, though individuals' complex health needs are also a factor, with Zijlstra and Vlaskamp (2005a) noting how both major and minor medical conditions impact on engagement in planned activities.

Vlaskamp and Nakken described how many are simply "lost in the whirl ... of physical and nursing care" (1999, p.108) and little improvement was indicated more recently when Van der Putten and Vlaskamp (2011) explored the nature of the activities 23 people experienced over 4 weeks in a single Dutch day centre. They found that 63% of the time was spent in activities either related to personal care (potentially more complex or time consuming for those with profound intellectual disabilities), beginning or ending the day, or waiting and resting.

These studies do strongly point to high levels of inactivity and although many were carried out by the same group of researchers, others have reached similar conclusions. Research consistently suggests that people with intellectual disabilities are physically less active than the population as a whole, for example in Australia (Temple et al. 2000, Temple and Walkley 2003); France (Salaun and Berthouze-Aranda 2011); Taiwan (Lin et al. 2010) and England, where over 1550 people were surveyed (Emerson et al. 2005). Robertson et al. (2000) sought the perspectives of care staff of 500 adults with intellectual disabilities in the UK through questionnaire and structured interview. They concluded that 84% of men and 88% of women could be regarded as physically inactive with activity levels on average at that which would be expected of those in the 75 plus age group of the population as a whole. Those at particular risk of being physically inactive seem once again also to be those with more complex needs (Finlayson et al. 2009).

Mansell et al. (2002) suggested that such lack of occupational engagement is reflective of the performance of those supporting (either attributable to them, or the structure they are working in), contributing to secondary disability (see 2.3.3). Without the support needed for meaningful engagement in occupations, the right to develop through participation is infringed. Individuals have a prolonged preclusion from engagement in necessary or meaningful occupations due to factors outside their control (Whiteford 2000) and the injustice of *occupational deprivation* occurs. If the human occupational brain constantly needs the stimulation from engaging in a range of occupations to develop, as Wilcock

suggests (1995), lack of stimulation limits development, which is particularly tragic in the case of those for whom learning is already difficult.

2.3.5.2 Occupational alienation

The findings of studies both in the United Kingdom and elsewhere strongly point to a correlation between adaptive behaviour (that is skill level, or degree of intellectual disability) and total level of engagement (Mansell and Beadle-Brown 2012). Felce et al. (1999), for example, used non-participant observation of 56 people from 32 English day centres and residential homes and the actions of those supporting them to gain understanding of their occupational engagement. They found a highly significant association between levels of engagement and ability, concluding that those with more severe disabilities lived more segregated and under-occupied lives. Similarly, Allen and Hill-Tout's (1999) survey and time-use diaries indicated engagement in activities on average only 50% of the time people with intellectual disabilities and challenging behaviour attended English day services, though there was considerable variation between people and services. As data was gathered from reports completed by day centre staff, these figures may not be an entirely accurate picture, though if anything, they are possibly inflated and actual engagement levels may be even lower. A survey in the USA of siblings of adults with intellectual disabilities found that amongst the predictors for risk of having no daytime activities would appear to be a much higher level of emotional, behavioural and health problems and lower functional abilities (Taylor and Hodapp 2012), that is to say, those with complex needs.

A decade later little seemed to have changed with Emerson (2008) finding from a survey of activity over the preceding month that people with profound intellectual disabilities were notably less likely than others to have participated in a wide range of meaningful activities. A plea has been made for more attention to be paid to their specific needs and an increased focus on stimulating and meaningful day time activities, to avoid them being "forgotten and ... at home with nothing to do" (PMLD Network 2009b, p.13). Mansell and Beadle Brown (2012) concluded similarly about the lack of improvement over time.

The evidence therefore suggests, perhaps unsurprisingly, that those with the lowest levels of occupational engagement are those with the most severe disabilities and the more severely disabled someone is, the more likely that they will be under-occupied. If the only activities available to people do not offer meaningful or enriching occupational experiences (as described in 2.3.2) then as well as being occupationally deprived, they then can also become alienated from their occupational nature through lack of opportunity to engage in an individually meaningful way. This *occupational alienation* arguably infringes another proposed occupational right (Townsend and Wilcock 2004) to experience occupation as meaningful and enriching. People with profound intellectual disabilities and other complex needs appear at particular risk of this.

2.3.5.3 Occupational marginalisation from lack of meaningful engagement in occupation at home

Engagement in occupations relates additionally to empowerment, inclusion in society and citizenship. People without the opportunities to make everyday choices and decisions and to exercise autonomy as they participate in a wide variety of occupations lack self-determination and may become *occupationally marginalised* (Townsend and Wilcock 2004). In Western culture, there is a general expectation that people will sustain a level of occupation consistent with their age, which can be an indicator of status (Felce and Emerson 2004). Exclusion from everyday expectations (such as to have and to maintain one's own home) are however all too often experienced by people with profound intellectual disabilities and they remain amongst those in society at greatest risk of this marginalisation (Dawkins 2009). Being marginalised in the eyes of those providing support puts people in positions where they are at risk of abusive care practices such as those revealed to be commonplace in the Winterbourne View residential home (Department of Health 2012).

Using family members and carers as informants, Mencap (2011) researched the needs, services and occupational lives of 81 adults with profound intellectual and multiple disabilities living in a single London borough. Their findings suggested that on average people were away from home for only 20-35 hours per week (3-5 hours per day) and awake at home for an average of 12-15 hours per day. Many of

the activities in which people were described as engaging at home seemed largely passive in nature, with one individual spending 48 hours per week/ 7 hours per day “chilling”, another watching television for 5 hours per day and a third spending 4 hours per day “listening to the radio”. The exact nature of time spent during those hours is unclear in the study’s findings and the potential of sharing quieter time in periods of ‘hanging out’ to provide contact and presence and to be a valued activity has been demonstrated by Johnson et al (2012 p.336). Nonetheless, Mencap’s findings are suggestive of extensive periods of unoccupied time. Ensuring that there is plenty of opportunity for engagement in activities at home seems all the more important for people who may spend extended periods of time there if occupational injustice is to be avoided.

A person’s home presents a myriad of opportunities for regular, repetitive involvement, however partially, in ordinary daily activities (Mansell and Beadle-Brown 2012). Supporting partial, but meaningful, engagement in ordinary activities such as cooking, cleaning, gardening and one’s own self-care is an alternative to the ‘hotel’ model of care illustrated in Figure 2.8, where people are inactive whilst those who support them cook and clean (Jones and Lowe 2005).

Participation in domestic life is relatively ignored in discussions about people with intellectual disabilities’ community participation. Verdonschot et al. (2009) found it referred to as a domain of community participation in only one of the publications they systematically reviewed, this being a United States study by Wilhite and Keller (1996). The inclusion criteria for their review seem however not to have retrieved studies related to active support that I review in section 3.4.1. The importance of domestic life is however recognised in theoretical models of human functioning such as the International Classification of Functioning, Disability and Health (WHO 2001) and the American Association on Intellectual and Developmental Disabilities theoretical model on intellectual disabilities (Wehmeyer et al. 2008). It is also included as one of the agreed dimensions in the single coherent quality of life framework agreed by the International Association for the Scientific Study of Intellectual Disabilities (IASSID) (Mansell and Beadle-Brown 2012).



Figure 2.8 Vicious Circle of disempowerment in 'hotel' models (Jones and Lowe 2005, p.122)

Some of the studies referred to previously point to particularly low levels of engagement in household or domestic activity at home. For example, Felce et al. (1999) using non-participant observation found people with varying levels of intellectual disabilities to be engaged in domestic activities at home on average 12.9% of the time. The range of 0 - 27.8% indicated, however, that some people, particularly those with more severe disabilities, had no involvement in this at all. Similarly, Felce and Lowe (2000b) surveyed the residential services of 36 Welsh people with severe intellectual disabilities and particularly severe challenging behaviour, once again finding limited evidence of engagement in activity and participation in domestic life. Felce, Perry and Kerr (2011) then undertook secondary analysis of data from other studies on the extent of participation in household activity of 721 adults in Wales and England and again found a strong association with adaptive behaviour, in other words, with levels of individuals' skills.

Finlayson et al. (2009), noting the very low levels of physical activity of 433 Scottish adults with intellectual disabilities (and especially those with more severe intellectual disabilities) found that overall only 8.3% regularly became involved in housework and 4.2% in gardening at home. They argued that increased engagement in these activities could result in increased physical activity and therefore fitness. Moreover, such participation also allows development of skills which may be transferable to other occupations. Harr et al. (2011) used a mixed methods case study to explore how the engagement of one American man with moderate intellectual disability and spina bifida's engagement in a household task of washing the dishes influenced his participation elsewhere in the community and at work. They noted not only the increase in his skills, but also his increased self-determination and satisfaction with his occupational performance and the positive perceptions of others regarding his capabilities and how this carried over into community and work activities.

2.3.5.4 Policy responses to low levels of occupational engagement at home

Policy and expert opinion in the field of intellectual disabilities over the last 30 years has consistently promoted people's rights to have full and meaningful lives, to develop skills related to independence, to exercise choice and be fully included in society. Such policies include normalisation and social role valorisation (Wolfensberger 1992), the *Five Accomplishments* (O'Brien 1992) and *Valuing People* (Department of Health 2001). More recently, *Valuing People Now* (Department of Health 2009) and *Raising our sights* (Mansell 2010) make particular reference to the needs of those with complex needs such as those with profound intellectual disabilities. Those documents recognise the lack of progress towards improving their lives, with *Valuing People Now* explicitly 'including everyone' as a key priority (2009, p.5).

Interestingly, however, in concentrating on the, admittedly extremely important, promotion of community presence and participation, the risks of occupational deprivation, alienation and marginalisation from spending a lot of time at home with too little to do often seem to be missed. *Raising our sights* (Mansell 2010), implicitly takes an occupational approach in its review of services for people with profound intellectual and multiple disabilities and recommendations for

improvements. Even here however, despite clearly articulated goals of increased opportunities to participate in meaningful work, education and leisure activities outside the home, and skilled support to enable this, there is no mention of what people spend their time doing when they are at home. The focus of SCIE (2007) is similarly limited to community involvement with no mention of occupational engagement at home.



The evidence presented so far strongly suggests that many people with profound intellectual and multiple disabilities have extremely low levels of engagement in occupations, both generally and where they live. Those with the greatest needs seem the least occupied and at the most risk of occupational deprivation, alienation and marginalisation. Engagement seems to be linked to the opportunities available and the quality of support received and to individuals' social environment. In Chapter 3, I continue my review of the literature, moving on to a more in depth critique of the evidence regarding how we can avoid this occupational marginalisation, deprivation and/ or alienation, by supporting people with profound intellectual disabilities well to engage in their occupations. I focus in particular on the role that occupational therapists may have in this.

Chapter 3. LITERATURE REVIEW Part 2:

Occupational therapy supporting people with profound intellectual disabilities to engage in occupation

Having contextualised my topic, I continue my review of the literature in this chapter, moving on to a more critical discussion of *how* we can support people with profound intellectual disabilities well to engage in their occupations and the *kind* of relationship that best supports such engagement. I begin by explaining the strategy that I used to search for literature explored in this chapter, before evaluating the evidence base underpinning occupational therapy supporting people with profound intellectual disabilities to engage in occupations (in particular at home, for reasons explained in 3.5.1 and 5.4.1). I critique research evidence and theory from occupational therapy and occupational science, as well as related research and theory regarding *Active Support* and *Personalised Residential Supports* from outside the occupational therapy profession.

3.1 Data sources and search strategy

I searched within the PubMed, Allied and Complementary Medicine (AMED), Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PsychINFO databases for evidence published during the period 1994 – 2015. Drawing on and adding to the keywords used by Verdonschot et al. (2009) in their study on community participation, several terms for ‘population’ were combined with a broad range of keywords related to ‘outcome’ and ‘intervention’. I searched on title and/or abstract and limited returns to those relating to adolescents and adults and to sources in English.

Search #1 – population: using the following search terms:

Intellectual disability OR intellectual disabilities OR intellectually-disabled, OR intellectually disabled OR intellectually impaired OR intellectually handicapped OR mentally disabled persons OR mentally handicapped OR

mentally disabled OR mentally retarded OR mentally impaired OR mental retardation OR learning disabilities OR learning disability OR learning disorder OR developmental disabilities OR developmental disability OR developmentally impaired OR developmentally disabled OR learning difficulties OR learning difficulty OR complex needs.

Search #2 – outcome: using the following search terms:

Activities of daily living OR activities OR occupation OR engagement OR engage OR participation OR participate OR quality of life OR domestic OR home OR housekeeping OR domestic life OR homemaking OR recreation OR leisure OR hobbies

Search #3 – combined search #1 AND search #2 using AND

Search #4 – intervention: using the following search terms:

Occupational therapy OR occupational science OR occupational justice OR occupational injustice OR clinical reasoning OR active support OR personalised residential supports

Search #5 – combined search #3 AND search #4 using AND

My searches gave me a good idea of the publications in which relevant articles were likely to be published. Arranging to be alerted automatically each time a new edition of the following journals was published, facilitated a regular search of their contents pages (2009-2015) for potentially relevant articles:

Journal of Intellectual Disability Research; Journal of Applied Research in Intellectual Disabilities; Research in Developmental Disabilities; British Journal of Learning Disabilities; Intellectual and Developmental Disabilities; Tizard Learning Disability Review; Journal of Intellectual and Developmental Disability; American Journal on Intellectual and Developmental Disabilities; British Journal of Occupational Therapy; Australian Occupational Therapy Journal; Scandinavian Journal of Occupational Therapy; American Journal of Occupational Therapy;

Canadian Journal of Occupational Therapy; OJTR: Occupation, Participation and Health; Journal of Occupational Science.

3.2 Critical overview of evidence for occupational therapy supporting engagement

The literature from 1994 to 2015 contains a relatively small number of UK and international sources relevant to occupational therapy intervention supporting people with profound intellectual disabilities and complex needs to engage in occupation. Additionally, two research articles from outside these years seem particularly pertinent and still to have relevance despite their age. Most sources were published in peer-reviewed journals, mainly in occupational therapy (such as the British Journal of Occupational Therapy) but also occasionally in intellectual disabilities (such as the British Journal of Learning Disabilities). Additionally, there are some sources from non-peer reviewed newsletters and some grey literature, notably two unpublished theses, which I found from the bibliographies of sources produced by my searches.

This section gives an overview of this evidence, beginning with research studies, both the large proportion seeking the perspectives of occupational therapists about their own practice, as well as other types of qualitative and quantitative research. I then highlight reviews of the literature carried out by others, documents suggesting standards for practice in this area and finally opinion pieces, descriptions of practice and other types of evidence. In 3.3, I draw conclusions from this evidence about occupational therapy practice.

3.2.1 Research seeking views of occupational therapists about their own practice

Over half of the relevant research articles report research exploring the views of occupational therapists about their own practice. This reflects the emerging character of the evidence base, with many studies exploring the nature of current practice, as opposed to evaluating its effectiveness.

A number of authors have used **surveys** to gain the perspectives of larger numbers of occupational therapists (summarised in Table 3.1).

Author and year	Publication type	Population	Aim
Malic (1993)	Un-published masters dissertation	49 occupational therapists and assistants in one English county recorded and categorised a week of their work	Investigate occupational therapy service provided for people with intellectual disabilities
Pimentel and Ryan (1996)	Peer-reviewed journal	14 UK occupational therapists	Compare traditional hospital role with emerging community role (results guided subsequent interviews)
Bowring et al. (1999) and (2001)	non-peer reviewed newsletter	94 UK intellectual disability occupational therapy services	Investigate practice trends/ assessments used
O'Neal et al. (2007)	Peer-reviewed journal	145 occupational therapists (adults, developmental disabilities, including intellectual disabilities, USA)	Investigate how theory used to guide practice
Lillywhite and Haines (2010)	Peer-reviewed report (phase 1)	69 UK occupational therapists	Investigate nature of practice (results guided interviews in later phases)

Table 3.1 Research seeking occupational therapists' views by survey

These studies (or the survey parts of two that went on additionally to interview respondents) highlight that occupational therapists have a role with people with profound intellectual disabilities and other complex needs, but otherwise give us very little detail about this work. Findings are reported in terms of, for example, degree of intellectual disability and type of intervention, but terminology used is often vague and open to varying interpretations. This leads to uncertainty about the validity and reliability of conclusions regarding, for example, proportions of time spent doing particular types of work. The degree to which surveys can be expected to gain deep insight into complex topics, including engagement in occupation (as discussed in Chapter 2) and theory guiding practice (O'Neal et al. 2007), is questionable.

It is not surprising therefore that many researchers (summarised in Table 3.2) chose instead (or additionally) to **interview** occupational therapists about their work, which arguably has potential to gain fuller understanding of practice.

Author and year	Publication type	Method and Population	Aim
Llewelyn (1991)	Peer-reviewed journal	Focus groups 21 Australian occupational therapists.	Explore practice.
Pimentel and Ryan (1996)	Peer-reviewed journal	Semi-structured interviews (building on earlier survey findings) 14 UK occupational therapists.	Compare traditional hospital role with emerging community role
Tannous et al. (1999)	Peer-reviewed journal	12 Australian community occupational therapists, self-selecting as considerably experienced.	Elicit features of good practice. Interviews about work with one person they believed had resulted in positive outcomes
Francisco and Carlson (2002)	Peer-reviewed journal	Group and individual interviews. 6 Australian occupational therapists.	Explore issues faced/ strategies used when working with people from diverse cultural backgrounds.
Lillywhite and Atwal (2003)	Peer-reviewed journal	Interviews 7 specialist UK occupational therapists (2 years' + experience).	Gain perceptions of their own and others' core roles within their multi-disciplinary community teams.
Nelson et al. (2009)	Peer-reviewed journal	Multiple qualitative methods (short questionnaires, in-depth interviews, therapy plans and observation). 7 Australian occupational therapists.	Understand how they applied and combined approaches to meet complex needs of children with learning difficulties (including some with intellectual disabilities)
Lillywhite and Haines (2010)	Peer-reviewed report (phase 2)	8 focus groups 49 UK occupational therapists.	Understand nature of practice
Perez et al. (2012)	Peer-reviewed journal	10 Australian occupational therapists experienced in working with people with intellectual disabilities and behaviour support needs.	Explore contribution to addressing behaviours of concern/ supporting positive behaviour

Table 3.2 Research seeking occupational therapists' views by individual/ group interview

Tannous et al. (1999) made explicit their interest in occupational therapy practice with children and adults with intellectual disabilities and "high support needs" (p 25). Despite providing a definition, however, this seems to have been interpreted in different ways by their participants. In terms of judging relevance of findings to my research, this is a general issue in that it is often not clear when or whether participants are referring to their work with those with profound intellectual disabilities. Overall, these studies again suggest a definite occupational therapy role supporting the engagement of those with profound intellectual disabilities and other complex needs, but provide limited understanding of the exact nature of this role (see further 3.3).

There are arguably issues of representativeness in the above studies, in terms of whether individual (or even small groups of) occupational therapists describing their own practice can represent the practice of the whole profession. Participants in most studies were self-selecting and likely perhaps to be those with the most interest in expressing views, which may have been different to those that chose not to participate. On the other hand, some of the authors of these qualitative studies were explicit about the fact that they were not in any case seeking to generalise in this way – the findings of my previous research (Lillywhite and Haines 2010) and Perez et al. (2012), for example, explicitly do not claim necessarily to represent wider practice. The themes across interview, focus group and survey studies over time (explored in 3.3) are, nonetheless, remarkably consistent suggesting that these findings are useful for understanding wider practice.

The biggest limitation, I would suggest, in focusing so much on the views of occupational therapists is that we generally don't hear the voices of others, in particular families, support workers and, of course, people with intellectual disabilities themselves.

3.2.2 Other research using qualitative methodologies

A small number of other researchers have used a variety of qualitative methodologies to move beyond the perspectives of occupational therapists themselves and to gain something of the perspectives of others about occupational therapy with people with intellectual disabilities. For example, in Lillywhite and

Haines (2010), a latter phase involved interviewing five paid carers about the intervention someone they supported had received from an occupational therapist in a community intellectual disability team in the preceding year. Additional studies using other qualitative methodologies are summarised in Table 3.3.

Author and year	Publication type	Method and Population	Aim
Melton (1998)	Peer-reviewed journal	Semi-structured interviews in a naturally relevant environment, 5 individuals with mild intellectual disabilities	Explore the meaning of experiences cooking in occupational therapy.
Adams (2000)	Peer-reviewed journal	Semi-structured interviews: 10 health and/or social care service managers, 3 learning disability nurses, 4 social care team leaders and 3 support workers.	Gain views of stakeholders (though notably not people with intellectual disabilities themselves) about the occupational therapy received by those they supported.
Nelson et al. (2009)	Peer-reviewed journal	Observation of practice 7 Australian occupational therapists	Triangulate findings from interviews (see Table 3.2)
Harr et al. (2011)	Peer-reviewed journal	Case study, United States, one young man with moderate intellectual disabilities, visual impairment and spina bifida.	Explore the ways engaging in household tasks influenced participation at home, in the community and at work

Table 3.3 Research using other qualitative methodologies

Of particular interest and relevance to me (for reasons explored in 4.2) are those that used qualitative observational methods (in combination with interviews). Nelson et al. (2009) do not explain in detail the nature of their observations, for example exactly how they were carried out and whether the researchers were participant or non-participant observers. Nonetheless, findings from observation do enrich and deepen their findings. Particular insight comes from Harr et al.'s focus (2011) on the detail of one person's occupation and participation, using some quantitative data from scores on assessments such as the Canadian Occupational Performance Measure (Law et al. 2014), but mainly qualitative data from interviews and participant observation. In studying members of her own family, some might accuse Harr of lacking impartiality, but I rather feel that her

closeness helped deepen her exploration of this single case and her understanding of her brother's participation.

3.2.3 Quantitative research evaluating occupational therapy

In addition to the surveys reported in 3.2.1, there are five quantitative studies that have sought to evaluate specific occupational therapy interventions, summarised in Table 3.4.

Author and year	Publication type	Method and Population	Aim
Midence (1991)	Peer-reviewed journal	UK. 14 people with intellectual disabilities (seemingly also with complex needs, though number with profound intellectual disabilities is unclear) living in a locally-based hospital unit	Compare levels of engagement and staff interactions (at baseline and 5 month follow-up) after period of occupational therapy goal setting around engagement, support staff training, weekly support meetings and feedback
Green et al. (2003)	Peer-reviewed journal	UK. 2 adults with severe intellectual disabilities	Examine clinical effectiveness of sensory integrative therapy in response to behaviours of concern
a) Kottorp et al. (2003c) and b) Hällgren and Kottorp (2005)	Peer-reviewed journals	Sweden. Single-case designs: 3 people with moderate intellectual disabilities (study a); 5 people with mild and one moderate intellectual disabilities (study b). Engagement levels measured using time sampling, direct observation and 10-minute interval recording of behaviours of residents during different activity sessions.	Evaluate outcomes of occupational therapy intervention programme to develop skills at home and promote engagement. Motor and process ability measured at baseline and follow-up using Assessment of Motor and Process Skills (Fisher and Bray Jones 2012).
Urwin and Ballinger (2005)	Peer reviewed journal	UK. Single-case experimental design (A-B-A). 5 adults with moderate or severe intellectual disabilities and tactile sensory modulation disorder	Explore impact of sensory integration therapy on levels of engagement, maladaptive behaviour and function

Table 3.4 Quantitative research

The wide range of abilities amongst individuals with intellectual disabilities (and particularly those with complex needs) may explain the general use in this field of single-subject experimental rather than other quantitative designs. It is perhaps not surprising that initial research has tended to seek evidence on the effectiveness of interventions with individuals before moving on to more complex studies involving larger groups. The studies by Midence (1991) and Green et al. (2003) with participants with severe intellectual disabilities are of most relevance to my study (the others relating to those with mild or moderate intellectual disabilities). They evaluate sensory integrative therapy as a specialist treatment approach to promote adaptive behaviour (including engagement in occupation). O’Neal et al. (2007) noted the high proportion of the literature on occupational therapy in intellectual disabilities that relates to issues in sensory processing (including research involving children that I have not reviewed here).

The oldest study by Midence (1991), although strictly speaking outside my literature review, still stands out as distinctive 24 years later. He reported a 5 month-long occupational therapy intervention resulting in a small increase in engagement and (something he considered particularly positive) a larger increase in the amount of interaction between staff and residents. Although the landscape of intellectual disability services has changed a lot since then, my own work experience and research findings (Lillywhite and Haines 2010) suggest that occupational therapists still undertake work of the type evaluated by Midence. This study, although incompletely reported and now somewhat old, still tells something of the occupational therapy approach to supporting engagement and is therefore of direct relevance to my study.

3.2.4 Literature reviews and standards of practice

Three authors have carried out varying types of reviews of the evidence underpinning occupational therapy with people with intellectual disabilities, some leading to proposed standards of practice. The restricted nature of the evidence base, as established above, limits the relevance of these reviews, but I have briefly summarised them in Table 3.5. A particular limitation of COT (2013b) is that the principles were largely drawn from only one study, my own previous research (Lillywhite and Haines 2010), rather than a wider review of the literature. None of

these sources draw on literature from outside the field of occupational therapy (see Chapter 2 and 3.4 below, for example) that I strongly feel nonetheless informs and supports the profession's work.

Author and year	Publication type	Aim
Renton (1992)	Peer-reviewed journal	Reviewed literature on the profession's core skills.
Mountain (1998)	Peer-reviewed report	Collate such quality evidence underpinning community occupational therapy with people with intellectual disabilities as existed in order to describe the practice and to suggest future roles. Not a systematic review (included non-research based, more descriptive or anecdotal sources; omitted journals from outside the UK and those from intellectual disability field rather than occupational therapy).
Melton et al. (2001)	Non-peer reviewed OT news-letter	Proposed some quality standards in the form of a working tool of scenarios considered by the authors to be best practice (devised through combining available evidence with their experience from practice). Not all the evidence drawn on was cited in the article.
OTPLD (2003)	Standards of practice	A special interest group of UK occupational therapists in the field of intellectual disabilities proposed a set of partially evidence-based standards of practice.
COT (2013b)	Standards of practice	OTPLD (2003) standards were updated by the Learning Disabilities Specialist Section of the College of Occupational Therapists (COTSSPLD) (COT 2013b).

Table 3.5 Literature reviews and standards of practice

3.2.5 Opinion pieces and descriptions of practice

The remaining evidence consists of non-research-based evidence, such as opinion pieces, and descriptions of cases or practice (summarised in Table 3.6). Although none explicitly, or very obviously relate to those with profound intellectual disabilities, they do highlight the occupational therapy focus on the quality of individuals' occupational lives and on supporting engagement. The oldest source by Jones has the most direct relevance to my research. Although the words have changed somewhat over the intervening years, O'Brien's Five Service Accomplishments (rights, independence, choice, community presence and community participation) are still relevant today, as can be seen by their continued influence on more recent policy and standards, such as Department of Health (2009) and COT (2013b).

Author and year	Type of publication	Comments
Jones (1995)	Peer-reviewed journal	Related, then relatively new, theories of working with people with intellectual disabilities (e.g. Five Service Accomplishments (O'Brien 1992)/ value of partial participation) to occupational therapy. Proposed a competency-based and functional skills-focused frame of reference (as opposed to developing underlying capacities) considered likely to have greater impact on quality of life in the present.
Alguire et al. (2007)	Non-peer reviewed newsletter	Reported on garden cooking group with adults with intellectual disabilities in the United States, 55 years of age or older (none with profound intellectual disabilities)
Reynolds and Field (2012)	Peer-reviewed journal	Reported audit of effectiveness of occupational therapy treatment groups in a specialist assessment and treatment unit admitting those with intellectual disabilities, additional mental health difficulties and challenging behaviour.
Levy Wayne (2013)	Non-peer reviewed newsletter	Described a community-based service learning initiative in which American occupational therapy students ran occupation-based groups focusing on enhancing the quality of life of adults with intellectual disabilities.
Smith et al. (2010)	Peer-reviewed journal	Reflected on a work-based learning programme for people with intellectual disabilities in a forensic service.

Table 3.6 Opinion pieces and descriptions of practice

3.2.6 Summary

In the five previous sections I have explored evidence underpinning occupational therapy from the United Kingdom, the United States, Australia, various parts of mainland Europe and Taiwan. A significant proportion relates, as I have said to occupational therapists' own perspectives on their practice and only a small proportion specifically to those with profound intellectual disabilities, though other sources may still nonetheless serve to illuminate practice in that area.

3.3 Occupational therapy supporting engagement

I have so far presented an overall critique of the *nature* of the evidence related to occupational therapy with people with profound intellectual disabilities. With Lillywhite and Atwal's conclusion (2003) in mind that this aspect of occupational therapy could usefully be more clearly articulated, I explore in this section what can be gleaned from this evidence about the nature of occupational therapists' work supporting people's engagement in occupations at home.

3.3.1 A philosophy focused on occupation and meaningful engagement

In Chapter 2, I introduced theory from occupational science that informs and underpins occupational therapy practice. This included important notions that engaging (or not) in occupation impacts on health, quality of life and development and that those who are unable to access occupational opportunities generally available to others may experience occupational injustice.

Occupational therapists consistently refer to having expertise in occupation and a key role in supporting meaningful engagement in occupation and activity (Tannous et al. 1999, Perez et al. 2012). A keen interest in really understanding how people engage and what occupation means to them is clearly illustrated in, for example, Mahoney (2009) and Mahoney and Roberts (2009), where interviews and observations were used to explore in depth the occupational engagement of ten adults with moderate to severe intellectual disabilities in a United States day centre and the work of those supporting them there.

Focusing on engagement in occupation is one of the principles for practice in this field (College of Occupational Therapists 2013b). Occupational therapists themselves describe primarily focusing on increasing opportunities for meaningful engagement in occupation, making choices and developing occupational roles (Bowring et al. 1999, Tannous et al. 1999, Lillywhite and Atwal 2003, Perez et al. 2012). This is particularly important where individuals face barriers to such engagement and the role includes supporting others to have a more occupational focus.

Perez et al.'s findings suggest that use of occupational therapy practice models, such as the Model of Human Occupation (Kielhofner 2008) may help identify and articulate individuals' areas of strength or difficulty, providing an alternative perspective to behavioural or medical models used by others in the multi-disciplinary team. That study also highlighted occupational therapists' belief that their core skill of activity analysis (analysing an activity in which an individual struggles to engage in order to understand its demands (Creek 2010)) allows recognition of how to adapt and grade activity to enable participation. This may involve a compensatory approach using knowledge of specialist adaptive equipment and assistive technology to support engagement (Perez et al. 2012).

3.3.2 Theoretical underpinnings: a multi-model approach involving complex clinical reasoning

Clinical reasoning is the process by which occupational therapists generate understanding of and make decisions about complex situations (Mattingly and Fleming 1994). Those authors and Fleming (1991) described the various procedural, interactive, conditional, narrative and pragmatic types of reasoning evident when observing occupational therapists and interviewing them about this practice. This theory does not seem though to have specifically been related to occupational therapy with people with intellectual disabilities.

What is apparent from the evidence base, however, is the way occupational therapists, explicitly or more often perhaps intuitively, use the theory and models referred to below, in combination with theory from outside the profession, in their reasoning. For example, O'Neal et al (2007) analysed the theories, models or frames of reference that United States occupational therapists working with people with intellectual disabilities were either explicit about using, or that were implicit in their descriptions. Some such theories were also referred to in the studies by Nelson et al (2009), Lillywhite and Haines (2010) and Perez et al (2012). In what Nelson et al refer to as a "multi-model approach" (2009, p.61), the following are examples of some of the theories on which it is said that occupational therapists may draw to support their clinical reasoning:

- Disability theory (Perez et al. 2012).

- Behavioural theory (Perez et al. 2012).
- Sensory and sensory integrative theory (O'Neal et al. 2007, Nelson et al. 2009).
- Biomechanics (O'Neal et al. 2007, Nelson et al. 2009).
- Cognitive disability and cognitive perceptual theory (Nelson et al. 2009).
- Psychosocial theory (Nelson et al. 2009).

Some occupational therapists have described using active support as a method of supporting people with severe and profound intellectual disabilities to engage in occupation (Goodman et al. 2009, Lillywhite and Haines 2010). The relevance of this theory to occupational therapy practice will be discussed further in 3.4.1.

3.3.3 Long-term, hands on involvement

Occupational therapists interviewed in Australia by Tannous et al. (1999) and in the UK by Lillywhite and Haines (2010) consistently described complex and changing needs requiring two particular qualities in their work with people with intellectual disabilities:

- *Long-term involvement.* Getting to know someone may take time and an intervention needs to be sufficiently lengthy to enable rapport and relationship to develop (COT 2013). Individual and external factors (including the time needed to effect attitudinal change amongst those providing support) may make progress slow (Tannous et al. 1999).
- *Practical input and doing activities with people.* 'Hands on' interventions empowering the person and changing perceptions of others (including those providing support) towards them have been described as particularly important (Tannous et al. 1999).

Two Swedish studies sought to evaluate the effectiveness of long-term, practical interventions of this type. Kottorp et al. (2003c) used the AMPS (see further 3.3.5.1 below) to evaluate the outcomes of a person-centred intervention programme to develop three women with moderate intellectual disabilities' skills in activities of daily living at home. This involved occupations meaningful to each participant in which they wanted to improve their performance. It appeared to

enhance the women's process skills (though it was unclear whether there were actual changes in motor ability and awareness of disability). Hällgren and Kottorp (2005) then evaluated a refined programme in a similarly-designed second study, this time with five adults with mild and one with moderate intellectual disabilities. The findings supported the earlier study, with the authors concluding that the programme could improve occupational performance in both process *and* motor ability. These two studies provide some evidence for the effectiveness of such work with individuals with mild and moderate intellectual disabilities, but the extent to which the findings translate to those with severe and profound intellectual disabilities is uncertain.

3.3.4 Empowering people

Working in a person-centred way is generally at the heart of intellectual disabilities policy today (see for example Department of Health 2009). Occupational therapists believe their approach, however, to be particularly person-centred, with a focus on empowering those with whom they are working to make choices, including taking risks (Tannous et al. 1999). Key occasions to become involved seem to be at times of transition and change and when motivation to engage in activities is reduced: use of theory regarding volition (Kielhofner 2008) supports an understanding of the ways individuals' interests, values and beliefs about their own capacities can impact on the occupational choices they make (Lillywhite and Haines 2010). In a study that I previously mentioned in 2.3.5.3, Harr et al. (2011) observed how one young man's increasing competence and independence in the single activity of washing the dishes influenced both his self-confidence and the perceptions of his father towards him.

3.3.5 Understanding the impact of intellectual disabilities on occupational engagement

Supporting people well requires good understanding of how intellectual disabilities impact on engagement in occupation, but gaining this may not always be easy. Vlaskamp (2005a, 2005b) highlighted the challenges professionals face assessing specific impairments and functional abilities of people with profound intellectual disabilities, whether for diagnosis, to establish current status, or to provide information to guide intervention. The degree of intellectual disability,

along with motor, sensory and communication impairments and complex health needs, can mean that developmental tests and other assessments that might be used with others are often less feasible. Assessment is therefore “*a real feat of skill*” (Vlaskamp 2005a, p.152) and complex reasoning, more sensitive standardised assessments and a more functional approach are needed when assessing:

“... engaging in meaningful activities ... in close relationship with contextual factors” (Vlaskamp 2005a, p.154).

To me, this suggests a need to go further than assessing underlying capacities and occupational therapy assessment may be particularly relevant to gaining a real understanding of individuals’ strengths and needs. An opinion piece on how occupational therapists assess people with intellectual disabilities (Dwyer and Reep 2008) offers an interesting, albeit not research-based, perspective from two highly experienced practitioners. Their suggestion was that occupational therapists have a different focus on “enhancing occupational performance rather than trying to restore any underlying impairments” (2008, p.10). Their emphasis on assessing performance by observing people doing occupations, links with Vlaskamp’s reference to context (2005a).

Support for Dwyer and Reep’s (2008) assertion comes from the occupational therapists whose views Lillywhite and I (2010) previously sought. We found that an overall purpose of occupational therapy assessment was to establish exactly how intellectual disability impacts on occupational performance and this is now stated as a principle of practice in this field (College of Occupational Therapists 2013b). The particular need to establish this in a population unlikely to be able to verbalise this impact themselves was emphasised. Occupational therapists described multiple sources of information, including particular emphasis on direct observation in the environment where occupation would naturally be carried out. The importance of gaining full understanding by observing engagement in multiple environments was also stressed by Perez et al.’s respondents (2012) and this is important when disability is seen from the perspective of interactionist models such as the ICF (WHO 2001).

The views of proxies, such as family and carers who know the person well, are very important (Pawlyn and Carnaby 2013, Vlaskamp 2005b), but occupational therapy's notable approach of assessment through observing performance does contribute to the more functional one called for by Vlaskamp (2005a).

Occupational therapists have suggested that it can lead to objective and really good understanding of strengths and support needs (Lillywhite and Haines 2010).

3.3.5.1 Specific assessment tools related to occupational engagement

The literature suggests that occupational therapists have sought to develop standardised assessment tools, with tested validity and reliability, to support them in obtaining this good understanding of the occupational performance of those with intellectual disabilities. For example:

- Swee Hong et al. (2000) reported on the early stages of development of an initial assessment of the occupational performance of those with severe intellectual disabilities, highlighting the challenge of developing something easy to use, which yet produced meaningful information.
- Dychawy-Rosner (2003) investigated the content validity of the IRENA Daily Activity Assessment to measure occupational performance of adults with intellectual disabilities.
- Jang et al. (2009) examined the psychometric properties of the Loewenstein Occupational Therapy Cognitive Assessment (LOTCA), an occupational therapy assessment measuring specific underlying capacities, concluding that it had sufficiently high internal consistency and criterion validity to be suitable for measuring the cognitive abilities and visual perception of those with mild, moderate and severe intellectual disabilities (the relevance to those with profound intellectual disabilities remaining uncertain).

My own experience and lack of further reference to these three assessments in the literature suggests, however, that they are not much used in current practice. The following tools are reported to be the ones that United Kingdom occupational therapists use the most when assessing the occupational performance of people

with intellectual disabilities and complex needs, including profound intellectual disabilities (Lillywhite and Haines 2010):

- The Assessment of Motor and Process Skills (AMPS) (Fisher and Bray Jones 2012) and the Model of Human Occupation Screening Tool (MOHOST) (Parkinson et al. 2006), both MOHO assessments (Kielhofner 2008). Blount (2007) found that 54% of her respondents used the MOHOST and 48% the AMPS.
- Other MOHO assessments:
 - Volitional Questionnaire (de las Heras et al. 2007), which gains insight into motivation for occupation through observing individuals whilst doing and which was used within research by Mahoney et al. (2013).
 - Assessment of Communication and Interaction Skills (Forsyth et al. 1998), which can provide insight into communication in the context of occupation.
 - Residential Environment Impact Survey (Fisher et al. 2008), which can illustrate the impact of the environment on occupation (see further 3.3.6).
- The Pool Activity Level Instrument for Occupational Profiling (PAL) (Pool 2012), whose strong validity (Wenborn et al. 2012) and usefulness for gaining understanding of the levels at which people with profound intellectual disabilities can engage in activity was previously referred to in 2.3.2.

Other than the PAL, the AMPS (which assesses the impact of motor and process skills on occupational performance) is underpinned with the most evidence, with four studies investigating its specific use with those with intellectual disabilities (Kottorp et al. 2003a, Kottorp et al. 2003b, Hällgren and Kottorp 2005, Kottorp 2008). These concluded that there is a good fit with the assessment's multi-faceted rasch model when assessing those with mild intellectual disabilities, but an apparently less good fit with those who have moderate-severe intellectual disabilities. The extent to which it is a sufficiently sensitive assessment tool for those with severe and profound intellectual disabilities remains a matter of debate,

with one respondent to Pimentel and Ryan's survey (1996) suggesting that the AMPS was "inappropriate" for those with profound intellectual disabilities (1996, p.317).

Echoing the challenges highlighted by Vlaskamp (2005a), occupational therapists have long highlighted the paucity of valid and reliable tools that can measure occupational engagement of people with intellectual disabilities generally and those with profound intellectual disability in particular (for example, Pimentel and Ryan 1996, Plimmer 1996). Inability to use the whole of a particular assessment, may not preclude value in using part of it, however, to illuminate a particular aspect of someone with profound intellectual disabilities' functioning (Vlaskamp 2005a). It is perhaps not surprising therefore, that when occupational therapists have found it ineffective to administer standardised tools in a rigid way, they have reported adapting them. The 100 occupational therapists surveyed by Blount (2007) acknowledged that they found a need to modify tools to make them usable when assessing individuals' complex needs. I disagree however with Blount's conclusion that this rendered the tools invalid. My more cautious suggestion, supported by the earlier point made by Vlaskamp, would rather be that when tools have been administered in this non-standardised way we can be *less certain* about the extent to which the results are valid and reliable. When carefully combined with reasoning, findings may still be useful in practice.

Lillywhite and Haines (2010) also found that occupational therapists tailor assessments to the needs of the individuals they are working with. For example, the PAL is validated for assessing the levels at which people with dementia engage in activity (Wenborn et al. 2012), but occupational therapists nonetheless described finding it insightful to use with those with alternative cognitive impairments, namely severe and profound intellectual disabilities. Hawes and Houlder (2010) concluded from preliminary research in a community intellectual disability team over 6 months, that the MOHOST (Parkinson et al. 2006) is a reliable, clinically useful and flexible tool for assessing occupational performance. Their study however, along with those by Blount (2007), Lillywhite and Haines (2010) and Parkinson et al. (2014) all suggest that people with profound intellectual disabilities tend to score very low on such assessments and that the

MOHOST is therefore insufficiently sensitive to indicate change in those with severely impaired occupational performance. For this reason, the MOHOExpLor, a new tool intended to capture more subtle shifts in occupational performance, is being developed (Parkinson et al. 2014).



In conclusion, assessment of people with profound intellectual disabilities cannot be a rigid procedure, but is better seen as a process (Vlaskamp 2005a). Occupational therapists use standardised assessments some of the time, but they emphasise observational assessment in context and in particular a need for flexibility, creativity, trial and error and persistence and use of clinical reasoning to analyse complex situations and gain a good understanding of the impact of intellectual disabilities on engagement (Lillywhite and Haines 2010).

3.3.6 The impact of the environment and sensory needs on engagement in occupation and behaviour

Occupations are performed in specific physical, social, organisational and cultural environments (Kielhofner 2008). An individual's home environment consists not just of the physical space, but also those they live with and the quality, type and culture of support received there. Occupational therapists consider that an understanding of this, achieved in part through emphasising assessment in environments where occupations are naturally carried out, is essential when supporting engagement (Lillywhite and Haines 2010). Occupational therapy often involves adaptation of the environment in some way and this may include adapting the social environment by encouraging a change to the way someone is supported (see further 3.3.7).

The importance of considering how the environment may influence behaviour is stressed (Perez et al. 2012). Occupational therapists have highlighted how understanding an individual's sensory processing needs and how the environment impacts on these can be an important part of their work, particularly with those who have profound intellectual disabilities and other complex needs (Lillywhite and Haines 2010). Unmet needs can contribute to behaviours experienced by

others as very challenging and occupational therapy referrals often relate to individuals whose behaviour appears related to sensory issues (Perez et al. 2012). A review of the caseloads of four occupational therapists in a community service for adults with intellectual disabilities in the UK, suggested that 21% of their clients behaved in ways possibly indicative of issues with sensory processing with an even higher figure of 40% found in the United States (Reisman and Hanschu 1992).

O'Neal (2007) found that 70% of American occupational therapists working with adults with intellectual disabilities referred to using sensory stimulation and sensorimotor therapy frequently and 92% to using sensory integration theory at least occasionally. UK occupational therapists also describe carrying out sensory assessment and intervention, including sensory integration therapy (Lillywhite and Haines 2010). Recognising that behaviours may be sensory-seeking or sensory-avoiding and the link with the demands and opportunities of the environment may therefore be an important contribution to team efforts to support positive behaviours. Experimental research (for example, Green et al. 2003, Urwin and Ballinger 2005) has explored the impact of sensory integration therapy by occupational therapists on levels of engagement, maladaptive behaviour and function of individuals with a range of intellectual disabilities, some severe. With the maladaptive behaviours of all of Urwin and Ballinger's participants decreasing significantly and the engagement level of one participant increasing significantly, these studies suggest that this therapy is promising, though the lack of controls limits the conclusions that can be drawn. With more research focusing on children than adults (see for example Iwanaga et al. 2014, Schaaf et al. 2012) and on those on the autistic spectrum than on those with intellectual disabilities, there remains a lack of consensus as to the effectiveness of sensory integration therapy, in particular with adults with severe and profound intellectual disabilities. The Council on Children with Disabilities (2012) reached the overall conclusion that research regarding the effectiveness of sensory integration therapy is still limited and inconclusive.

Although the importance of considering the sensory responsiveness of individuals with profound intellectual disabilities is still evident in the literature (for example

Vlaskamp and Cuppen-Fontaine 2007, Lima et al. 2012), they do not seem to have been the focus of *sensory integration* research since Reisman's single case study (1993) in which sensory integration therapy was used to reduce self-injurious behaviour in one adult with profound intellectual disabilities. Lima et al.'s (2012) case report on work with one young boy with profound intellectual disabilities is from neither an occupational therapy nor a sensory integration perspective, but suggests useful ways in which a combination of both behavioural and physiological measurements (such as electro dermal responses) may be used to assess sensory responsiveness.

3.3.7 Building relationships: collaborative working

Tannous et al.'s (1999) findings suggest that the outcomes from occupational therapy with people with intellectual disabilities come out of the type of relationship and rapport built with people. They noted that occupational therapists described a reciprocal rather than one-way relationship, where the therapist also learns from the person with intellectual disabilities. Melton's (1998) participants with mild intellectual disabilities reported valuing their occupational therapist's empowering style, respectful attitude, sensitivity to particular circumstances and ability to take on different roles when teaching skills.

A core principle of occupational therapy is to work collaboratively, not only with people with intellectual disabilities themselves, but also with others to meet their needs (COT 2013a, 2013b). This includes colleagues in multi-professional teams, as collaboration and multi-or inter-disciplinary assessment with them and with mainstream or generic health and social care services is essential fully to understand and meet people's needs (Emerson et al. 2009, Goodman et al. 2009, Vlaskamp 2005b). Lillywhite and Haines (2010) found specific examples of collaboration, including complex seating, positioning and posture management alongside physiotherapy and multi-disciplinary input around eating and drinking with physiotherapy and speech and language therapy. The service managers interviewed by Adams (2000) saw the way that occupational therapy enriched the multi-disciplinary team as a particular strength.

A particularly important aspect of occupational therapists' collaborative work, which is the focus of the remainder of this section, is with family members and those who are paid to support people with intellectual disabilities on a day to day basis in residential, day, work and other services (Lillywhite and Haines 2010).

3.3.7.1 Consultative role supporting enhanced quality of support

Bronfenbrenner's ecological systems theory (2005) emphasises the way that an individual's development is shaped by the interactions between themselves and the systems of which they are part. Professionals, including occupational therapists, have an extremely important role when inputting into support systems, in changing perceptions and improving the quality of care, which is particularly important with a workforce that is often poorly paid and trained and that may turnover rapidly (Bubb 2014). The training needs of the intellectual disability workforce are acknowledged in government policy (Department of Health 2009) and the provision of training programmes (Chadwick et al. 2014, Tredinnick and Cocks 2014). In particular, experiential training by health professionals is acknowledged as important if recommendations are to be successfully and consistently followed (Bradshaw and Goldbart 2013).

It was previously suggested in 2.3.3 that the only predictor of engagement in activity other than level of ability, is the practice of those providing support (Mansell et al. 2003b) and Philips and Rose (2010) concluded that levels of staff interaction and support and staff attitudes towards residents' behaviour were most predictive of the breakdown of living arrangements. Mahoney et al. (2013) found from their three studies that adults with intellectual disabilities often had enhanced volition and engaged more actively when engaged in a co-occupation with someone else, as previously described in 2.3.2 (Mahoney and Roberts 2009). They suggested that occupational therapy is most likely successfully to support occupational engagement by focusing on building rapport and enabling co-occupation between people with intellectual disabilities and those that support them (Mahoney et al. 2013). Family members interviewed by Mansell (2010) consistently suggested that the quality of support workers' relationships with those they supported was of primary importance, with values and attitudes at least

as important as experience. He concluded that “good services focus on the quality of staff relationships with the disabled person” (2010, p.11).

The need for occupational therapists to train and give feedback to direct care staff was recognised by Midence (1991) whose observational study of people with intellectual disabilities and complex needs at home suggested an increase in both levels of engagement in activity and, in particular, staff-resident interaction, following training sessions and weekly feedback meetings over five months. Lillywhite and Haines (2010) found that occupational therapists support others to recognise the value and importance of meaningful occupation and that support workers seem to react positively to training provided (one specifically commenting on the value of training around engaging people with profound learning disabilities in activity). The need for occupational therapists to provide training to support staff about the value of occupation and ways to support occupational engagement is a principle of practice (COT 2013b), though there does not seem to have been a response to the long standing suggestion that further research is needed into how the profession could contribute to improving the quality of support at home (Mountain 1998).

Health professionals have described the challenges involved in this consultative role of improving care through getting support staff to change their practice (for example Chadwick et al. (2006) in relation to speech and language therapy). Encouraging people to work in a more occupational or enabling way may mean supporting a change in beliefs, attitudes and perceptions (Tannous et al. 1999) and building up sufficient rapport to achieve this can take time (COT 2013) (see 3.3.3). The findings of my previous research (Lillywhite and Haines (2010) suggest that in order to motivate staff teams to work in different ways, occupational therapists seem to prefer to work alongside them, negotiating rather than dictating and remaining closely involved with support workers and managers to facilitate implementation of recommendations following intervention. Recommendations need to be realistic and achievable and there may be a need to compromise on what can be achieved due to the nature of the staff team providing ongoing support.

3.3.8 Conclusion: a particular role with those with complex needs

The literature I have reviewed tells us something about the role of occupational therapists with individuals with varying degrees of intellectual disabilities. Some findings have emphasised a particular role with those whose needs are more complex, for example, Mountain (1998) concluding that occupational therapists need to address the particular needs of those with complex needs arising from intellectual disabilities combined with physical disability, mental health needs, or behaviours about which there is concern. When working with others to support positive behaviours occupational therapists have highlighted the alternative occupational and sensory perspectives they may bring to a team attempting to understand why an individual may find the need to behave in a particular way (Perez et al. 2012). The occupational therapists surveyed by Bowring et al. (1999) and interviewed by Lillywhite and Haines (2010) believed they had an important role with those with such complex needs, including those with profound intellectual disabilities and some described prioritising this work.

3.4 Other approaches to supporting engagement

In this section I broaden the review to include two other approaches to supporting engagement in occupation from outside the occupational therapy literature: active support and personalised residential supports. It is particularly important to explore the relevance of active support, as this is the method of supporting people with severe and profound intellectual disabilities to engage in activity that is underpinned by the most research evidence, but also because it is a method that occupational therapists have themselves described using (Goodman et al. 2009, Lillywhite and Haines 2010).

3.4.1 Active support

The term “active support” is used inclusively here to refer to both of the very similar variants of this approach, that is what Mansell and Beadle-Brown (2012) call ‘active support’ and Ashman et al. (2010) call ‘person-centred active support’.

Active support focuses on the quality of the relationship between the persons providing and receiving support. This is an enabling relationship, rather than one involving ‘doing for’ as in the ‘hotel’ model of care illustrated in Figure 2.8 (Mansell

and Beadle-Brown 2012, Ashman et al. 2010). Those authors describe the following four essential qualities in this enabling relationship, which:

- Supports engagement in meaningful activity and relationships.
- Sees the potential of supporting such engagement in every moment, emphasising opportunities for ordinary everyday activity around the home rather than setting up special activity.
- Involves getting the amount and type of support right, grading this support creatively to ensure that the person experiences success. This requires breaking the activity into steps using the behavioural approach of task analysis. Although participation is positively reinforced through for example praise and attention, the emphasis is on the intrinsic reinforcement of the activity itself.
- Maximises opportunities for people to make real choices and have control over how they spend their time.

Interactive training of staff directly with people with intellectual disabilities is emphasised and there are systems for planning, recording, monitoring and leading implementation within staff teams (Mansell and Beadle-Brown 2012).

Participation, or engagement, is said to increase because more activity is available, support is more skilled and effective (and more equitably distributed towards those requiring it the most) and because only as much support as is necessary to enable engagement is given. This “virtuous circle of positive interaction and empowerment” (Jones and Lowe 2005, p.123), is illustrated in Figure 3.7, the opposite of the vicious circle of disempowerment previously described in the hotel model of care.

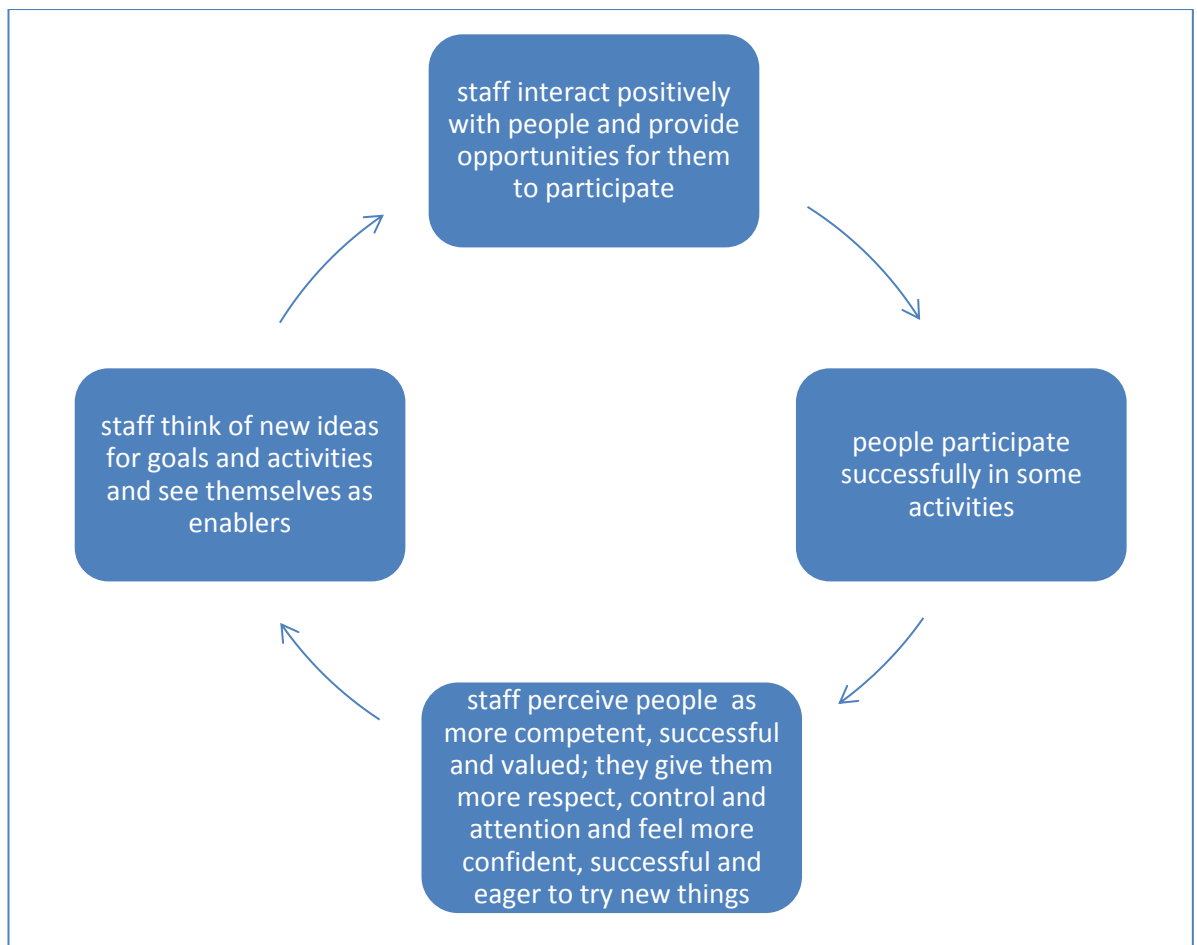


Figure 3.7 Virtuous circle of positive interaction and empowerment (Jones and Lowe 2005, p.123)

My literature search strategy (described in 3.1) produced a total of 30 research articles, 5 commentary and opinion pieces, 3 reviews of the literature and a practice description about active support. Additionally, I discovered an additional two research articles prior to the search period of 1994-2015 and two recent books about active support (Mansell and Beadle-Brown 2012, Ashman et al. 2010). Most of the research studies were carried out in England or Wales, with the exception of seven Australian studies (Stancliffe et al. 2007, Fyffe et al. 2008, Koritsas et al. 2008, Stancliffe et al. 2008a, Riches et al. 2011, Stancliffe et al. 2011, Mansell et al. 2013), one from Taiwan (Chou et al. 2011) and one from New Zealand (Graham et al. 2013). A number of these research studies were published together in a special active support-themed edition of the *Journal of Intellectual and Developmental Disabilities* in 2008.

Much of the research evidence consists of quantitative studies evaluating the effect of implementation of active support on engagement in occupation and quality of staff support. Examples of these include:

- Many studies using multiple baseline before and after designs (e.g. Jones et al. 1999, Felce et al. 2000a, Stancliffe et al. 2007, Stancliffe et al. 2008a, Stancliffe et al, 2010, Stancliffe et al. 2011, Totsika et al, 2010, Beadle-Brown et al, 2012, Mansell et al. 2013).
- A smaller number of studies comparing services where active support has been implemented with those not trained in this method (e.g. Bradshaw et al. 2004, Mansell et al. 2002, Felce et al. 2002, Mansell et al. 2008, Chou et al. 2011).
- A single case study (Toogood et al. 2009).

Some studies have evaluated implementation of active support across the whole of an organisation providing support services and these larger studies allow some comparison of the impact on engagement amongst those with different levels of adaptive and challenging behaviour (Mansell et al. 2003a, Mansell et al. 2003b, Ashman and Beadle-Brown 2006). Some more recent studies have also begun to evaluate the effect of active support on other variables, for example frequency of challenging behaviour (Koritsas et al. 2008, Toogood et al. 2009, Stancliffe et al. 2010, Beadle-Brown et al. 2012), depression (Stancliffe et al. 2010) and opportunities for choice (Koritsas et al. 2008, Beadle-Brown et al. 2012).

Only three studies have used a qualitative methodology, a small proportion (less than 10%) of the research into active support: Totsika et al. (2008) explored the experiences of those participating in active support interactive training; Fyffe et al. (2008) interviewed support staff and service managers to explore organisational factors associated with implementing active support; and Graham et al. (2013) explored the experience of active support from the perspectives of support staff and managers and also family members of residents.

Commentaries and opinion pieces include Williams' argument (2005) that active support should only be seen as one way of supporting people and improving their lives; and debate about whether or not active support is inherently person-centred

(Harman and Sanderson 2008, Jones and Lowe 2008) (my own understanding being that it is so and that if you are not being person-centred, you are not following active support).

Three reviews of this “impressive body of evidence” (Mansell and Beadle-Brown 2012, p.86) underpinning active support have been published (Stancliffe et al. 2008c, Mansell and Beadle-Brown 2012, Hamelin and Sturmey 2011). From these and my own critique of the literature, I have reached the following conclusions about this way of supporting people:

- When full training in active support has been completed, this consistently seems to lead to increased engagement in activity by adults with severe and profound intellectual disabilities living in small homes of 1-7 residents with 24 hour staffing (Stancliffe et al. 2008c).
- Active support has mostly been shown to lead to significant increases in staff assistance (Stancliffe et al. 2008c).
- Some studies suggest that active support is most effective when used with people with lower levels of adaptive behaviour (and therefore higher support needs) (Mansell and Beadle-Brown 2012).
- Well-implemented active support can overcome and compensate for societal/ environmental disablement and enable even those with the greatest support needs to engage in meaningful activities and relationships at levels usually achieved by those with less disability.
- Increases in engagement are smaller where implementation is weak (Mansell and Beadle-Brown 2012) for example experiential training for staff is missing (Jones et al. 2001b, Ashman and Beadle-Brown 2006, Beadle-Brown et al. 2012).
- Weaknesses in the designs of some studies require conclusions to be tentative, Hamelin and Sturmey (2011) for example concluded from their systematic review of experimental evaluations of active support that the quality of the evidence means that it should be regarded as a “promising treatment” (2011, p.168) as opposed to an evidence-based practice.

- There is only limited qualitative research on active support and a lack in particular of research evidence about the nature of more and less effective enabling relationships.

Many of the characteristics of active support seem similar to those described of occupational therapy in 3.3. Both approaches seem to share a common aim and, as previously said, it is an approach that occupational therapists themselves describe sometimes using. It is unclear, however, exactly *how* occupational therapists use active support and the extent to which they use it in the ways described within the active support literature.

3.4.2 Personalised residential supports

In extensive Australian research, Cocks and Boaden (2011) explored the characteristics of what they named “personalised residential support” (PRS) for those with developmental disabilities, including intellectual disabilities. They began by reviewing existing empirical research and descriptive literature relevant to this, though they did not consider any of the occupational therapy evidence I have cited, nor (particularly surprisingly) the extensive evidence around active support discussed above, which leads me to question the thoroughness of this review). They then explored case studies of the support of six adults with intellectual disabilities with low, moderate and high support needs over two years, at the same time surveying 18 individuals considered to have expertise in developing, supporting or publishing about personalised residential supports. Finally, they gained the perspectives of a number of adults with intellectual disabilities who participated in a focus group. All data was analysed iteratively and by conciliation and consensus, they proposed a “PRS quality framework” (2011, p.725) consisting of 9 themes, themselves broken down into 28 attributes.

Parts of this framework seem very relevant to my research (for example the focus on supporting engagement in typical household activities) and the most pertinent aspects are illustrated in Figure 3.8. Perhaps not surprisingly, there are many similarities with the points I have made in the previous sections drawing on literature from occupational therapy and active support, for example similar person-centred focuses on the person being in control and at the centre of support

arrangements; the needs for planning and leadership (Beadle-Brown et al. 2014 and 2015) and for support to be creative and flexible.



Figure 3.8 Personalised Residential Supports Quality Framework (from Cocks and Boaden 2011, pp. 725-729)

3.5 Conclusion: research needs

The literature explored so far suggests strongly that people with profound intellectual disabilities are at risk of occupational injustice where support is insufficient to enable engagement in occupations. Occupational therapists describe supporting achievement of such engagement, but the overall evidence base for this role is limited and more detailed understanding of its exact nature is needed.

The existence of approaches such as active support and personalised residential supports makes it clear that it is not only occupational therapists who are concerned with people's engagement in occupations at home. There is a substantial body of evidence suggesting that active support is a promising method of supporting this issue and it is an approach that occupational therapists themselves have described using. Although similarities between these approaches and occupational therapy can be seen, the existing evidence does not make clear any differences or overlaps between them.

This final part of my review outlines aspects of this topic about which further research is required, focusing on both knowledge and methodological gaps in the literature. Making connections with research priorities identified by others, I end by stating the question that this study has sought to answer and its aims.

3.5.1 Aspects in need of further research

Further research is needed into the following aspects of this topic:

1. Engagement in occupation by those with profound intellectual disabilities and other complex needs

Research in the field of intellectual disabilities has generally focused either on the population as a whole, or on (occasionally with) those regarded as higher functioning (Belva and Matson 2013, Norah Fry Research Centre 2009). People with profound intellectual disabilities and others with complex needs are populations that are arguably particularly hard to study. They are marginalised in research, both generally, and specifically within the limited occupational therapy evidence base.

2. Nature of meaningful engagement in occupation

What engaging meaningfully in occupation might mean for someone with profound intellectual disabilities could be understood and illustrated better. Research is needed that, for example, provides a fuller understanding of the nature of engagement in an occupation at a “sensory level” and the concept of “co-occupation” between the person and whoever is supporting them to engage.

3. Quality of life and engagement in occupation at home

People with profound intellectual disabilities tend to have a low level of engagement in occupation at home, but the need to respond to this is often surprisingly absent in policy. If, as is suggested by Mencap (2011), people may spend a lot of time at home, then as well as promoting community inclusion, there is a need to focus on the *quality* of the time that is spent there, the occupations people are supported to engage in and how to support people effectively to engage in occupations there. With the exception of the active support literature, however, this is a neglected area of research (Verdonschot et al. 2009).

4. Developing skilled support

An intellectual disabilities research scoping project identified a particular need to understand better the support needs of those with profound intellectual disabilities and how support staff can work in a more person-centred and effective way, including allowing people more control over their lives (Norah Fry Research Centre 2009). Occupational therapists have highlighted their consultancy role improving the quality of support given at home (Lillywhite and Haines 2010) and this aspect of the occupational therapy role has long been identified as an area in need of further understanding (for example Mountain 1998). Research is needed into the ways that occupational therapists overcome the challenges of getting a staff team to adopt a new way of working.

5. The occupational therapy role and contribution

We know something of the methods such as active support and personalised residential supports that are reputed to be effective when working with those with complex needs to support engagement at home. We need to know in much more detail how occupational therapists use such techniques (or perhaps use them differently from others) and about the additional or alternative methods they may use.

3.5.2 Alternative research designs

There are also gaps in methodology and method in the existing research in this field and insight may be gained from exploring this topic in different ways from those others have tended to use. Porter and Lacey (2005) reviewed and compared articles in the intellectual disabilities field from two years a decade apart (1990-1 and 2000-1) and made a number of recommendations regarding research priorities. As my conclusions seem to fit within five of their priorities, I have used these to structure my conclusions.

1. Research that builds on the research of others

The active support literature is a good example of a body of research amassed through researchers building on and developing the findings of previous studies. This is not, however, something that researchers have always done in the intellectual disabilities field (Norah Fry Research Centre

2009, Porter and Lacey 2005), wasting an opportunity to develop further the findings of earlier studies and risking duplication. It is also notably absent in the literature on occupational therapy and people with intellectual disabilities. I realise now, for example, having reviewed the literature more thoroughly, how many of the points made by our participants in Lillywhite and Haines (2010) had, unknown to us, been made by respondents in earlier interviews and surveys.

2. Research that is ecologically valid, using alternative methodologies and epistemologies

Perhaps due to the predominant influence of psychiatry, psychology and education research in the intellectual disability field, there is a very definite trend towards quantitative research from a positivist or post-positivist epistemology (Porter and Lacey 2005). There are relatively few qualitative studies and very little research in this field from alternative social constructionist and interpretivist stances. Studies using qualitative methodologies and methods and in particular using *qualitative* observation (as opposed to much more prevalent quantitative, non-participant observation) are notably absent (Norah Fry Research Centre 2009). Simmons and Watson (2014) reiterated this absence of participant observation in studies researching children with profound intellectual disabilities. They concluded that research in this field is “under-developed”, with “a genuine gap in our methodological ‘tool box’ for researching ... in respectful, ethical and authentic ways” (2014, p.148). Occupational therapy with people with intellectual disabilities is an aspect of the social world that we could understand better and a qualitative methodology with a focus on subjectivity and meanings, that reflects the real world in which interventions occur and that includes participant observation as a method of data collection seems to have potential to produce deep understanding and new insights.

3. Research using a methodology consistent with the theory underpinning the intervention

The evidence (see 3.3.3) suggests that successful outcomes arise from occupational therapy that is creative, flexible, hands-on and long-term

(Lillywhite and Haines 2010). In order to gain insight into this occupational therapy and the clinical reasoning underpinning it, it to me seems important to use a research design with similar characteristics.

4. Research that provides more than simple outcome measures

Although measuring the effectiveness of interventions is important, there is an additional need for studies that produce more detailed insight into the complex problem of how to support people effectively to engage in occupations. Porter and Lacey (2005) suggested that in addition to measuring outcomes, there is a need for research that can explore the *process* by which change occurs and thereby the kind of support that enables new learning.

5. Research that gains the views of those with intellectual disabilities

Porter and Lacey (2005) highlighted the lack of research gathering the views of people with intellectual disabilities themselves. Although since then there have been some notable examples of participatory research (for example Williams et al. 2010, Williams et al. 2012), the perspectives of those with complex needs, such as profound intellectual disabilities are notably still absent. The views of proxies such as carers are important, but qualitative observation could provide an opportunity to gain something of their lived experience and, with sufficiently rich description, to illustrate the nature of their lives.

3.6 Research question and aims

This research has sought to answer the following question:

In what ways does an occupational therapist support people with profound intellectual and multiple disabilities to engage in occupation in ways they find meaningful at home?

Aims

1. To understand the particular ways an occupational therapist supports people with profound intellectual and multiple disabilities to engage in their occupations at home in ways that are meaningful to them, through exploration, rich description and analysis of this practice, including:
 - Its various forms.
 - The reasoning behind choosing these forms and adapting them to individuals' needs.
 - Underpinning values and theories.
 - The ways it addresses issues of occupational justice faced by people with profound intellectual and multiple disabilities.
2. To establish the ways in which the approaches the occupational therapist takes to supporting engagement relate to or differ from others described in the literature.
3. To gain a better understanding of occupational therapists' consultancy role with those who support people with intellectual disabilities on a day to day basis.
4. To generate professional knowledge, understanding and theory which could be used to inform the practice of occupational therapists, services providing support to people with intellectual disabilities and other professionals with a role in improving the quality of care and support provided.

Chapter 4. METHODOLOGICAL APPROACH

4.1 Introduction: Conceptual framework and philosophical assumptions

My literature review concludes that the range and type of occupations in which an individual engages are important determinants of health and quality of life and that injustice occurs if some are denied occupational opportunities available to others. I have cited examples from the many quantitative studies investigating the lives of people with intellectual disabilities and the actions taken by those supporting them (for example Jones et al. 1999, Zijlstra and Vlaskamp 2005a, Stancliffe et al. 2010). These studies, mostly using non-participant observation to quantify time use and actions taken by staff in support, tell us that people are often not very occupied.

What seems to be missing, however, is more detailed exploration and investigation into exactly what happens when one person successfully supports another with profound intellectual disabilities to engage in occupation. Occupational therapists suggest that they are able to support people with intellectual disabilities to engage in occupation in situations where others struggle (Lillywhite and Haines 2010), but there is a notable absence of detail regarding exactly *how* they do this and whether what they do differs from methods of supporting engagement that have the most evidence in the literature.

My research question links to theory about the nature of this occupational therapy relationship. Sensitising concepts (Carpenter and Suto 2008) from the profession's concerns and my own world view have inevitably shaped the study and the philosophical assumptions underlying my choices in the design of this research need to be made explicit (Cousin 2009, Weaver and Olson 2006). Values, such as person-centredness and assumptions (that engagement in meaningful occupation is important for health and wellbeing, for example) underpin occupational therapy. Additionally, I bring my own personal biography to the research design (my connection with people with intellectual disabilities over

more than 20 years). The concepts, assumptions, expectations, beliefs and theories informing and supporting my research form my conceptual framework (Huberman and Miles 2002) (see further 4.4.1).

Going beyond mere methodological discussion, I therefore examine in this chapter:

- My philosophical assumptions about the nature of reality (ontology).
- How can I know what is known (epistemology).
- My values (axiology) (Carpenter and Suto 2008).

Reading this, I am acutely (even uncomfortably) aware that I previously completed a piece of qualitative research in which we did not do this in any explicit way (Lillywhite and Haines 2010). In fact, I think we took what Dyson and Brown (2006, p.2) refer to as the “ignorance is bliss” approach to the relationship between research philosophy and methodologies, or research strategies. This leads me to reflect on what difference it might have made to the rigour and trustworthiness of that research had we more deliberately or fully explored our conscious or unconscious background assumptions about the research topic (Dyson and Brown 2006) and more fully justified our claims to have created knowledge.

I have taken Dyson and Brown’s advice (2006) not to begin at the philosophical level with rigid decisions about key positions, as this denies the possibility of the design being informed by other assumptions and risks embedding into it all the criticisms of such positions made by others. Instead, I will begin by discussing decisions about methodology before exploring in 4.3.4 the implicit assumptions regarding my own position as researcher and the effect this may have had on creation of the data.

4.2 Identifying my methodology

I begin by discussing the kind of study suggested by my research question, before moving on to describe in detail my reasons for choosing a qualitative case study methodology. I also consider some alternative choices I could have made.

4.2.1 What kind of research study?

My research question sought new insights into a little understood situation, assessing the phenomena of occupational therapy in new light and potentially generating ideas for further research. This study's purpose was therefore exploratory rather than descriptive or explanatory. Robson (2002) suggests that a flexible design is appropriate for such an exploratory study, with detail evolving as it progresses.

Discussing the "science of the unique", Rolfe highlights the difficulties of describing the concerns of persons (rather than people) using a "science of large numbers" (2000, p.42). With a hypothetico-deductive approach, I would derive a hypothesis (about engaging people in occupation) and test this by experiment or observation, enabling it to be rejected or retained for the time being (Willig 2008). I was however not looking to test an existing theory, but for new insights into practice. I required an approach that could facilitate theory development (Carpenter and Suto 2008) and allow me to reason inductively rather than deductively (Nicholls 2009).

Touching on epistemological and ontological matters that I consider in more detail later, could a study with a positivist epistemology answer my research question? It would aim to produce objective knowledge and impartial and unbiased understanding (Willig 2008). It would imply accessing a "truth" out there, separable from myself, about the interactions of occupational therapists with people with intellectual disabilities that in principle could be known and that would enable prediction to be made (Cousin 2009). It would use a survey or other standardised research instrument to filter out my unconsciously selective perception and biases (Dyson and Brown 2006). Would getting the opinion of 200 experts achieve the depth of understanding I am seeking? If occupational therapists are not always fully mindful of their practice (Reid 2009), it may not be something they are able to describe adequately in response to a survey. This is a limitation of some of the studies previously explored in 3.2.1.

I find it difficult to conceive of a standardised research instrument that could produce sufficiently in depth knowledge about the topic in which I am interested, or a randomised controlled trial that could evaluate a type of occupational therapy

intervention, which I know to be so different with every person. I conclude therefore that my research question does not suggest a positivist or post-positivist quantitative methodology, but rather a qualitative design. This would more likely allow the presentation of multiple realities or truths (Robson 2002), the different, yet valid, interpretations that the various players may have about these occupational therapy interventions. Varying interpretations may add to understanding of a phenomenon even where they differ from objective accounts of what has occurred (Carpenter and Suto 2008).

I am interested then in the views of these players, the occupational therapists, the people with intellectual disabilities, the support workers who participate in my research. As well as seeking an outside etic perspective, I wished to understand and reflect their emic perspectives as insiders within the culture (Carpenter and Suto 2008), researching with them rather than on them (Finlay 2006). Instead of a positivistic distancing of myself, my research question suggested a need for interaction between myself and my participants and that I myself was a data collection tool (Robson 2002). I discuss the implications of this more active researcher role in more detail later.

Nicholls (2009) highlights the important role that methodology, the particular philosophical and ethical approach I have taken to developing knowledge (Hammell 2006), has in linking research philosophy and methods. I am now much more aware of the multi-paradigmatic nature of qualitative research (Carpenter and Suto 2008) than I was when carrying out previous research (Lillywhite and Haines 2010). Describing the methodology in that research merely as “qualitative” perhaps limited the degree to which we thought about the kind of knowledge we were creating. I next justify the choice of case study methodology to address my particular research question and explore the kind of case study I have conducted. I then consider this methodology in relation to others I could have used (notably ethnography and grounded theory) before exploring the theoretical perspectives and research philosophy underpinning my design.

4.2.2 Qualitative case study methodology

Without jumping ahead to a discussion on methods (see Chapter 5), my research question suggested a need to gain data from multiple sources. Although wanting occupational therapists' views on their interventions, my experience suggested that individual or group interviews alone might be insufficient for the detail of what they do and why to become visible (Lillywhite and Haines 2010). This is illustrative, perhaps, of the general difficulty researchers face in accessing tacit knowledge (Rolfe 2000). Rather than relying only on asking occupational therapists about their practice, I therefore sought a methodology that could accommodate observing practice, as for example Mattingly and Fleming (1994) did when researching occupational therapists' clinical reasoning.

Case study methodology starts with a curiosity about a particular case and asks what is going on in it (Cousin 2009). Yin's description (2009, p.9) of case studies classically being used to establish "the how and why of a complex human situation" immediately suggests relevance. They can generate understanding through systematic exploration (Simons 2009) and are well-suited to broad and in particular "how" (or "in what way") research questions (Cousin 2009).

There are differing views about whether case study research is a methodology at all, with some describing it as merely a method. I lean to the view of Hammersley, Foster and Gomm (2000) who regard it a distinct research strategy (i.e. methodology). Certainly this is the sense I get from Stake (1995), Yin (2009) and Simons, (2009) whose definition seems to fit particularly well here:

"In-depth exploration from multiple perspectives of the complexity and uniqueness of a particular project, policy, institution, programme or system in a 'real-life' context. It is ... inclusive of different methods and ... the primary purpose is to generate in-depth understanding..." (Simons 2009, p.21).

This diverse methodology has been used in many different ways, though Willig (2008) identifies five relevant defining features:

- A focus on the particular rather than the general – the subtlety and complexity of the case (Bassegy 1999).

- Close attention paid to context – social truths are complex and embedded (Bassey 1999) and phenomena are integrated systems which cannot be understood in isolation (Thomas 2011). Attending to context allows thick description (Stake 1995).
- Information from diverse sources for in depth understanding (Merriam 1998).
- A focus on change and development over time.
- Theory generation, though in a specific way that I will discuss further in 4.2.3.3.

I concluded that case study research could allow deep exploration of the “particularity, complexity and uniqueness”, to use Stake’s classic definition (1995, p. xi), of occupational therapy in a real life context (Simons 2009, Yin 2009). It relies on inductive reasoning and multiple sources of information (Merriam 2009, Simons 2009). Its flexibility and ability to accommodate a diverse range of naturalistic, holistic, ethnographic, phenomenological and biographical methods of data collection and analysis seemed particularly appropriate for exploration of a complex phenomenon. A purpose of in depth understanding and knowledge to inform professional practice fits with my aims.

Could one or more interactions where an occupational therapist supports an individual with intellectual disabilities to engage in their occupations be regarded as a “case” or “cases” to be investigated? Key authors differ in their definitions of a “case”, as can be seen in Table 4.1. There is disagreement, for example about whether relationships and processes can be studied using this methodology, with Stake (2008) stating that the doctoring of a child cannot be regarded as a case, but Cousin (2009) implying that such a phenomenon is well-suited.

My overall conclusion was that an occupational therapy intervention could indeed be a contemporary phenomenon with boundaries not clearly evident that could be studied in its real-life context (Yin 2009), or a particular project or system (Simons 2009). It is an entity with a unique life that we do not sufficiently understand.

Author	Definition of “case”
Yin (2009, p.18), 2009	Investigates a contemporary phenomenon in depth, in its real life context, especially when boundaries between phenomenon and context are not clearly evident
Stake (2008, p.120-1)	a bounded system, a special something to be studied; an object, person, committee, programme, but not a problem, relationship, event, process, or theme; an entity with a unique life, something we do not sufficiently understand and want to
Merriam (1998, p.27)	“an intensive, holistic description and analysis of a single instance, phenomenon or social unit”
Simons (2009, p.4)	A broad definition, including a particular project, policy, institution, programme, process or system
Denscombe (2007)	Appropriate for researching processes and relationships
Willig (2008)	an organisation, city, group of people, community, patient, school, intervention, situation, incident, or experience
Thomas (2011, p.9)	“Case study is ... a focus and the focus is on one thing, looked at in depth and from many angles”

Table 4.1 Varying definitions of a “case”

4.2.3 Nature of this case study

Using this methodology requires specifying the physical borders, population, range of activities, time-span and actors within the case (Cousin 2009). In this section I describe in detail the design of this case study explaining and justifying my exploration of a single case of the occupational therapy of a small group of people.

My conceptual framework is discussed further in 4.4.1. Such initial theory (Hamel et al. 1993), study propositions (Yin 2009), or issues in my mind (Stake 2008) played a role in organising my case study, for example structuring my observations, interviews, and document reviews. Cases are progressively focused (Yin 2009) and my etic issues therefore changed as the study evolved, and emic issues of the actors emerged. This focus on uncovering emic issues is something that case study research has in common with ethnography.

The various types of case study are described in different ways in the literature and deciding whether a descriptive, interpretative or evaluative case study (Merriam 1998), an intrinsic or instrumental one (Stake 1995), or a critical, extreme, representative or revelatory one (Yin 2009) was required, involved considerable thought. Thomas (2011) explores the various classifications and his original and well-considered conceptualisation of the different types according to subject, purpose, approach and process allowed me to construct the kind of case that I considered relevant to my research question, as I now explain. The design of the case is also summarised in Appendix 1.

4.2.3.1 Subject

The case forms a good example of occupational therapy with people with profound intellectual disabilities. It is a key, or exemplary, case (Thomas 2011), though note that I am not implying that the case is “best practice”. The word “exemplary” is used here in the sense of giving example (serving as an illustration or example of something) rather than necessarily setting example (of such quality that others would do well to copy it) (Stevenson et al. 2010).

4.2.3.2 Purpose

The research question has an exploratory purpose at its heart. It is a puzzlement, where I am seeking in depth understanding of what is happening and why in this occupational therapy and possibly theory (Thomas 2011). The selected case is an exemplar of the general phenomenon identified in my research question and I have explored how that phenomenon exists within it (Stake 2008). Beyond merely gaining intrinsic understanding of itself, this case study is an instrumental tool (Stake 1995) illustrating and facilitating understanding of the occupational therapy of which it is an example.

4.2.3.3 Approach

The approach I have taken requires detailed consideration and Thomas (2011) summarises the varying experimental, descriptive, interpretative, illustrative, theory-testing or theory-building approaches that are possible.

At its core, my approach has been to illustrate and bring the case to life, presenting a rich picture of it and making it real for my reader, who can then to an extent

share the experience and make sense of it using their own knowledge and experience (Flyvbjerg 2006). Such story-telling (predominantly narrative), or picture-drawing (predominantly descriptive or analytical) accounts of the case (Bassey 1999) are however more discursive than theory-seeking, whereas my research question seems to require an approach that goes beyond mere illustration. The following is a summary of specific aspects of the broader approach that I have taken.

a. *An interpretive and social constructionist approach*

Authors that I have drawn on most in designing this research, such as Stake, Bassey, Thomas and Simons, all favour approaching broadly from within the interpretive paradigm, unlike Yin whose work leans more towards positivism (Bassey 1999). In section 4.3, I discuss in more detail the interpretive and social constructionist approach I have taken.

b. *An approach valuing subjective understanding*

Simons (2009) and Thomas (2011) both challenge a criticism that is sometimes levelled at case study research, particularly from those who research from within the positivist paradigm, that it is too subjective. Whatever methods I adopt, eliminating subjectivity is not achievable (Simons 2009) as it is inherent in the judgements I make and the views I express and in any case, I am exploring subjectively experienced phenomena. The approach I have taken is to acknowledge my subjective understanding and to see it as a strength of my methodology, as it is what has helped me understand what went on in the case. I remained reflexive and the impact of my values, predispositions and feelings on the study is explicit (Simons 2009). See further 4.3.4 about my role and position as researcher.

c. *A theory-building approach allowing specific types of generalisation*

To answer my research question, my case needs to represent something beyond itself and some kind of generalisability beyond the specific setting needs to be possible. I need therefore to be clear about the extent to which I can formulate propositional or analytical generalisations (Stake 1995, Yin 2009), or build a

theory, model, or framework of ideas to explain an aspect of the occupational engagement of people with intellectual disabilities using a single case study.

Generalisation (at least in the sense used in quantitative research) has no meaning in case study research (Cresswell 2007). My purpose is clearly not to gather a sample of cases to enable generalisation to some population. Stake advises not over-emphasising generalisation, as the real purpose of case study research is particularisation:

“damage occurs when the commitment to generalise or to theorise runs so strong that the researcher’s attention is drawn away from features important for understanding the case itself” (1995, p.8).

Any general understanding that comes out of my case is from insights developed through in-depth exploration of the particular (Simons 2009). In Chapters 6-8, I do however make some claims to knowledge beyond the case itself and in 4.3.3 I explain my justification for doing this.

4.2.3.4 Process

The process followed – the case’s structure and style and the manner in which it was carried out – is the final aspect of design. I considered the merits of exploring multiple, or a set of individual, case studies, versus a single case study. Stake (1995) contrasts single case studies with multiple (or collective) ones where a number of cases are studied together and compared to investigate the phenomenon of which they are an example. Studying a small number of cases in this way (either in parallel, or sequentially) involves comparing different examples and highlighting contrasts (Thomas 2011). This could arguably have led to good understanding of how occupational therapy supports people’s occupational engagement, though multiple case studies risk neglecting complexity, depth and uniqueness (Cousin 2009) which is why Stake (2008) advises choosing no more than four cases.

The alternative approach that I ended up taking was to carry out what Yin (2009) and Thomas (2011) respectively termed an embedded or nested case study. This is where a small number of nested sub-units (people in this instance) are related

and contrasted within the broader single case of which they are an integral part. At the outset, I was uncertain whether I would do a single, multiple or nested case study, as decisions about this depended largely on the nature of the cases available at the time of selection. I was clear all along, however, that I might only need a single case to answer my research question (Simons 2009) if it turned out to be a good enough exemplar (see 4.2.3.1) of the occupational therapy I was interested in. It turned out to be a single, nested case.

4.2.3.5 Other aspects of the case study's nature

a. Emergent design

It is in the nature of a case study that its design is emergent rather than fixed (Dyson and Genishi 2005, Simons 2009). Focus and methods have shifted in small, but important, ways with my growing understanding. Some ethical issues associated with having an evolving design are discussed in 5.4.2.1.

b. Trustworthy, credible and rigorous

The design has incorporated all of the following indicators of trustworthiness (Bassey 1999):

- Sufficiently prolonged engagement with data sources to become immersed and build the trust of actors.
- Persistent observation of emerging issues – searching for the salient features of the case, focusing attention on them and trying to develop understanding of them.
- Opportunity to check raw data with their sources – returning to the setting regularly, enabled repeated opportunities to, for example, seek comments on a recorded observation.

For further discussion of trustworthiness and the quality of the study, see 5.5.5.

c. Evolving out of user-consultation

This research was not user-led, emancipatory or participatory (Grant et al. 2005), but fundamental to its design was meaningful user involvement in the form of

consultation before data collection and collaboration with participants upon case selection (see further 5.4.1).

4.2.4 Consideration of case study in relation to other methodologies

I now relate my chosen case study methodology to others with potential to answer my research question, notably ethnography and grounded theory.

4.2.4.1 Ethnography

Ethnography aims to gain an insider view of life through engaging with people over time (Carpenter and Suto 2008). It can be used to explore experiences and social interactions and their symbolic meaning (Hammersley and Atkinson 2007), providing thick description and explanation of a social group's culture and structure, thus explaining why people behave as they do (Finlay 2006). Culture and structure is expressed within routines and patterns of daily life and inferred from people's actions, interactions and emotions (Carpenter and Suto 2008).

Are occupational therapists working with people with intellectual disabilities a culture sharing group suitable to be studied ethnographically? Culture can be anything that binds a group of people together (Nicholls 2009) including common interests and values, or the following of a particular code. A culture sharing group shares learned acquired behaviours (Cresswell 2007) and Carpenter and Suto (2008) describe these within health care, for example in a common setting such as a particular ward or unit. Occupational therapists who work with people with intellectual disabilities seem to share a unique way of working (Lillywhite and Haines 2010) similar perhaps to Nicholls' description (2009) of a specific culture common to speech and language therapists. Ethnographies often explore sub-cultures, perhaps running counter to a wider community culture (Willig 2008). Ethnography could therefore be an appropriate methodology to investigate a professional group seemingly working in a different way to other multi-disciplinary team members.

Ethnography has an exploratory orientation towards some aspect of the life of those studied (Hammersley and Atkinson 2007). It is a relatively open-ended approach, starting with and given direction by foreshadowed problems (Malinowski 1926), but opening up in the light of what is seen and heard (Agar

1980). It involves interpretation of the meanings, functions and consequences of the actions, practices, language and structure of the culture sharing group and uses anthropological concepts such as myths, stories and rituals (Cresswell 2007). Using an ethnographic methodology, I could have generated a rich and detailed picture and theorisation of the shared cultural meanings underlying the behaviours and actions of occupational therapists in their work with people with intellectual disabilities.

Critical ethnography

Thomas describes *critical* ethnography as “conventional ethnography with a political purpose” (1993, p.4). Madison (2012) explains how it begins with:

“a compelling sense of duty and commitment, based on principles of human freedom and well-being and, hence, a compassion for the suffering of living beings ... to address processes of unfairness or injustice [sic] within a particular lived domain” (2012, p.5).

Certainly, my research emerges from my strong conviction that the occupational lives of people with intellectual disabilities are not as they could be and a wish to contribute to promoting equity and occupational justice for them. Inherently political, I have sought to highlight voices often remaining unheard, underlying discourses and the ways that power and control operate within the lives of individuals with intellectual disabilities, limiting choices and potential identities. Drawing on critical ethnography, my research contributes to emancipatory knowledge and to discourses of occupational and social justice (Madison 2012).

Critical ethnographic case studies

Case-focused, as opposed to community-focused, ethnographic studies are possible (Angrosino 2007a) and Stake (2008), Yin (2009) and Simons (2009) all agree that case study research can be approached ethnographically. In many ways, I have combined the two methodologies and carried out an ethnographic case study. This differs from ethnographic research per se, focusing on the particular case, but still aspiring to understand its socio-cultural aspects (Simons 2009). As will become clear in the discussion of my findings, cultural aspects of the occupational therapy practice and of the case setting are key to the case.

I did at one point begin to refer to carrying out a critical ethnographic case study, but reverted to describing it as a case study, albeit very much influenced by ethnographic and critical ethnographic theory and methods and focused at times on cultural aspects of the case. This allowed me to focus additionally on non-sociocultural aspects.

4.2.4.2 Grounded theory

Researching from a similar ontological and epistemological position, I could have decided to use a constructivist grounded theory methodology, along the lines proposed by Charmaz (2012). I discounted this, however, as whilst it may be possible to propose tentative theory in the sense described in 4.3.3 from the findings of this case study, generating theory is not my primary objective here: I am more concerned with *understanding* the case. I was also unsure that it would be possible to reach the necessary data saturation (Charmaz 2012) with a single case. I have however drawn on some aspects of constructivist grounded theory in my analysis of the data, as explained in Chapter 5.

4.2.4.3 Narrative inquiry

At an early stage of designing this study, I did consider using narrative inquiry to gather, analyse and represent a story of occupational therapy supporting engagement. Although aware that qualitative case study research can be approached narratively (Thomas 2011), I chose not to take this approach, but rather to remain open to including narrative analysis within the data analysis strategy that emerged (see 5.5.3 and 5.5.4). In the end, I did not use narrative analysis, but the importance of narrative in the findings (see discussion in 8.1) suggests that consciously doing this may have been insightful.

4.3 Theoretical perspectives and philosophical roots

Research is unavoidably committed to particular visions of and ways of knowing the world (Usher et al. 1997). Having identified a methodology, the next step is to describe the theoretical perspective, or philosophical stance, that informs it (Crotty 1998). Embedded in an inquiry using my particular understanding of case studies, informed by ethnography and gathering data using participant observation are assumptions and for transparency these need to be made explicit. Anthropology,

from cultural and cognitive schools, is deeply embedded in ethnographic research (Hammersley and Atkinson 2007), but in addition, Cresswell (2007), Carpenter and Suto (2008) and Hammersley and Atkinson (2007) all highlight the possible influences of other theoretical perspectives, including Marxism, feminism, critical theory, philosophical pragmatism, phenomenology, hermeneutics, postmodernism, sociology, structural functionalism, post-structuralism, constructionism and symbolic interactionism.

In this section, in which I explore the ontological and epistemological commitments implicit in this research, I make explicit the ways in which some of these perspectives are relevant. In particular, I recognise the importance of the theoretical perspective of social constructionism. Crotty (1998) suggests separating out discussion of such perspectives from ontological and epistemological discussion, but I have found these matters to be so relevant to each other that this did not seem helpful. Certainly other authors (e.g. Dyson and Brown 2006) often weave the discussions together and I will discuss them as they become relevant to the broadly interpretivist epistemological stance that I have adopted.

Three questions proposed by Willig (2008) have assisted my exploration and identification of the epistemological and ontological roots of case study research:

1. What kind of knowledge does this methodology aim to produce?
2. What kinds of assumptions does it make about the world?
3. How does it conceptualise my role as researcher in the research process?

Ontological and epistemological issues are inter-twined and difficult to conceptualise separately, as thinking about the construction of meaning involves thinking about the construction of meaningful reality (Crotty 1998).

Epistemological questions arise from ontological concerns (Carpenter and Suto 2008). For clarity however, I have tried to answer questions 1 and 2 separately, though I recognise that this is somewhat artificial.

4.3.1 What kind of knowledge?

The kind of knowledge that a methodology produces depends on its epistemological position (Crotty 1998). Epistemology concerns the nature of knowledge, ways of coming to know or constructing that knowledge (Finlay 2006, Cousin 2009) and the reliability of claims to knowledge (Hammell 2006):

“What kinds of knowledge are possible and how can we ensure that they are both adequate and legitimate” (Maynard 1994, p.10).

Exploring the characteristics of knowledge generated by this case study and the status readers should ascribe to it is essentially a discussion about whether we make meaning subjectively and independently of the object, or whether the object also contributes to the meaning constructed (Crotty 1998). A range of paradigms or perspectives are potentially inherent in my case study methodology. Authors describe this range in different ways and although I am not proposing an inflexible framework, I do find it helpful to think in terms of three broad paradigms described by Weaver and Olson (2006):

4.3.1.1 Research Paradigms

a. Positivism and post-positivism

Objectivist and positivist perspectives at one end of the range of paradigms would be inappropriate positions from which to answer my research question (as concluded in 4.2.1). An objectivist epistemological view, for example would see things as having meaningful reality aside from consciousness or thought (Crotty 1998) and that recognising an object is merely discovering a truth and meaning residing in it and that careful research can uncover. This was the spirit in which much early naturalistic ethnography was carried out (Hammersley and Atkinson 2007).

b. Interpretivism

This range of perspectives, including insights from constructivism and social constructionism is the broad paradigm with most relevance to my study. Cousin (2009) uses interpretivism to refer to perspectives that emphasise and foreground the hermeneutic search for meanings including phenomenology, symbolic

interactionism, constructivism and social constructionism. Choosing to research from within an interpretivist stance has implications for my position as a researcher, in terms of whether it is possible for me to be objective and how I handle my subjectivity as well as the closeness of my relationship with the actors in my case study.

Interpretivism goes further than simply observing people's outward behaviour: it enquires into meaning and intentions (Cousin 2009). People's actions have meaning which I wanted to understand and respect along with their interpretation of social phenomena (Finlay 2006). Interpretivist research can gain detailed, in depth understanding of phenomena as experienced by those in the setting (Finlay 2006, Weaver and Olson 2006). A broadly interpretivist stance seems therefore the relevant position from which to carry out this research.

c. Critical, radical, feminist, and emancipatory paradigm

This position concerns issues of power and justice and seeks to critique people's seemingly natural or inevitable experiences as in fact socially constructed and mediated (Finlay 2006). I recognise how relatively uncontested (though, as we shall see, complex) ideologies of independence and the nature of engagement in occupation underpin my research question and the practice of occupational therapists. My research inevitably involves some critique of the theories and knowledge that are integral to the practice of this group of professionals – the constructed meanings bequeathed to them by their culture (Crotty 1998). The influence of critical ethnography on my research design and my interest in occupational injustices faced by people with profound intellectual disabilities are examples of the influence of this paradigm on my research.

Some authors, for example Crotty (1998), describe a further broad paradigm of subjectivism and post-structuralism or postmodernism, though I have found it more helpful to consider these as theoretical perspectives informing some of the above paradigms.

4.3.1.2 Social constructionism

Social constructionism, deriving largely from the work of Mannheim (1936) and Berger and Luckmann (1966), has become increasingly influential within the

interpretivist paradigm (Willig 2008). Its radical change of thinking is particularly relevant when focusing, as I have, on practice (Gergen 2009).

Constructivism provides the understanding that, as human beings, we can only gain knowledge through the medium of our minds and bodies. Thus everything we know is unavoidably mediated and constrained – and thus *constructed* – by what we think and do (Yardley and Marks 2004). We give meaning to our sensory experience of an external stimulus and only our interpretations of that stimulus register in our awareness and memory (Stake 1995). Therefore knowledge cannot be said to be devoid of human construction.

Social constructionism goes further than this meaning making activity of the individual mind however, in recognising that human experience is essentially a social process. What we know is also therefore mediated or shaped by history, culture and language (Willig 2008) and how we describe and explain things comes out of our relationships (Gergen 2009). Crotty's definition is helpful:

“the view that all knowledge and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context.” (1998, p.42).

If meaning is constructed, rather than naturally present, we cannot understand the significance of events purely from their external appearances (Dyson and Brown 2006), as early naturalistic ethnographers attempted to do. We need to find out the meanings that have been constructed and negotiated by the persons concerned.

Constructionism is related to the phenomenological concept of intentionality, meaning consciousness relating to or directing something and in the process shaping it (Brentano 2012). To fully describe something requires considering both the object and the person experiencing it (Crotty 1998). Constructionism therefore foregrounds the interaction between subject and object and rejects both objectivism *and* subjectivism. Suggesting that meaning is constructed rather than discovered is not the same as saying that it is *created* or simply imposed – this

subjectivism, ignores the concept of intentionality. Objects in themselves may be regarded as meaningless, but they are full of *potential* meaning and are still vital in the generation of meaning (Crotty 1998). We have something to work with and actual meaning emerges (i.e. is constructed) as we engage with and interact with them.

Willig (2008) usefully points out that rather than meaning we cannot really know anything, constructionism implies “knowledges” rather than “knowledge” – the possibility of different ways of perceiving, describing and understanding something. Viewing research findings as constructed does not imply that they cannot reflect the social phenomena being researched (Hammersley and Atkinson 2007), but they cannot categorically be said to be truths. Knowledges may be useful (or not), liberating (or oppressive), but not true or valid (Crotty 1998). Stake (2008) highlights how, in case study research, although my interpretations may ultimately be emphasised more than those of the actors, I nonetheless attempt to preserve the multiple realities and different views of all concerned, for example by including many examples of actual words spoken in interviews in Chapter 7.

Issues of culture are important in this case and the social and cultural origin of meaning is at the heart of social constructionism. Culture directs what people do and organises what they experience (Crotty 1998) and is the source of human thought and behaviour, rather than its result (Geertz 1983). The lenses of our culture emphasise and endow some things with meaning and cause us to ignore others (Crotty 1998).

Social constructionism can either be viewed as “the construction of *social* reality”, a view seemingly espoused by Finlay (2006) and Dyson and Brown (2006), or “the social construction of reality”, the wider view that Crotty (1998) and Gergen (2009) take. As my research explores an aspect of the social world, however, choosing between these views is not essential.

[Aim of research from social constructionist perspective](#)

Research from a social constructionist perspective aims to identify the different ways social reality is constructed within a culture and how this affects experience and social practice (Willig 2008). It means assuming, for example, that

occupational therapists construct the reality of their world and that their interpretation of their experiences with others governs their actions. It invites reinterpretation and requires openness to new or deeper, perhaps unconventional, meaning (Crotty 1998). A constructionist or constructivist stance seems to lie at the core of Stake's views on case study research summed up in his (2008) description of:

"The researcher's central role as interpreter and gatherer of interpretations"
(2008, p.135)

Both Dyson and Brown (2006) and Cousin (2009) agree that contemporary ethnography fits with a range of different philosophical views of the world, including interpretivist and social constructionist paradigms.

4.3.1.3 Influence of symbolic interactionism

In researching from a social constructionist perspective, my thinking has also been influenced by symbolic interactionist ideas. Our actions are steeped in social or cultural meanings and guided by our motives, beliefs and values and by rules and dominant discourses (Hammersley and Atkinson 2007) as well as by our continually changing interpretations of stimuli. These stimuli do not have a 'given' quality, but have meaning that can vary between people (or over time) - they are symbols (Dyson and Brown 2006). Language is central to the construction of meaning (Willig 2008) and symbolic interactionism assists exploration of how this is generated in the process of social interaction and from exchange of mutually intelligible symbols (Dyson and Brown 2006).

The practice of occupational therapy involves acquisition of knowledge and skills, values, roles and attitudes, instilled through professional socialisation (Carpenter and Suto 2008). These shared assumptions may or may not be articulated. In carrying out my enquiry in the spirit of symbolic interactionism I have sought, as described by Crotty (1998), to uncover my participants' meanings and perceptions, against the backdrop of their culture. I have striven to see things from their perspective. I derived these meanings from the social context and their exchanges of symbols (Dyson and Brown 2006), such as the language used and signs given of their intentions. I have identified both dominant discourses and narratives within

the occupational therapy intervention and the case setting, as well as those that have been suppressed.

4.3.2 What kind of assumptions about the world?

The kind of knowledge produced by this research contains particular assumptions about the world. Examining these assumptions involves consideration of ontology, the study of being, the nature of existence, conceptions of the world and reality (Willig 2008, Crotty 1998). At the heart of the distinction between the two contrasting positions of realism and relativism is whether I believe that things have essential (or positive) properties, or instead that there are multiple realities (Nicholls 2009).

4.3.2.1 Realism

At the core of realism is a belief in a reality independent of awareness and that things exist independently of myself as a researcher and my research (Finlay 2006). Realism implies that data collected ought to provide me with information about how things really are – true and undistorted, or valid, representations of the world (Willig 2008).

Realism was characteristic of early naturalistic ethnography (Hammersley and Atkinson 2007). Naturalism shares with positivism a realist commitment to understanding social phenomena as objects that exist outside of the research. The researcher is outside the research, makes efforts to preserve objectivity and guard against potentially contaminative effects on the data and to remain true to the nature of what is being studied (Matza 1969).

Could a researcher portray occupational therapy (an aspect of the social world) in the way that naturalism claims it does and be as neutral as it suggests? In recent years, ethnographers have challenged naturalism's assumptions, questioning in particular the realist view that it is possible to represent social phenomena in a literal fashion (Hammersley and Atkinson 2007). If people construct the social world as they interpret it and act on their interpretations, I as researcher have inevitably also done this, shaping my understanding of those I am studying. Most ethnographers do not now research from this realist and naturalist position and

reject the idea that their accounts can represent social reality in a literal way (Hammersley and Atkinson 2007).

4.3.2.2 Relativism

Dyson and Brown (2006) equate the naive realist assumption that research can gain objective knowledge with materialism and highlight the ontological debate between materialists and idealists. Idealism (in the sense of the realms of ideas and concepts) underpins the position of relativism, at the opposite end of the ontological spectrum. This questions the world being 'out there' (Willig 2008), implies that there is no single reality outside of our perception and requires us to accept multiple realities and diverse interpretations. Abandoning the assumption that there is a social world independent of what I make of it means I have no direct access to reality and can only know through concepts in my mind (Dyson and Brown 2006). I need therefore to study people's internal meanings with which they make sense of the world.

Relativism is strong in qualitative case study research (Stake 2008). I made role choices as researcher and contributed uniquely to the study of this case and each reader derives their own unique meanings from this thesis, interpretations that they may consider to have different degrees of credibility or utility.

4.3.2.3 Ontology and social constructionism: in between positions

I am not evaluating the practice of occupational therapists. My research question does infer that different occupational therapists may nevertheless have some uniqueness or similarity of approach. Whilst leaning towards a relativist position and wanting to appreciate different realities, discovering that every occupational therapist practices differently may not really answer the research question. Am I perhaps suggesting that there is *some* truth out there?

Ontology is a spectrum and between extremes of realism and relativism a range of positions can be held (Willig 2008). For example, a subtle realist stance aims to represent reality whilst acknowledging that it can only really be known from the knower's particular perspective (Robson 2002). Different knowers will have different perspectives (Finlay 2006) and our attempts to represent these are not

the same as attaining truth. Knowledge therefore can only be seen as beliefs about which we can be reasonably confident (Robson 2002).

Both subtle and the similar perspective of *critical* realism acknowledge the interpretive element to meaning (Sayer 2000). Critical realism is a combination of the realist aim better to understand what is happening with the acknowledgement that research data may not allow direct access to this reality (Willig 2008). If we can only know imperfectly, we must critically scrutinise what we claim to ensure our understanding is as good as is possible (Finlay 2006). Working with what is currently taken to be knowledge while recognising that it may be erroneous it can still be reasonable to assume that we are describing things as they are rather than how we perceive or would like them to be (Hammersley and Atkinson 2007). We cannot entirely know the world, but we can know something of it when our provisional interpretations are well-informed (Cousin 2009).

Researchers often carry out case study research from a critical realist stance and Willig (2008) and Stake (2008) seem to be describing this when they acknowledge both the influence of external reality on our meaning making and how our meaning making is mediated. Crotty (1998) regards social constructionism as compatible with a critical or subtle realist ontology, saying that regarding meaningful reality as socially constructed is not the same as saying that it is not real. A certain relativism is, I would agree with him, however implied in recognising the possibilities of different knowledges and realities.

I would therefore position my research as somewhere to the relativist side of critical or subtle realism on the ontological spectrum. Flick (2009) advises to be clear, for example what I claim an interview transcript (for example) to represent – an objective account of events, the interviewee’s thinking, an insight into their view of the world, or something else besides (Willig 2008)? I do not claim that my textual description mirrors reality in a straightforward way, as my representation is inevitably going to be adrift (Cousin 2009, Crotty 1998).

4.3.3 Generalising findings beyond the case

My research design has implications for the extent to which and ways in which my findings have relevance beyond the specific case setting. Both Bassey (1999) and

Thomas (2011) query the relevance of scientific inductive generalisation in social research, because of the complexity of social events and difficulty stating the precise conditions under which something holds. As previously said, generalisability, in the sense used in quantitative research, has no meaning in case study research (Cresswell 2007). I have not gathered a sample of cases to enable generalisation to some population.

Even if I am not primarily trying to generalise in any direct sense to other as yet unexplored cases, however, some comparison is inevitable (Stake 2008). To answer my research question, the case needs to represent *something* beyond itself and some kind of application of the knowledge gained beyond the specific setting needs to be possible. What, therefore, can my single case study tell us more generally about the practice of occupational therapists or how to support people with profound intellectual disabilities? I argue that it is possible for both mine and my reader's existing generalisations to be modified on becoming acquainted with this new case in the following three ways.

4.3.3.1 Transferability: learning from naturalistic generalisation

As important as claims to knowledge made by me, are future readers' own interpretations of the case – the naturalistic generalisations that they make through their personal engagement with it (Stake 2008). In this thesis, I have hopefully included sufficient detail and rich description from detailed analysis to construct vicarious experience allowing readers to feel “there” as part of the case. They will be able to judge its plausibility, inevitably making comparisons with other familiar cases of their own. They may recognise similarities and differences and will thus modify, extend or add to their existing understandings of the world (Simons 2009):

“Knowledge is socially constructed and through their experiential and contextual accounts, case study researchers assist readers in the construction of knowledge” (Stake 1995, p.101).

The validity of the case can therefore be said to come from the connection to the reader's own situation and the insight it offers between the two (Thomas 2011). This kind of learning empowers readers personally to engage with and take action

on the findings of the case (Simons 2009), providing material for readers to learn on their own (Stake 1995), which is particularly relevant for professional practice (Thomas 2011).

My textual representation of the case is limited by the language, values and discourses available to me (Cousin 2009). Readers will approach my research with their own preconceptions and its meaning will therefore not be stable. Avoiding grand generalising claims, my text instead becomes:

“An invitation for the creative play of others” (Schostack 2002, p.230).

4.3.3.2 Exemplary knowledge: learning from fuzzy generalisations

Thomas also emphasises the exemplary knowledge rather than generalisability that comes from case studies. Distinct from induction, he refers to this as abduction, meaning the development of explanatory or theoretical ideas (Hammersley and Atkinson 2007), or thinking tools. Rather than generalising in a propositional sense as might be expected in positivist research (Simons 2009), my approach has been to focus more on exemplary knowledge, abduction and on phronesis, that is to say “practical knowledge ... based on personal experience ... that helps us to make sense of particular situations” (Thomas 2011, p.214).

Abduction seems to me be akin to communicating findings from case study research using Stake’s speculative and tentative assertions made in the form of a “petite generalisation” (1995, p.7), or Bassey’s “fuzzy generalisations” or (even more tentative) “fuzzy propositions” (1999, p.51). A fuzzy generalisation is:

“a statement that makes no absolute claim to knowledge, but hedges its claim with uncertainties” (Bassey 1999, p.51).

A general statement to “do x instead of y and people with profound intellectual disabilities will be more occupationally engaged” would rather be qualified with the idea of possibility but not certainty or measure of probability (“it may be that doing x instead of y...”). This clearly recognises that there are likely to be exceptions and that fuzzy generalisations only have credibility when contextualised.

4.3.3.3 Theory building

Flyvbjerg (2006) highlights how case studies can be ideal for generalising using falsification, exploring cases that runs counter to a rule. Despite having some assumptions about my topic however, I do not have a clearly established explanatory framework and therefore am not seeking to test theory.

Case studies can be used to develop or refine theory and explanations that may help understand other cases and situations (Willig 2008). Analytic, or theoretical, generalisation to other populations may be possible if the research is robust and well-reasoned (Nicholls 2009). As well as the fuzzy or petite generalisations referred to above, modifications of grand generalisations (Stake 2008), or assertions (Cousin 2009), may therefore be possible.

Theory is especially important in case study research, as it is what connects ideas, explains patterns and holds the whole case together (Thomas 2011). Using fuzzy generalisations, I have cautiously (in order not to lose denseness of narrative and contextual detail in the search for theory) gone beyond a picture-drawing approach in this exploratory case study. I have taken what Bassey (1999), Simons (2009) and Thomas (2011) refer to as a theory-seeking, theory-generating, or (my preferred term due to its resonance with social constructionism) theory-building approach to the case. I have explored it using the theoretical framework (see 4.4.2 below) and have sought a theory of the case (Simons 2009). This is not something “immovable and immutable” (Thomas 2011, p.214), but rather a tool for thinking about and understanding the topic and explaining my findings. It can subsequently be tested by others and discarded, retained, or amended as appropriate, with Yin (2009), for example, seeing defining questions and hypotheses for subsequent testing as the main use for exploratory case studies. My outcome is a theory in the form of a worthwhile and convincing argument supporting a small number of fuzzy generalisations (Bassey 1999) to strengthen our understanding and interpretation of the behaviour of an occupational therapist supporting occupational engagement.

4.3.4 What role as researcher?

My position and the roles I took influenced the data I gathered and locating myself within the case is therefore important (Dyson and Genishi 2005). In this section I consider the nature of my role as researcher, which turns on the extent to which I am seen as the author, or witness of my findings.

A positivist approach might involve taking all possible steps to reduce my “contamination” of data collection and analysis (Willig 2008). Subjectivity would be a negative to seek to erase from the research process by, for example, attempting to deny my own presence and impact, distancing myself by writing in the third person. Both positivism and naturalism assume that I can standardise out my contaminative effects or become a “neutral vessel of cultural experience” (Hammersley and Atkinson 2007, p.15).

This attempt at objectivity is a “false trail” (Simons 2009, p.163), unachievable with me being part of the world I am studying. The occupational therapy researched is experienced subjectively and judgements I have made and views I have expressed are inherently subjective. I cannot position myself outside what I am studying, ignoring the fact that my identity and standpoint have fundamentally shaped the research, my relationship with the participants and the findings. My participants will have interpreted my personal biography (gender, class, experience, sexuality and so on) in socially prescribed ways (Fortier 1998). I am an occupational therapist, I have over 20 years’ experience working with people with intellectual disabilities, and I am implicated in what I am studying. My values, experiences and knowledge have affected my understanding of the data:

“We cannot escape the social world in order to study it” (Hammersley and Atkinson 2007, p.10).

Angrosino describes a contemporary ethnography, influenced by postmodernism (2007a) and relying on participant observation, which accepts that an account can never be objective, but instead reflects the researcher and is a collaboration. Clifford’s definition of ethnography helpfully sums up my stance in this case study:

“A series of partial truths that emerge out of an open-ended series of contingent power laden encounters that reflect the personal and ideological characteristics of both researcher and researched.” (1986, p.14).

Social constructionism suggests that I have been a central figure in the research process, the key research instrument (Carpenter and Suto 2008, Cousin 2009, Hammersley and Atkinson 2007), constructing the findings, albeit jointly with my participants. Inter-subjectivity between us is fostered and valued (Finlay 2006) and it has allowed the depth of understanding I was seeking. I made choices, including about how much to participate personally in observed activity, or to remain neutral or be critical; how to dress and where to position myself; how much to talk to people and in what way; and how to balance distance and intimacy (Dyson and Genishi 2005, Stake 1995). Such decisions depended on what best suited my purpose and the participants (Simons 2009), and my role varied at different stages. To facilitate participant observation, I consciously developed collaborative relationships with Esther and other participants, making my interest in their perspectives apparent and hopefully sending the message that I was researching with them not merely on or about them (Simons 2009).

Put metaphorically, rather than a treasure hunt, the research was rather more like a builder constructing a house, where the same bricks (i.e. the data) could have been used to build a variety of different dwellings (Willig 2008). Subjective understanding can, however, be seen as a strength of this case study, as something that has contributed to my insight and understanding.

4.3.5 Reflexivity

Making my knowledge, understanding and values explicit has involved adopting a reflexive stance. The quality of reflexivity relates closely to the trustworthiness of accounts (Hammersley and Atkinson 2007), with Fortier’s description (1998) of how her observations were shaped by contrasts between her personal beliefs and lifestyle and those of her participants enhancing credibility. Personal reflexivity abandons ideas of neutrality and allowed me to become an active participant in this qualitative research (Hammersley and Atkinson 2007).

Reflexivity involved getting to know myself as a researcher and making my knowledge, understanding and values, predispositions and feelings explicit. Clarifying how they impacted on the case (Simons 2009), enabled distinction between situations where my subjectivity contributed to my developing insight from those where I may potentially have been coming from a position of bias, or at least helped me to be more aware of this. Since beginning this research in September 2009, I kept a journal in which I have reflected on the process of developing and carrying it out. Returning to a number of reflective entries within this and, following the example provided by Williams and Paterson (2009), I drew up a "Subjectivity statement", which I found it useful to return to and add to during data collection, analysis and write up. Extracts from this have been included in Appendix 2).

In my reflective journal and memos, I reflected on the following aspects, some of which are explored later in Chapter 8):

- My thoughts and emotional reactions to what transpired and anything unexpected, surprising or unusual, in particular anything that caused me to review my foreshadowed issues.
- My observations and reactions to people and the setting, for example when I found it difficult to empathise with someone.
- Critical incidents, especially those that aroused strong feelings (positive or negative) in me, which could indicate lack of neutrality, for example avoiding situations where I might experience negative feelings, or seeking out situations likely to lead to more positive ones (Robson 2002).
- How my values, preconceptions and reactions affected the progress of the research and influenced interpretation of data.
- Any conflicting interpretations about the case that emerged from my collaboration with participants (Flewitt 2005).
- How my own presence might have influenced the findings.
- All decisions I made, in order to provide a decision/ audit trail.

4.4 Theoretical and conceptual frameworks

To conclude this discussion on methodological approaches, I now summarise the inter-related conceptual and theoretical frameworks that can be seen as underpinning this research.

4.4.1 Conceptual framework

Whether rudimentary or elaborate, a conceptual framework “explains, either graphically or in narrative form, the main thing to be studied - the key factors, constructs or variables - and the presumed relationships among them” (Miles and Huberman 1994, p.18). Qualitative studies are often relatively unstructured, with conceptual frameworks emerging gradually, which can permit a unique understanding from data grounded in participants’ experiences (Simons 2009). Too tight a framework risks missing important and particularly unexpected features, but studies do nonetheless require at least some explicit idea of what information to seek (Miles and Huberman 1994), as they otherwise risk being unbounded and unfocused. Particularly with a case study, this can lead to indiscriminate, or insufficiently selective, data collection and an unrealistically time consuming volume of data to interpret (Simons 2009). Beginning with at least some conceptual framework provides clarity and focus, easing later data analysis (Simons 2009).

The breadth of this framework can depend on what is already known about the phenomenon (Miles and Huberman 1994). Chapters 2 and 3 illustrate that I do know something conceptually of both what is well and less well understood about occupational therapists’ work supporting occupational engagement and therefore come to this study with orienting ideas (Miles and Huberman 1994), sensitising concepts (Carpenter and Suto 2008) or foreshadowed issues (Simons 2009). This background knowledge and my initial thoughts form my conceptual framework, that is to say “the current version of [my] map of the territory being investigated” (Miles and Huberman 1994, p.20).

I explored discrete theoretical constructs, events, settings and behaviours and their inter-relationships that theory and my experience suggested were relevant

(Miles and Huberman 1994) and developed a conceptual framework which, at the point of beginning to explore the case, consisted of the following:

- Social and interactionist models of disability and the ideologies of “independence” and “interdependence”.
- Person-centredness and person-centred practice.
- The meaning of meaningful engagement in occupation, including concepts of volition, motivation, attention and alertness.
- Occupational (in)justice.
- Occupational therapy theory including analysis, grading and adaptation of activity.
- The nature of effective support to enable engagement in occupation.

My further-developed thoughts, as my orienting ideas became progressively refocused (Simons 2009), can be seen in the discussion in Chapter 8.

4.4.2 Theoretical framework

Drawing on theories can help to explain issues under investigation. My theoretical framework represents an integration of such theories, essentially a lens through which I have looked at the data (Merriam 1998). It overlaps with my conceptual framework, as some concepts there are also theories that I have drawn on, for example the concept of volition, which is so central to the topic.

The following theories are of particular relevance:

- Occupational therapy theory, including the Model of Human Occupation (Kielhofner 2008), which I consider helpful for understanding occupational engagement by individuals with profound intellectual disabilities: in particular, the impact of volition – personal capacity and effectiveness, values and interests (Kielhofner 2008) – on their engagement and the impact of the opportunities, resources, constraints and demands within the physical and social environment on how they think, feel and act.

- Clinical reasoning (procedural, interactive, conditional, narrative and pragmatic) underpinning the actions of the occupational therapists as they support occupational engagement (Fleming 1991).
- Social constructionism – my story of the case (the findings in chapters 6 and 7) is, as will be seen, a social construction with my research participants and in particular Esther.
- Symbolic interactionism (Blumer 1992) can help explain the occupational therapy of individuals with profound intellectual disabilities which, as a social encounter, has a meaning that is not necessarily a ‘given’ (Dyson and Brown 2006). Participant observation, one of my key methods of data collection is rooted in symbolic interaction (Rock 2007). Social interaction observed involved the exchange of human symbols based upon meanings given to people and objects involved (Crotty 1998). These included the actions of Esther and others and the language used, for example in interviews, to negotiate such meanings.
- Ethnography and critical ethnography supporting exploration of experiences and social interactions (Hammersley and Atkinson 2007) of occupational therapists, people with intellectual disabilities and those supporting them. This illuminated symbolic meanings and why people do what they do (Finlay 2006). Culture is expressed within the patterns, routines and interactions of Esther and of those living and working in Cavendish House (Carpenter and Suto 2008). Ethnography and anthropology more generally supported my construction of a rich and detailed picture and theorisation of the cultural meanings underlying their behaviours and actions (in Chapter 8).



Having explored the kind of knowledge this research has produced, the kind of assumptions it makes about the world and my role as a researcher, I move on in the next chapter to describe how I collected and analysed data and how I resolved ethical issues inherent in exploring the case.

Chapter 5. METHODS OF DATA COLLECTION AND ANALYSIS

5.1 Introduction

In this chapter, I describe the choices I made regarding research methods, all of which were characteristic of both case study and ethnographic research (Hammersley and Atkinson 2007) as summarised in Table 5.1.

Fairly small scale	I focused on just one case of occupational therapy involving Matt, Steve, Harold, Becky and Jane, five people with intellectual disabilities (see further 5.2.3).
Research in the field for in depth understanding in context - iterative inquiry exploring the dynamics of social interaction, as it took place.	I immersed myself in Cavendish House, where these five people lived and where Esther was providing occupational therapy. I worked closely with her to understand her behaviour from both emic and etic viewpoints.
Range of data sources, appropriate to and epistemologically compatible with my research question (Willig 2008).	I was a participant observer of practice (and additionally of video recordings of practice). I interviewed – both relatively informal conversations and more formal interviews – Esther and relevant others (for example support workers and service managers). I analysed documents (including case notes) and artefacts
Relatively unstructured data collection	The research design evolved rather than being fixed and fully detailed at the start.

Table 5.1 Overview of Methods of data collection

I explain how I selected the case and recruited participants and naturally their names and the names of organisations have been changed to preserve anonymity.

An attraction of case study research was the ability to use multiple methods of data collection and I explain how these gave valuable scope for triangulation of data source and how, as Cousin suggests (2009), I gained value from critical consideration of evidence from different sources.

I then consider some of the ethical issues inherent in using these methods to explore my case before turning to my strategy for analysis of the data collected. My earlier ontological discussion suggested that traditional concepts of validity and reliability may be less relevant to my research. Instead, I justify how I balanced an adaptable and flexible approach with the need to carry out this case study in a rigorous way, using prolonged involvement, an audit trail, reflexivity and triangulation of data source to guard against threats to trustworthiness.

5.2 Selecting the case and accessing the field

In case study research a purposive selection of routes of investigation most likely to produce the information needed is appropriate (Finlay 2006, Cresswell 2007). As explained in 5.2.3, the nature of the case was not completely clear at the outset and, rather, it crystalised gradually and, as explained in 5.2.3, the case crystalised gradually. When referring to decisions about the case and participants within it, I have deliberately used the term “selecting” rather than “sampling”. The latter term is inappropriate for a case study which in no way seeks a portion representative of a larger whole (Thomas 2011), or even necessarily something that is typical, for as will become evident, this case may not be a typical occupational therapy intervention. Using specific criteria related to my research question and relying on my judgment, I selected an environment that was an exemplar of practice (Finlay 2006) (see 4.2.3.1) and, of primary importance (Stake 2006, Simons 2009), a case there that seemed to offer opportunity to learn. Following the advice of Carpenter and Suto (2008), I chose my informants for their cultural competence rather than their representativeness, sometimes selecting theoretically, i.e. by consciously choosing the next participant (a specific support worker perhaps) in a way that allowed me to collect data that I could compare with what I already had (Agar 1980).

5.2.1 Negotiating access and participation

In 5.4, I explain the process of gaining ethical and research governance approval to allow me to seek to recruit participants from amongst the staff and service users of two National Health Service (NHS) Trusts in Southern England (Trusts A and B) and Futures (a not-for-profit organisation providing support to people with intellectual disabilities). This required negotiation, as I no longer work for the NHS and needed to demonstrate relevance to the Trusts' research priorities. As an outsider, I needed to rely on others with insider status within these cultural groups as gatekeepers (Cresswell 2007). For example, in Trust A, the very first stage before formally applying for ethical and research governance approval required 'adoption' of my study by the Trust's Intellectual Disabilities Research Group. The role of gatekeepers was important, though their clinical priorities and institutional power, as suggested by Finlay (2006), had influence on who I was able to recruit and the types of accounts I was able to access. Their support was valuable in confirming the relevance of my research topic, though gaining this did significantly slow my progress.

5.2.2 Recruitment

Recruitment was in three stages:

5.2.2.1 Recruiting the occupational therapist

Initially, I had research and governance approval to recruit an occupational therapist from NHS Trust A. I sought participants who:

- i. Worked as occupational therapists within that Trust and who were registered with the Health and Care Professions Council.
- ii. Considered themselves to be experienced in supporting people with profound intellectual disabilities to engage in their occupations at home.
- iii. Regularly undertook this kind of work and therefore thought they would be likely to have relevant people on their waiting list or caseload at the time of data collection.

I deliberately decided not to define level of experience precisely e.g. by pinning this down to years or job grade, as I considered experience of the particular type of

work I was interested in of primary importance. I clarified the aims of the research with potential participants and in the light of that established that they considered themselves to have a relevant level of experience.

As I know and am known to the occupational therapists I was potentially recruiting, I paid particular attention to reducing any possibility of coercion, by not contacting potential participants directly, but rather providing opportunity for them to contact me to express their interest (see further 5.4.2). Participant information sheets, clearly explaining the nature of the research and what would be expected (see Appendix 3), together with a covering letter, were forwarded by a gatekeeper from the Learning Disabilities Research Group of Trust A to occupational therapists working in that Trust's community learning disability teams. Six occupational therapists chose to attend an information session about the research at the end of their regular team meeting. There, I explained the research further and answered questions, before asking them to contact me should they wish to consider participating. They were also asked to pass on the information to relevant others within Trust A who might be interested, i.e. using 'snowballing' (Braun and Clarke 2013, p.57).

In the end, no occupational therapist from NHS Trust A volunteered to participate, seemingly because (from subsequent conversations with some of those who considered taking part) circumstances had resulted in them no longer being able to provide the type of extensive intervention I was interested in researching. An occupational therapist from NHS Trust B with whom I had previously worked, Esther, heard about the study and enquired about participating. This serendipitous contact was to have a major and positive influence on the direction of my study. I knew that Esther was an experienced and respected occupational therapist, and could see that she was motivated to participate and clearly met my inclusion criteria. As she was also the only person who had expressed an interest, I decided to take the onerous step of applying for additional research governance approval from NHS Trust B, delaying data collection for nearly four months. Once I received this approval, Esther then formally consented to participate (see Appendix 4).

5.2.2.2 Recruiting participants with intellectual disabilities

Esther therefore became my first participant and also my primary gatekeeper for recruitment of further participants. I worked closely with her to gain her confidence and agree criteria for a case that could be explored. My previous experience as an occupational therapist in this field, as well as already knowing her, hopefully enhanced my credibility and assisted in negotiating access to a suitable case, as suggested by Llewellyn (1995). As the nature of occupational therapy in this field can be very varied, case selection was dependent on Esther's typical work and on the needs of those on her caseload and waiting list. We discussed in general terms that did not identify individuals to me, potential participants who met all inclusion criteria, in that:

- They had intellectual disabilities and complex needs within the definition in section 1.3 above.
- Were aged 18 or over.
- Were eligible for occupational therapy and on Esther's caseload or waiting list.
- Occupational therapy was needed to support engagement in occupations at home (for whatever reason) and that this looked likely to require significant input (i.e. not merely a small number of contacts).

We identified a small number of potential cases that seemed to offer the most potential for relevant learning (Simons 2009) and came to a mutual decision on the merits of one particular setting, Cavendish House, in which Esther had previously worked with residents Matt and Harold. As described in more detail in Chapter 6, she and her community team colleagues had identified on-going needs regarding engagement in activity at home amongst them and the other adults with intellectual disabilities living there.

We then followed a series of carefully planned recruitment procedures to ensure both that there was no coercion and that the measures outlined in the Mental Capacity Act (MCA) (GB Parliament 2005) were followed in recruiting Matt, Becky, Harold, Jane and Steve. These are described in more detail in 5.4.3.3. The first approach was by Esther to nearest family members (Matt and Becky), or advocates

(Harold, Jane and Steve) to explain that she would be working with each person and to identify whether there was any interest in finding out more about them participating in this research. They were not fully identified to me until there was an initial indication of interest from those family members or advocates.

5.2.2.3 Recruiting other participants

As suggested by Dyson & Genishi (2005) and Simons (2009) and as I expected, it became apparent that others were relevant to the case and therefore potentially useful participants to interview or observe. An occupational therapy assistant (Sarah), support workers (for example, Jean, Olly and Doug), a nurse (Adam) and service managers (Sue and Norma) all supported my learning about the case and provided a variety of perspective. Interestingly, no family members became participants, as none became involved in the occupational therapy that was the subject of the case. This is, I conclude, reflective of the limited involvement that the families of Harold, Jane, Matt, Steve and Becky had in their lives.

These potential participants were approached by Esther in the first instance and then by me only once they had shown initial interest in finding out more. They were selected purposively using the following inclusion criteria:

- People who seemed of relevance to the case of the occupational therapy of those living at Cavendish House.
- Who were aged 18 or over.
- Who had capacity to consent to participate.

All potential participants received an appropriate information sheet (see Appendix 5) and were given an opportunity for me to go through this and answer any questions before giving written consent (see Appendix 6) if they wished to participate.

5.2.3 The boundaries of the case

There is consensus in the literature on case study research about the need to define the bounded system (Stake 1995) that is the case, making clear its analytical frame or object (Thomas 2011). The nature of my case crystallised gradually. Features such as physical borders, range of activities, time-span and those actors

that were within and outside it, though nonetheless potentially significant as context (Cousin 2009), became clear. I see it as a case of occupational therapy and, more specifically, it can be described as:

“The occupational therapy that supports the occupational engagement at home of a small number of people with profound intellectual and multiple disabilities living together in one house.”

Its evolving nature meant that it was difficult to predict in advance how many participants I would seek to recruit and the length of time they might be involved. Who I might or might not want to recruit as a research participant was dependent on the case selected and influenced by Esther's decisions regarding the direction and extent of intervention. Data saturation, the point where returns diminish and new data collected adds no new theoretical insights (Charmaz 2012), is not necessarily the objective of case study research. My decisions regarding whether I had reached this, or at least data sufficiency (Bowen 2011) did have some influence on whether for example I recruited another support worker as participant. Essentially, data collection drove further data collection, beginning with one occupational therapist and the people with intellectual disabilities she was working with. I considered whether this in itself allowed sufficient understanding, or whether new participants – potentially, though this did not prove necessary, further occupational therapists and their clients – needed to be brought into the study. Data collection came to a natural end however once Esther completed her work and discharged those living in Cavendish House from her caseload.

The story of the case is described in detail in chapters 6 and 7.

5.3 Methods of Data Collection

In this section I explain how, to gain in depth understanding in context, I spent time in the field with Esther, immersing myself in the case setting. I explored the dynamics of social interaction as it took place, working and participating closely with protagonists to understand their behaviour. Data collection was iterative and primary sources of data were participant observation of practice and relatively

informal interviews or conversations with the participants. Other methods (Robson 2002) were also used when these showed potential to give insight (Robson 2002), for example documentary analysis of occupational therapy case notes. Aspects of the case were also videoed, both to allow me to observe situations when it was not possible to be present, as well as also to trigger reflection on the case within interviews (Haw and Hadfield 2011).

These multiple methods gave valuable scope for gathering varying perceptions, clarifying meaning (Stake 2008) and enhancing expressiveness of the data (Flick 2009). Constructionist qualitative researchers are sceptical about the value of triangulation (Silverman 2013) due to the possibility of erroneous convergence of data towards the same point, but I am not suggesting that such triangulation of data source allowed access to a single truth about the case. Rather, it recognises the complexity of the case and contributed to my identification of different realities in it and the ways they converged and diverged (Stake 2008, Simons 2009).

5.3.1 Participant observation

I considered observation to be essential to gain access to the information I needed to answer my research question. To begin with, my review of the literature and my own previous experience of interviewing occupational therapists about their work with people with intellectual disabilities (Lillywhite and Haines 2010), suggested that interviewing alone would be insufficient. Analysing data from the focus groups in that study led me to realise how mere reliance on speaking to occupational therapists might not allow access in sufficient depth to the details and subtleties of their interventions and their tacit thinking and clinical reasoning. This was a conclusion Mattingly and Fleming (1994) also reached when studying the clinical reasoning of occupational therapists. Interviews may allow access to accounts of practices, but the practices themselves are only accessible when observed (Flick 2009). Observation allowed gathering of data on the fine detail of social interactions as they happened and within their wider socio-cultural context, data that I could subsequently explore in interviews.

Secondly, I am very conscious that the voices of people with intellectual disabilities and complex needs have often been silent in research about them, with such

research either consisting of quantitative psychological or psychometric assessments (Porter and Lacey 2005), or qualitative research seeking the views of families and support staff about their lives. I justify the necessity of gathering data by the arguably intrusive method of participant observation in people's homes in 5.4.3 below.

Participant observation is rooted in the theoretical background of symbolic interactionism (Rock 2007). In order to really understand situations and to gain the perspectives of the actors involved in them, I needed to be fully immersed and to establish and maintain relationships (Angrosino 2005). Kielhofner (1981) describes how he found that fully participating in a study with people with intellectual disabilities allowed access to otherwise hidden features of the setting and achieved deeper understanding of the practices and perspectives of those observed.

Considering the five dimensions of research observation described by Flick (2009), I would describe my observations as:

- Participant (rather than non-participant).
- Apparent (rather than in any way covert).
- Neither highly systematic nor totally unsystematic, but certainly flexible and responsive to evolving events.
- In naturally occurring (rather than artificial) situations.
- Reflexive – that is involving self-observation as well as observation of others.

Gold (1958) describes a classic typology of potential participant observer roles. Not being normally part of the social setting of Cavendish House and not having a natural reason, aside from research, for being present, I conclude that rather than acting as a “participant as observer”, I took on the role of “observer as participant” (1958, p.217).

Following the phases of observation described by Flick (2009), I began with descriptive observations to orientate myself to the case site and build relationships with the actors, the “hanging around” familiarisation phase described by Mattingly

and Fleming (1994). Gradually gaining access to the field and to relevant persons did seem to allow my presence to become more 'normal', with the aim of reducing reactivity in the form of guarded behaviour by participants (Spradley 1980), though I explore further in Chapter 8 the nature of my presence in the field. Some of this early data turned out to be sensitising as much as research data in that it was useful for understanding the context but not necessarily directly relevant to my research question. My observations progressively became more concrete and focused as, drawing on my tentative conceptual framework, I concentrated on those aspects that seemed most relevant to the research question (Angrosino 2005). In the latter stages observations became more selective to find further evidence or examples of the kinds of practices and processes seen in the focused observations.

I concentrated my observations on nine aspects of social situations (Spradley 1980) that is to say spaces, actors, activities, objects, acts, events, time, goals and feelings. Observation is fatiguing and I needed to maximise the usefulness of each visit, so I set observational goals and recognised the limits of my own capacity (Flick 2009). I ensured that I was reflexive about some of the challenges of participant observation such as selecting situations where the research issue was most likely to be visible and avoiding losing the critical external perspective of the stranger, or going native (Angrosino 2005). I reflect further on some of these challenges in 8.6.5.

5.3.1.1 Field notes

I found the advice of Emerson, Fretz and Shaw (2011) in their classic text on writing ethnographic field notes extremely useful in helping me to devise an effective and practicable system that worked for me. I intended to take as many notes as I could during participant observations, but quickly realised that I did not feel very comfortable doing this, wondering whether it made participants (and potential future participants) more wary of my presence. I was also very conscious of being in what was the home of some participants and felt awkward about the idea of carrying a clipboard or notebook and writing extensive notes about people there.

a. Jottings

I therefore limited my writing in the field itself to what Emerson et al. (2011, p.29) call 'jottings', that is to say brief written notes, such as an impression, a key word or phrase, a symbol or abbreviation, a question I asked or a sentence someone said. Some of these I recorded immediately, others at the first opportunity (e.g. as soon as I was out of the house or perhaps on a strategic visit to the toilet). These jottings were invaluable mnemonic devices for me to use to construct my field notes later. As I became more practised at these jottings, I became better at recognising and capturing the key aspects of what I was observing that would be the most useful reminders for me to transform into vivid descriptions in later field notes. I found Emerson et al.'s advice (2011) particularly helpful to:

- Record actual words, rather than summarised dialogue.
- Record concrete sensory descriptions (e.g. what I saw and heard using active verbs) rather than my interpretations of actions.
- Avoid evaluating or forming impressions about events, or guessing at people's motives or internal states.
- Record markers that might help me remember the sequence of events.

On occasions, I audio recorded jottings as soon as practicable upon leaving Cavendish House as a convenient and quick way to capture them.

b. Writing up field notes

I tried to begin writing up field notes from these jottings immediately, or at least as soon as possible after leaving the field. Long train journeys back from Cavendish House were helpful in providing an opportunity to do this. Emerson et al. (2011) advise against talking with others about what has been observed until full field notes have been written, though I often needed to compromise on this, particularly when I wanted to interview Esther about what I had just observed her doing. On reflection, I conclude that any impact on the psychological immediacy of my field notes (as Emerson et al. (2011) warn is possible) was outweighed by the value of gaining Esther's immediate perspective on those occasions.

I focused on recording experiences while they were still fresh, trying not to allow my internal editor to distract me from the scene I was trying to evoke with

concerns of grammar and sentence structure. Emerson et al. (2011, p.40) suggest writing “spontaneously ... as a conversation”, referring to my jottings, but also experimenting with a combination of methods to promote recall:

- Tracing events in chronological order as I observed or experienced them (which I found particularly helpful for recall).
- Starting with seemingly critical incidents and detailing these as thoroughly as possible.
- Focusing in turn on different types of events related to my areas of interest.

Once my thoughts were recorded in this raw form, I returned to them and added to, reorganised and polished them to some extent to form field notes that were constructions of my personal experiences of what I had observed. I was surprised to find that writing the field notes took substantially longer than the actual observations.

When I wrote field notes, I was inevitably, to a greater or lesser extent writing my retrospective reinterpretations of what I had observed, that is writing from a position of later insight. In order to preserve the process and experience of constructing meaning, however, I did at times try writing descriptions of events as they had actually happened, excluding meanings, as far as possible, until writing about how I had realised or constructed those meanings. Further suggestions from Emerson et al. (2011) that I found useful were to:

- Write with an intended audience of myself as future reader and not worrying about consistency of voice or style.
- Pay particular attention to initial impressions before the way the setting looks, smells, sounds and the way people behave became too commonplace.
- Use lots of adjectives and adverbs to evoke vivid images, focusing on sensory details and on action and movement.

- Register my own reactions to events or any contradictory emotions I might experience. Use these to increase my sensitivity to what might be happening, or significant to those in the setting.
- Keep my evaluations and judgements and my developing analysis explicitly separate from description. I did this by:
 - Placing any brief reflective, or analytical points (perhaps interpreting or questioning) in asides within [square brackets] in the midst of my descriptive writing.
 - Placing any more detailed or elaborate analytical commentaries in separate paragraphs or sections, again within [square brackets].
 - Keeping more detailed analysis in separate memos (see 5.5.3.5).
- Attempt to represent the flow of exchanges between participants, using inverted commas when quoting verbatim, but otherwise to use indirect quotation or paraphrasing of dialogue, along with descriptions of body language.
- Represent multiple voices and points of view, including my own, avoiding an omniscient perspective, which would not sit with my interpretive stance. There are varying perspectives/ points of view within my field notes and my wording makes clear when I was representing my own first person feelings and reactions and when, I was rather using what I had observed of someone to infer something of their thoughts and feelings.
- Make my presence evident within the field notes so that they are clearly a record of an event as seen and heard by me.

In 8.6.5 I reflect on some of the dissatisfaction I felt at times with the quality of my field notes, but how over time I changed my views on what I had written.

5.3.2 Videoing aspects of the case

Some aspects of the case were video-recorded (either by myself or by a participant) within one or other of two different modalities (Haw and Hadfield 2011):

- Videoing in an extractive modality provided data on the specific social interactions captured, allowing me either to revisit what I had myself observed, or to have some access to situations I was unable to observe. I found this particularly useful in capturing the perspective of participants with intellectual disabilities on their occupational therapy, allowing better interpretation of non-verbal cues to meaning, e.g. vocalisations, body language and facial expression (Simons 2009).
- Video recordings were also used in a reflective modality within interviews (see 5.3.2), to capture Esther's interpretations and constructions by asking her to reflect on content recorded. Techniques such as thinking aloud and critical incident analysis (of aspects of the case that seemed significant either to myself or Esther) allowed exploration of fragmented and tacit understanding of professional phenomena (Haw and Hadfield 2011) such as her clinical reasoning. This was a technique used by Richardson (2006) in her exploration of physiotherapists' practice.

As much as forming research data in themselves, the video recordings were also valuable "triggers" for research data in the form of either my field notes (when used in an extractive modality) or interview transcripts (when used in reflective modality). Although I would like to have been able to include video data in this thesis, I did not set out to do this due to the need to preserve participants' anonymity.

See section 5.4.4 below for further justification of the use of video recording in this study, including to facilitate user consultation with people with intellectual disabilities about this research.

5.3.3 Interviewing

A limitation of relying on observation is that, even with supplementary video recording, some of the practices I wanted to see were inevitably missed. Practices that occur infrequently will be observed only with luck and very careful selection of observation situations (Flick 2009). As can be seen in the research activity timeline in Figure 5.3, I carried out participant observation of Esther with Matt, Steve, Jane, Becky and Harold and/ or other participants at Cavendish House on 17

separate occasions (and these are summarised in Table 5.2). Despite this however, the distance between my home and the house, my own availability not always coinciding with key events and a number of miscommunications between Esther, Sarah and support staff regarding timing, all meant that I was not present and able to observe as much of what went on as I had originally hoped. Interviews were therefore essential in allowing participants to discuss aspects of the case that happened when I could not be present. This however was not the primary reason for collecting data in this way.

Date	Duration	Participants living at Cavendish House	Participants working at Cavendish House	Occupational therapy participants
11.12.12	3 hours	Matt, Steve, Harold	Norma, Doug, Jean, Tracy	Esther, Sarah
4.1.13	3.5 hours	Harold	Norma, Robert, Ivan	Esther
25.1.13	1.5 hours	Becky, Matt	Norma, Dina	Esther
25.3.13	4 hours	Becky, Harold, Matt	Jean, Olly, Robert, Dina	Esther
27.3.13	2 hours	Steve, Harold, Becky	Sarah, Julie, Ivan	Esther,
28.3.13	2.5 hours	Jane, Becky, Steve	Doug, Tracy, Olly, Ivan	Esther,
2.4.13	2 hours	Harold, Jane, Steve	Jean, Paula, Doug, Ivan	Esther,
5.4.13	5 hours	Jane, Becky, Harold	Ivan, Jean	Esther,
10.4.13	2 hours	Steve	Sue, Dina	Esther
12.4.13	3 hours	Becky, Matt	Dina, Tracy, Jean	Esther
24.5.13	1.5 hours	Steve	Paula, Gemma	Esther, Sarah
7.6.13	5 hours	Harold, Mo, Matt, Becky, Steve	Jean, Doug, Tracy, Dina, Sue, Norma,	Esther, Sarah
21.6.13	4 hours	Mo	Gemma	Esther
27.6.13	5 hours	Harold, Steve, Mo, Matt	Doug, Jean, Ivan, Robert, Norma, Olly, Jean	Esther, Sarah
28.6.13	4 hours	Mo Harold, Jane Steve, Matt, Becky	Doug, Jean, Dina, Julie, Gemma, Sue	Esther, Sarah
26.7.13	3 hours	Matt, Steve, Jane	Doug, Gemma, Julie, Sue	Esther
30.7.13	1.5 hours	Harold, Becky, Mo, Steve	Jean, Olly, Doug, Paula, Julie	Sarah,

Table 5.2 Summary of observations at Cavendish House ¹

¹ see “Cast of Characters” on p.8 (and also Chapter 6) for further explanation of role of each participant

The main purpose of my 25 interviews of participants was to deepen my understanding and to assist my interpretation of what I myself observed through gaining interviewees' perspectives in addition to my own (Dyson and Genishi 2005). Some interviews were pre-arranged, formal and semi-structured. Many however were relatively quick and informal – more like opportunistic conversations – exploring an aspect of the case that I had just observed. The immediacy, for example, of questioning Esther about the reasons for actions she had just taken, did seem to generate insight into practice that more abstract interviewing later and out of context might not. These informal interviews were similar to the conversations that Mattingly and Fleming (1994) described using to assist in their interpretation of observed behaviour when exploring occupational therapists' clinical reasoning. Richardson also describes how her interviews gave valuable insights into physiotherapists' thinking and reasoning, enhancing her portrayal and interpretations of observed behaviour (2006).

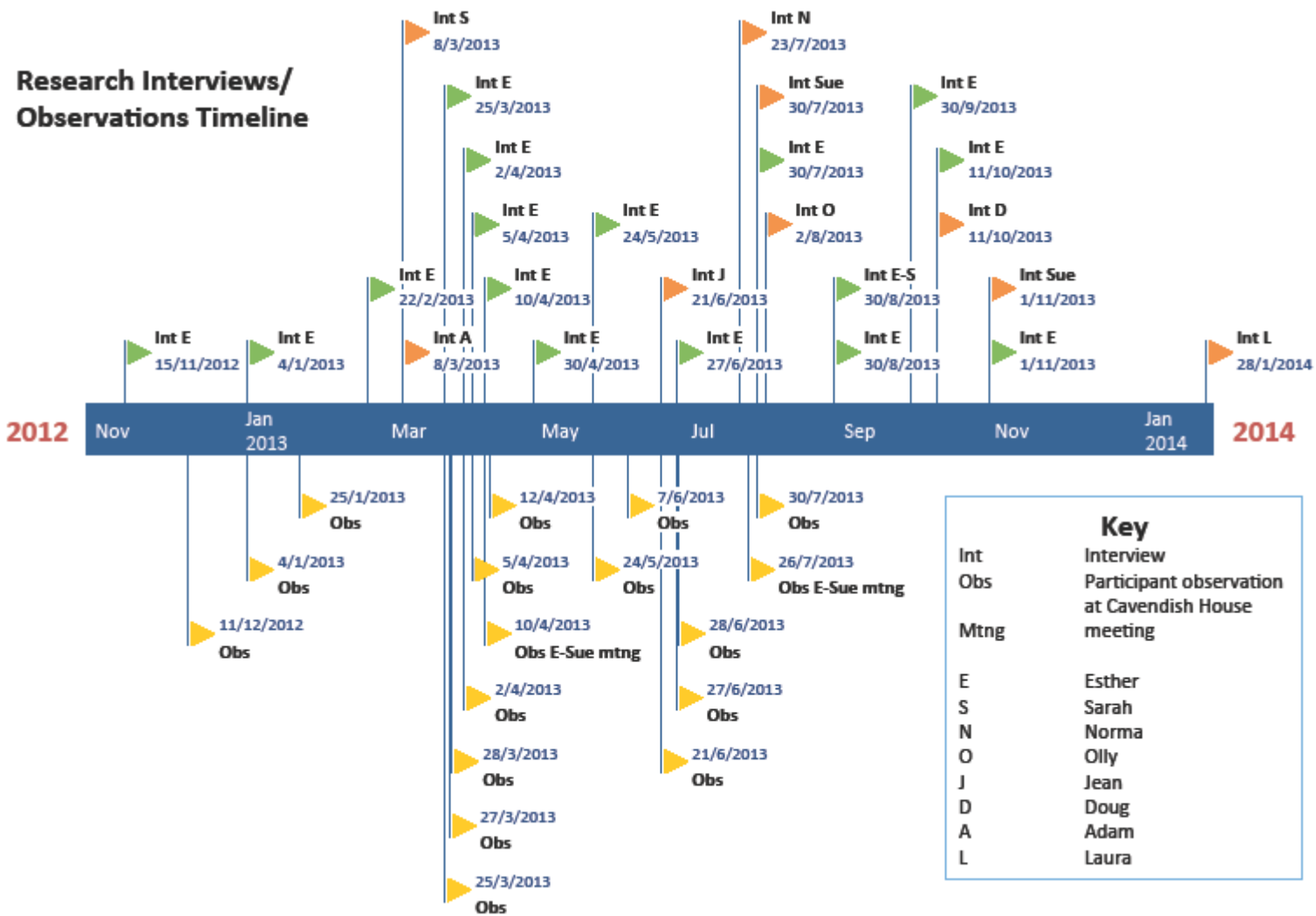


Figure 5.3
Research
Activity
timeline

5.3.4 Documents and artefacts

Esther was required by the standards of practice of her profession to record clinical notes about her work with her clients (COT 2010) and she also created other documents and artefacts as part of occupational therapy with Matt, Steve, Jane, Harold, and Becky. These included reports, session plans, objects of reference and discovery bags, as described and explained further in Chapters 6 and 7. I gathered numerous examples of these (or photos of them in some cases) to use as secondary data, as an additional way of gaining access to Esther's thoughts and clinical reasoning. They often revealed areas to explore further in interviews and she talked me through a number of them.

5.3.5 The case record

Bassey (1999) emphasises the need for systematic recording of data and warns against collecting more data than it is realistic to analyse. The case record for this study consisted of my jottings made in the field (3 notebooks), but other data were contained and organised electronically using NVivo Computer Assisted Qualitative Data Analysis Software (QSR 2013), including:

- Field notes.
- Photocopies and photos/electronic (jpg, pdf or word) files of documents and artefacts, such as occupational therapy reports and notes.
- Audio recordings (mp3 files) of my thoughts captured soon after leaving the field.
- Audio recordings (mp3 files) of interviews with participants and transcripts of these interviews.
- Video recordings (mp4 files) of aspects of the case.

Unsure at the outset, how much of the data collected I would transcribe and whether a complete transcription of all interviews and videos was necessary, I considered choosing pragmatically only to transcribe those aspects that appeared to be relevant to the research question. Aware, however, that any gain in time could come with a risk of overlooking data that might later deepen analysis (Dyson and Genishi 2005) I therefore transcribed the whole of every interview (formal or informal) and made detailed field notes on the content of each video recording.

5.4 Ethics and governance

I took care to ensure that this research was ethical in maintaining respect for democracy, truth, people and for research itself (Bassey 1999). Before exploring in this section some potentially controversial aspects, it is worth stating my strong belief that people with intellectual disabilities – including those lacking capacity – have a right to have their support needs researched. One could in fact argue the immorality of not doing this (Gunn and Taylor 1993):

“people with [intellectual] disabilities [are] among the least privileged and most vulnerable [and] if their circumstances are to improve there is an urgent need to facilitate rigorous and ethical research into issues of importance to [them], their families and support systems.” (Dalton and McVilly 2004, p.60)

With only limited exceptions, e.g. Williams (2007), the particular dearth of research using people with profound intellectual disabilities as informants identified by Coles (2001) appears to remain.

Obtaining ethical and governance approval for this study was complex and challenging for a variety of reasons. In the nature of case study research, its design evolved and was therefore not straightforward to explain fully in advance. I was encroaching on the potentially sensitive area of interactions between client and professional and the occupational therapy I was interested in happened not in a clinical setting, but in people’s homes, where I was seeking to observe and even video record.

People with profound intellectual disabilities were unlikely to be able to give informed consent to participate in this research even after taking all steps to maximise their ability to do so as suggested by Department of Health (2008b). This implied probably having to proceed on the basis that it was in people’s best interests to have their needs researched. I was aware that an ethics committee would likely regard them as vulnerable and, though this might be challenged on the grounds that it serves to reinforce negative perceptions and expectations, it did mean a very strong case of benefit to them was needed. I provided as much detail as possible in submissions to ethics committees and to prospective participants to

demonstrate the design of this study was ethical, that any risks to participation were minimised and residual risks proportionate to potential benefits.

This research was approved by the University of Brighton Faculty of Health and Social Sciences Research Ethics and Governance Committee and the National Health Service (NHS) National Research Ethics Service (NRES) (Ref: 12/LO/0319) (see Appendix 7). Approval from the latter body was necessary because occupational therapist Esther was an NHS employee and Matt, Steve, Becky, Jane and Harold were her NHS service users. The possibility of them not having capacity to consent to participate themselves was an additional reason for needing NHS NRES approval (Department of Health 2008b). Research governance approval (INVOLVE and NRES 2009) was granted by two NHS Trusts to allow me to seek participants from amongst their staff and service users. I began discussions with these ethics committees and research governance departments in advance of application and was thus able to take into account their helpful advice as the study design developed. My experience was that the process of gaining ethical approval, rather than merely a “hurdle” to get through, was genuinely an opportunity that improved my research design and I value the helpful feedback I received from ethics panels.

I now discuss in turn a number of ethical issues raised by this case study and explain how I responded to these in the design of the study. I have included detailed discussion in order that the reader has sufficient information to judge the integrity of my research using the virtues of courage, respectfulness, resoluteness, sincerity, humility and reflexivity, outlined by Macfarlane (2009).

5.4.1 Relevance to occupational therapy and to people with intellectual disabilities

The relevance of my research idea and the study’s design needed to be justified to potential participants, including those with intellectual disabilities (Dalton and McVilly 2004). Whilst my study is not user-led, emancipatory or participatory (Grant et al. 2005), I was keen from the outset for it to be non-tokenistically collaborative or at least consultative. Consulting and discussing research ideas

with stakeholders is a requirement for all studies considered by NHS NRES (INVOLVE and NRES 2009).

Meaningful consultation with those who have profound intellectual disabilities is difficult. Following Tuffrey Wijne, et al. (2008) and as recommended by Dalton and McVilly (2004), I consulted with a research advisory group consisting of a small number of people with mild-moderate intellectual disabilities who had themselves previously been research participants. I considered them to be a nearer equivalent to my participants than the alternative of consulting with family and carers of people with profound intellectual disabilities.

These consultees raised interesting points supporting the rationale for the study and the need for the research question to be addressed. One consultee, for example, spoke of the importance to him of having a routine and all could think of examples of people they knew who were under-occupied. They agreed on the importance of understanding how to support people well and gave examples of what they considered to be good and bad support. I took points made by the group regarding observation and video recording into account (see 5.4.4) and will act on their strong recommendation that the findings should be written up accessibly and presented to people with intellectual disabilities e.g. to advocacy groups and Learning Disability Partnership Boards. They also said that a list of people who have helped with the research should be included, and I have acknowledged their help in this thesis.

I also considered the relevance of the study to occupational therapists through informal discussion and more formal consultation with two groups of occupational therapists experienced at working with people with intellectual disabilities. Both groups agreed on the need for this research, with one group highlighting how they needed to be particularly creative when supporting occupational engagement in staffed homes. This comment was instrumental in my decision to narrow the focus of the study to an exploration of occupational therapy supporting people's engagement *at home* (rather than elsewhere).

5.4.2 Informed consent

This study raised some issues related to informed consent that I now move on to discuss, including the fact that people with profound intellectual disabilities were very likely not going to be able to give this.

5.4.2.1 Evolving design

It is in the nature of case study research that a study's design will, to an extent, evolve dependent on the nature of the case selected (Thomas 2011). An evolving design makes some aspects (e.g. exact issues to be explored, nature and exact number of participants, plans for recruitment and data collection methods) difficult to describe with complete certainty until the case has been selected or even later. The experience of taking part in the research is difficult to describe to prospective participants.

Sufficient information is needed however to convince ethics committees and others that an ethical approach will be taken and to ensure that participants can give truly informed consent at the outset. NRES pressed, for example, for more specific quantification of participant numbers than I felt able to give in advance and I reluctantly attempted to provide this in the form of likely maxima of up to 4 occupational therapist participants, 6 participants with intellectual disabilities and 8 other participants. This gave a predicted total maximum of 18 participants, taking part in the study for anything from a few days to 9 months. I felt uncomfortable with these estimates, as I was uncertain that they were very meaningful, though some did prove to be reasonably accurate. Occupational therapist Esther participated for the longest amount of time as she was recruited first, then becoming involved in the process of selecting the case and recruiting the other participants.

Ensuring that participants had full information about the range of possible forms of participation that might be asked of them in an evolving study required a particularly detailed means of explanation. To describe the research unambiguously, I designed clearly-worded participant information sheets specifically for each type of participant, individualised to need where necessary (see Appendices 3, 5, 8 and 9). I supplemented these verbally, to ensure they had

the information they needed to make an informed, specific and voluntary decision, taking into account all the possible experiences I could predict a participant might have in the study.

Although participants signed a consent form (see Appendices 4, 6, 10 and 11), I regarded this consent as provisional (Simons 2009) and I adopted the process consent model (Dewing 2007), sometimes known as rolling consent, involving on-going decision-making and repeated informed consent. This meant regularly checking and re-checking that participants wished to remain involved as my observations and interviews proceeded and as the realities of being a participant, (including what it felt like to be observed and the amount of time involved) became apparent.

5.4.2.2 Recruiting peripheral participants

As well as the key participants (Esther and the individuals with intellectual disabilities) an unknown number of more peripheral participants were to become part of the case, for example some support workers and service managers. I sought consent from each such person as soon as it became clear that they were of potential relevance to the case and before any data was gathered from them. To minimise risk of coercion, first approach to these people was by Esther rather than me.

5.4.2.3 Recruiting adults without capacity

This research sought access to the lives of people with severe and profound intellectual disabilities who were very likely not (fully at least) to understand its purpose and the reason for my presence in their home. My justification for this is similar to that used by Tuffrey Wijne et al. (2008) in their sensitive research with terminally ill people with intellectual disabilities: the importance of understanding and gaining insight into the experiences of those who lack capacity in order to develop a research evidence base for how we can best support them. In relation to people lacking capacity due to dementia, McKeown et al. (2010) describe the:

“hugely missed opportunity if [they] are excluded from the very thing that could be used to gain a fuller understanding of their disease” (2010, p.1936).

I would also argue that research is needed that captures something of the perspective of people with severe and profound intellectual disabilities themselves (rather than relying solely on other informants such as family members or support staff). As I discuss further in 5.4.4, this requires them participating in research and gaining their perspective by observing them and interpreting their behaviours.

The extent to which issues of capacity and consent have been considered in research involving observation of people with intellectual disabilities varies considerably. Some (Hallrup et al, 2010; Owen et al, 2008) state unambiguously that all participants gave informed consent, or describe in detail how legal provisions regarding recruitment of people lacking capacity were followed (e.g. Williams et al. 2007). Many authors, however, do not explicitly mention issues of capacity and consent (Messent 2003, Lofgren- Martensen 2004). In one particular study, undisclosed participant observation over 10 years for me raises some serious ethical issues (Monaghan and Cumella 2009).

Sections 30-33 of the Mental Capacity Act 2005 (“MCA”) (GB Parliament 2005) can enable “intrusive research” (any research legally requiring consent) to be carried out lawfully with people lacking capacity. The steps described below that I took to ensure that this study complied with these provisions were based on my understanding of the legal position from a number of sources (Department of Health 2008a, Department of Health 2008b, Dimond 2009, University of Leicester and University of Bristol 2011).

a. Assessing capacity and maximising ability to give informed consent

There is no ‘blanket incapacity’ under the MCA and lack of capacity cannot be assumed on the grounds of diagnosis, e.g. of profound intellectual disabilities. As the person needing a decision to be made about research participation, it was my responsibility to ensure that each potential participant’s capacity to make the specific decision at that particular point in time was assessed. My experience working with people with intellectual disabilities over 20 years as an occupational therapist and in other capacities meant I had experience of presenting information in accessible ways and of judging how well someone understood this. It had also given me a familiarity with the legal position regarding consent and capacity.

I was aware that there could be considered a conflict of interest for me to assess the capacity of potential participants with profound intellectual disabilities to participate in this study myself. Although I remained involved, Esther (similarly used to assessing capacity) therefore took the lead and made the ultimate decisions regarding this. She did this using NHS Trust B's "Mental Capacity under the MCA 2005 Assessment Form" and in discussion with Norma (Cavendish House Assistant Manager), Sarah (Occupational Therapy Assistant) and myself.

Mo, the most able resident in Cavendish House, had a moderate intellectual disability and features in the case only in a small way. She was assessed as potentially having capacity to consent to participation herself. Drawing on information from those more familiar with her communication preferences and on guidelines such as Department of Health (2010) and Mencap (2010), we therefore individualised and adapted information about the study. Using a simplified, "easy read" participant information sheet emphasising only the key messages, with supplementary verbal and gestural explanation and role play, her capacity was maximised to the point where she *was* able to give informed consent to participate for herself.

Matt, Becky, Harold, Jane and Steve were all assessed by Esther as not having capacity to make the decision about participation themselves. Following assessment, it was concluded that no adaptation to the presentation of the information could maximise their capacity sufficiently. Therefore decisions about their participation were made in their best interests in consultation with others in accordance with sections 30-33 of the MCA (see sub-sections e and f below).

b. Connection between research and condition affecting capacity

This study relates specifically to the needs of people with intellectual disabilities. It therefore meets the requirement in s31(2) MCA for a clear connection with the "impairing condition" affecting capacity with potential to contribute to the knowledge base for the treatment, care or support of those I was seeking to recruit.

c. Ineffective to use only those able to give consent

With a strong underlying presumption of enabling people to make decisions for themselves and only taking decisions for them when absolutely necessary, section

31(4) of the MCA requires using participants who *are* able to give consent where possible. Restricting recruitment in this way only to adults who *did* have capacity would, however, have been ineffective in answering my research question and would not have allowed me to capture anything of the perspective of people with profound intellectual disabilities themselves.

d. Potential benefit without disproportionate burden

Direct personal benefit from being a research participant is not necessary (Dimond 2009), as the Act allows recruitment where the research intends to further knowledge of causes, treatment or care of a condition affecting prospective participants. I considered that participating had potential to contribute towards all of the following indirect benefits suggested by Dimond:

- Developing more effective ways of treating /managing their condition.
- Improving quality of healthcare, or other services.
- Reducing risk of harm, exclusion or disadvantage.
- Knowledge of effects of mental incapacity (i.e. intellectual disabilities here) on health and day to day life.

As decisions had to be made in participants' best interests and compatible with what we knew of their broader interests (University of Leicester and University of Bristol 2011):

- These benefits had to outweigh any risks, which needed to be negligible.
- Participating had to not significantly interfere with freedom of action or privacy.
- The research had to not be unduly invasive or restrictive.

It is not unusual for there to be several people present in the environment of settings such as Cavendish House and I judged that my presence would be unlikely to be experienced as unusual. I felt that my research methods were reasonably commensurate with support activities and clinical interventions that prospective participants might usually experience and thus that the risks would not exceed those of routine support and services (Dalton and McVilly 2004). There appeared

to be sufficient potential benefits to allow me to explore the occupational engagement of participants lacking capacity.

e. Consultation

Judging whether benefits outweighed risks required taking the time – directly, or through consultation with those that knew prospective participants well – to get to know something of their beliefs and values, wishes and feelings, in order to gain some idea of what decision they might make were they to have capacity.

Reasonable arrangements are required by the MCA to seek the advice (though note not the consent) of an appropriate consultee about whether or not it was in the best interests of individuals lacking capacity to participate. A “personal consultee” was sought for each prospective participant, someone who knew them well and was interested in their welfare, but who did not care for them in a professional or paid capacity (Department of Health 2008b). Taking into account assistant manager Norma’s advice about who we might imagine people might trust to be consulted regarding important life decisions, family members, or friends took on this role for Matt, Becky and Steve. Paid advocates unconnected with the project acted as “nominated consultees” for Harold and Jane.

I devised specific information sheets for consultees (see Appendix 8) and they were asked to consider the broad aims of the research, whether the person would be content to take part or whether doing so might upset them, and the risks, benefits and practicalities of this. Esther and I worked together to explain the Participant Information Sheet and what participating in this study would involve to these consultees, answering any questions. If they agreed that it was in an individual's best interests to take part in the study, they were asked to sign a "Best Interests Form" to this effect (see Appendix 10). Respecting their advice, I would not have included someone in the study if they had advised against this, though in the event, it was agreed to be in the best interests of all individuals.

The process is illustrated in my field note following consultation with Harold’s Independent Mental Capacity Advocate (IMCA):

IMCA engaged in pleasantries but was careful to keep some formality to proceedings. Thorough consideration of MCA Guidance, whether or not it was

appropriate to act and in what way (i.e. not making any decisions but advising). IMCA was clear she needed time to reflect and gather information from others before deciding. Esther and I went through the PIS and answered questions e.g. about would the research disadvantage Harold in any way.... She seemed broadly positive about it (tone of voice, enthusiastic comments etc.). We confirmed that the IMCA could be present at any of the times Harold is part of the research.

Harold's communication - how will we know if he is happy or not? Esther and IMCA agreed that his responses are generally quite neutral - it is difficult to know for sure he is enjoying something, but if unhappy he will 'make noises' and push person away. IMCA asked re anonymity - is there a risk of Harold being identified in report. I said I would refer to 'the south of England' rather than naming the location and leave out details of unusual diagnosis." (Field note 4.1.13)

Consultees were given the option of being present during certain parts of the research e.g. during observations of the participant, though none took up this option. I was open to continuing to consult with the consultees throughout the period that individuals participated in the study as I felt this was important in ensuring that each individual could participate in decisions and that signs of objection were noticed and responded to.

f. Participating in decisions and signs of objection

Not having capacity to make an informed decision about participating in the research, did not preclude being enabled to *participate* in all decisions about involvement, including the acceptability of the research methods and my presence. I therefore sought *assent* from participants, if not consent in the strict legal sense. This met the additional safeguard in section 33 of the Act that nothing should be done to which someone appears to object.

Following Tuffrey Wijne et al. (2010) and Hubert & Hollins (2007), I used the principle of process consent (Dewing 2007) to pay constant attention to willingness to engage. Taking into account participants' ways of communicating, I discussed in advance examples of behaviours that might indicate distress or

unwillingness and agreed to respond to these by either removing myself that day or by withdrawing the participant from the study as appropriate. My experience working in this field assisted in my judgement, but I made such decisions in close collaboration with others, including in particular Esther. In the event no such signs of objection were observed.

5.4.2.4 Avoiding coercion

A final issue related to informed consent was to ensure that recruitment methods minimised any risk of participants feeling coerced to participate. Potential occupational therapists were provided with information about the study in writing and were then asked to contact me to find out more. This meant them contacting me rather than me contacting them, thus minimising risk of coercion. Once, Esther was recruited, she suggested possible people with intellectual disabilities on her caseload whose occupational therapy might be relevant to my research question. I then worked closely with her to devise a way of selecting them that was ethical and non-coercive. This involved initial approaches to them, or their family or carers, by her and not by me. Only once they or their carers showed some initial interest did I have any contact with them to provide further information and answer questions.

Within the case, certain individuals (e.g. some support workers or family members) might have wished not to participate and I was explicit when talking to them about the research that they were under no obligation. What I observed of, or what was said by anyone who had not consented to participate did not become research data.

5.4.3 Observational study in people's homes

Gathering data by participant observation, particularly in people's own homes is an intrusive method. I felt however that it was necessary to answer my research question and the best way of accessing something of the views and perspectives of people with intellectual disabilities and complex needs themselves, who would otherwise find it difficult to verbalise or understand the research issue (Tuffrey-Wijne et al. 2008). Their voices have often been silenced, with research either consisting of quantitative psychological or psychometric assessments, or

qualitative research seeking the views of families and support staff about their lives:

“Participant observation is the most effective method of collecting data in the case of people with little or no speech [providing] the means to discover and interpret ... touch, gesture, non-verbal sounds, eye contact, facial expressions and behavioural manifestations of sadness, joy, contentment, anger, affection and unease.” (Hubert and Hollins 2007, p.123).

Ware (2004) does however caution against merely substituting my voice for that of the family or carers, which clearly does nothing to reduce marginalisation. Previous experience as a support worker and occupational therapist with people with profound intellectual disabilities, had given me experience interpreting non-verbal communication, though of course I was not initially familiar with the participants with intellectual disabilities in this study. I therefore interpreted nonverbal communication with the assistance of information from others who knew the particular individual well and who could say, for example "when he does x/ makes sound y/ makes facial expression z, we think it means that he is enjoying something/ distressed/ tired.”

My consultation group of people with intellectual disabilities suggested that before observing I should get to know people and explain what was going to happen and that when observing, I could sit down rather than stand up, if possible. They said that they themselves might find it easier to be observed, if someone known to them were also there (e.g. a member of support staff or family member); and they warned that it could get too crowded, when observing perhaps in a kitchen and that I would need to be alert to health and safety risks. I took into account all these points when carrying out observations.

5.4.4 Video recording

Some aspects of the case were video recorded. As explained in 5.3.2, these video recordings allowed me to observe aspects of the case when I could not physically be present and allowed participants to watch and reflect on aspects of the case during interviews. Such video footage is not included in the findings, to preserve anonymity.

The consultation group were supportive of the use of video recording in the study. They felt that provided I was not filming secretly, even if someone could not give consent, it might be ok to video them for "the common good". One person had been filmed for television and really liked and was very proud of this, though she said she would want to see the footage before others. Another said he would also be curious about what had been recorded and would want to have his own copy. Another (himself involved in training support staff) liked the idea of using a video camera to record what was happening as he thought this could be useful for training purposes. The responses of the group to the idea of using video recording do I feel provide some support for the choice to video record some aspects of the case.

An additional purpose of the video recordings was to facilitate this type of consultation with people with intellectual disabilities about the research. The consultation group found it difficult fully to imagine what my research was to involve. They suggested that if they could watch excerpts from research video recordings, this would help with on-going consultation. I therefore gained ethical and research governance agreement that certain clips from the video recordings (anonymised using pixilation), could be shown in future consultations. No participant would be identifiable in these clips and specific consent for this purpose was sought from participants (and best interests decisions sought from the consultees of participants who did not have capacity to consent).

5.4.5 Anonymity and confidentiality

There are arguments in favour of research participants not remaining anonymous, for example to celebrate the lives of the protagonists with intellectual disabilities in the case (Simons 2009) and to promote self-advocacy. Efforts were nonetheless taken to ensure that all participants remained anonymous because:

- Participants who wished to be identifiable (or consultees involved in best interests decisions) might not have thought through all consequences of this, or might be anticipating particular findings.
- I cannot guarantee that readers of the study will form fair and sensitive judgements of the case.

As I have written up the case, I have taken care that the combination of incidental details, for example about participants' occupation, location, age, gender and ethnicity, do not lead to them becoming inadvertently identifiable. Where necessary some of these details have been changed.

I only gathered personal data about participants that was relevant to my research question and took all precautions to ensure that it was stored securely. This included:

- Keeping 'hard' copies of personal data (e.g. written notes) in a locked filing cabinet at my workplace.
- Only keeping personal information on encrypted password-protected laptop computers, iPad or memory sticks for as long as was necessary for it to be transferred from Cavendish House to my workplace.
- Storing electronic personal data on the secure University of Brighton server, password-protected to give access only to myself.
- Taking particular care regarding the security arrangements for audio and video recordings.
- Anonymising or coding data with a pseudonym at the earliest opportunity so that it could not be linked to the individual who supplied it. For example, participants' actual names were not be used on field notes audio or video tapes, or electronic file names. Transcripts of interviews referred to participants by pseudonym rather than by name and words spoken by an interviewee that could lead to them becoming identifiable were omitted from transcripts (or altered).
- Other than participants in the case, raw data has only been seen by myself and my supervisors and no individual is identifiable in this thesis.

Although confidentiality has been maintained, I do quote the actual words used by participants in this thesis. Participants were alerted to this in information sheets and explicitly consented to this. No identifiable/ personal information is used in such verbatim quotations to ensure that participants remain anonymous.

Participants were very open in interviews and may inadvertently have revealed things they did not intend to and I sought to offer them some control over what ultimately became public. When in the field, I remained alert to signs that a participant wished to keep something private (e.g. I observed that one participant seemed visibly uncomfortable during an interview and asked whether there was anything he had said that he wanted me not to transcribe). Generally, at the end of interviews or observations, I asked individuals for permission to use the content or whether anything needed excluding.

On completion of this doctoral study, personal (i.e. non-anonymised) data will be disposed of sensitively and securely, i.e. electronic files permanently deleted and paper copies shredded. Anonymised research data will however be kept on the secure password-protected University of Brighton server for 10 years in accordance with the University of Brighton research standards.

5.4.6 Sub-optimal care

I was prepared, should circumstances have arisen where confidentiality might need to be breached in order to avoid future harm to a participant or third party. Instances of criminal activity, violence, abuse, neglect or poor practice (either the practice of Esther, or other practice within Cavendish House) might have been revealed, disclosed, or observed. The possibility of needing to respond in this way in such specific circumstances, was highlighted in all information sheets (see Appendices 3, 5, 8 and 9).

Esther was herself under a duty of care to respond to any matters of concern within Cavendish House in the ordinary course of her role, which naturally in any case sought to promote good standards of support there. I discussed any concerns I had with her (and in fact none emerged of which she was not already aware) and felt it appropriate to leave it to her clinical judgement to respond to this, judging that this completed my responsibility to act.

As both researcher and occupational therapist myself, I recognised my dual duty of care and responsibility to act on any concerns I might have about Esther's practice, including potentially disclosing confidential information in order to prevent serious harm, injury or damage, in accordance with my Code of Ethics and

Professional Conduct (COT 2010). Although this proved unnecessary, I was prepared to discuss any such concerns with my research supervisors and if necessary to follow local policies and procedures, including multi-agency policies and procedures for safeguarding vulnerable adults.

5.4.7 Portrayal of individuals

As explained previously in 4.3.3, I have sought in this thesis to present findings in sufficient detail to retain connection with context, to provide a worthwhile and convincing argument in support of my conclusions, to allow readers to consider their own interpretations and to provide an adequate audit trail. Participants could however feel let down by their portrayal in the case report and this could have an impact on how they see themselves or others within the case see them.

As suggested by Bassey (1999), I have tried to research from a position of respect for all participants, including the motivations I attribute to what I have observed and how they are portrayed in the case report. It may be constructed by me, but I have given Esther opportunity to respond to the accuracy, relevance or fairness of her portrayal and to edit or add in comments (Simons 2009). Due to staffing changes at Cavendish House, it did not prove possible to gain the perspectives of other participants on the findings.

5.4.8 Participation over an extended period

There was a definite risk of inconvenience to participants from taking part in this research over an extended period of time. I made continuous effort to ensure that all participants knew that they genuinely could withdraw from the study at any point without needing to explain their decision. For example, I reminded Esther of this and remained alert to signs of discomfort or uncertainty. Consent given at the outset was revisited regularly as the research proceeded and the realities of being a participant in this study became apparent.

Another issue is that extended periods of participant observation can lead to expectations of a continuing relationship that I am unable to meet (Tuffrey-Wijne et al. 2008). Over time, a relationship developed between me and participants, including those with intellectual disabilities. I therefore tried to be clear about my

reasons for being present and that the relationship would be time limited (or at least to act in a way that did not give the impression that it would be anything other than that). I considered how I might withdraw from Cavendish House and terminate such relationships in a gradual, planned and respectful way, seeking for example not to end contact suddenly or unexpectedly. The nature of the setting, with different people on shift every time I visited did mean, however, that I did not achieve this as fully as I would have liked.

5.4.9 Sensitive topic

Researching the relationship between a professional and their clients is a sensitive topic and I have tried to remain aware that Esther could feel that her practice was being judged, causing her to question that practice. I tried to question in a sensitive manner that I genuinely do not feel has caused any upset and in fact she has stated on a number of occasions how valuable she has found being part of this research as an opportunity to reflect on her practice. Should any upset have been caused however, I would have given the option to pause or terminate observation or interview and would have reminded her that she could withdraw from the study if she wished and without necessarily having to give a reason. I had suggestions as to sources of further support ready to provide should this have been necessary.

5.4.10 Reflexivity and conclusion

I feel that there is integrity in the design of this study and that the benefits of participation can be said, using proportionate reason (Angrosino 2007a) to have outweighed any residual risks. Participants with capacity (and the consultees of those without) were alerted to these residual risks of participation by explicit reference in information sheets. The intrusiveness of participating in the research has been minimised for participants. I consider the experience for participants with intellectual disabilities as not radically different from the way they would usually experience occupational therapy and thus reasonably commensurate with and no riskier than routine support and services (Dalton and McVilly 2004). Safeguards were in place to minimise consequences of any risks that did arise.

I have included a lot of detail in this thesis about the ethical aspects of the research as I feel this to be important in order for the reader to have the information they need to judge the integrity of the study.

5.5 Methods of data analysis

Analysis in case study research is:

“a search for some coherency ... laying out our best guesses, without hiding the contradictions and the instability” (Dyson and Genishi 2005, p.37).

Vast quantities of data can be accumulated and Stake cautions against a "daunting data mountain" (2006, p.46) potentially greater than is realistic to analyse. He advises focusing on the "best" data, by always keeping the case and key issues in mind, something that can be challenging in practice. In this section, I introduce my strategy for analysis of data and explain how this enabled thorough exploration of the data.

5.5.1 Overall data analysis strategy

In developing an analysis strategy, I sought forms of analysis that were both appropriate to my research question and consistent with social constructionism and my theoretical frameworks. This suggested an inductive analysis, grounded in the data collected, but at the same time also acknowledged to be mediated by my own knowledge and experience (Dyson and Genishi 2005). Rather than identifying something already existing in the data, I have actively interpreted as much as analysed (Stake 1995) and findings were constructed jointly by myself and the actors in the case (Thomas 2011), in particular Esther. Rather than the data speaking for themselves, I have *selected* meaning and ultimately in chapters 6 and 7 tell a particular story (Simons 2009). A different researcher would likely construct different findings about the topic from studying a different case. As I analysed the work of Esther, I therefore also considered my own role in constructing the research findings.

In order to undertake this interpretative qualitative analysis, I needed methods that would ensure a more than merely descriptive analysis, allowing me to notice patterns that link to my theoretical frameworks (Braun and Clarke 2013) and

thereby gain a sufficiently deep understanding and a conceptual account of my case. From the moment I began collecting data, I pointedly thought analytically and critically about it using questions such as those in Table 5.3.

- In what different ways does Esther (for example) make sense of her experiences/ the topic discussed?
- Why might she be doing that in this way (rather than another way)?
- In that situation would I feel different from/ similar to her and why?
- What assumptions does she make in talking about the world?
- What kind of world is 'revealed' through her account?
- What meanings, ideas, assumptions underpin this pattern of meaning-making?
- What are the implications of this pattern for the participants/ for my topic/ for society/ for this field?

Table 5.4 Example questions to promote an analytical reading of research data (from Braun and Clarke 2013, p.179)

By taking an interpretive stance and, for example, examining the case through my particular theoretical lenses (social constructionism, occupational science, Model of Human Occupation) I hoped to move beyond what was more obvious within the data at a surface level and to notice and link patterns or meanings to broader theory, whilst at the same time taking care not to impose meaning on it from this theory.

Analysis began as soon as I started data collection and involved experimenting with working with the data in both formal and more intuitive ways described below. Although planned in advance, as I collected and began to analyse data, my analytic strategy evolved gradually into something unique to me and to this case and Saldaña (2013) reassures as to the legitimacy of such emergent strategies.

Stake (2006) and Yin (2009) both have systematic procedures for analysis of cases. In addition to my use of such more formal coding and categorising procedures (see 5.5.3), both Simons (2009) and Thomas (2011) support developing a more intuitive, affective, hermeneutic and imaginative approach to analysis. They

highlight how this can lead to holistic insights and suggest particular relevance for uncovering tacit knowledge and phronesis that is so relevant to answering my research question (Thomas 2011). I have interpreted Simons' description of a more intuitive "dancing with the data" (2009, p.140) approach to analysis as validating a creative approach where I have deliberately looked at the data in varying different ways to see what (if any) insight emerges. This has included concept, or cognitive mapping, to model the data and emerging themes visually (see Appendix 12). Simons (2009) and Thomas (2011) both highlight how artistic forms, such as story boards can help with interpretation of the disparate elements of the case. In 5.5.4, I describe later stages of the analysis, including more intuitive methods of analysis considering the narrative and dramaturgical aspects of the case, when moving into what Saldaña (2013) refers to as second cycle coding.

5.5.2 Familiarisation and data management

An efficient, systematic process was required to manage the large amount of varying types of data collected and I was clear from the start that I would use Computer Assisted Qualitative Data Analysis Software (CAQDAS) for this purpose. Initially, my intention was to use NVivo 10 software (QSR 2013) primarily as a way of facilitating the management of this large volume of data, as recommended by Cousin (2009). Certainly, I found it reassuring that having the whole project stored as one NVivo project file meant that loss of data or analysis was extremely unlikely. As suggested by Bazeley and Jackson (2013) every time I closed this NVivo project file, I saved a new backup copy in a separate location with that day's date. This not only protected against data loss, but also contributed to an audit trail of the analysis process.

I quickly realised, however, that the software was far more than a mere storage facility. NVivo 10's coding, mapping and querying tools proved invaluable and facilitated a thorough interpretive analysis. In hindsight, I find it difficult to imagine manually analysing that volume of data as thoroughly as I believe I was able to using the software. I added each new data source (audio or video recording, interview transcript, field note, document, or memo) to the NVivo project file and immediately coded descriptively (see 5.5.3.1). I quickly began to recognise the importance of naming sources and organising them in a consistent

and logical way within the project file, for example beginning the file name of interviews with the interviewee's name so that all those interviews became grouped together.

After completing each interview or observation, I developed a habit of recording my immediate thoughts about the content and process in the form of a memo (see 5.5.3.5). I familiarised myself with my sources by immersing myself in them, reading and re-reading documents, listening again to audio recordings and adding to memos as thoughts occurred to me. As I transcribed interviews, I flagged points in the data that seemed to me to be of particular interest, for example (following Saldaña (2013)) by annotating, formatting in bold or underlining to ensure that I would remember to concentrate on those areas during later analysis.

5.5.3 First cycle coding and categorising procedures

Although perhaps an over-simplification, my analysis of the data can be seen as having two phases:

- An initial phase of exploratory coding – what Saldaña (2013, p.58) calls “first cycle coding” – in which I used an eclectic combination of coding methods, as I explain shortly.
- A subsequent “second cycle coding” phase, which I describe in 5.5.4.

Drawing on the suggestions of a number of different authors (in particular Simons 2009, Thomas 2011, Braun and Clarke 2013, Saldaña 2013), I gradually devised a strategy combining a number of coding methods to help organise and make sense of the data in this exploratory, or first cycle, phase.

Whilst my research question and the foreshadowed issues in my mind inevitably provided some initial shape to the analysis, guiding me towards the potentially more relevant data, I followed a more inductive approach than that suggested by Yin (2009), largely deriving codes and categories from the data themselves. In the initial stages this included some more descriptive coding based on the semantic meaning of the data, though increasingly I used more conceptual researcher-derived codes (Braun and Clarke 2013) as I questioned the data and explored

more implicit meanings using my assumptions and theoretical and conceptual frameworks (Bazeley 2013).

From the array of choices outlined by Saldaña (2013), I deliberately applied the coding methods described in the following sections, gradually refining my first-cycle coding strategy as I went. I instinctively felt that I did not want to be constrained by a rigid process (as stated previously, wanting to follow my intuition in analysing the data). It therefore seemed to me that an eclectic coding strategy, involving a repertoire of methods (Saldaña 2013) would work well by enabling me to look at the data from different perspectives. Although not carrying out a grounded theory study, I found that aspects of the analytical ideas from constructivist grounded theory (Charmaz 2012) supported an understanding of my case, as will become apparent. The resulting 'Codebook' is reproduced in Appendix 13.

5.5.3.1 Initial stages: Attribute and Descriptive coding

Attribute and descriptive coding, two preliminary methods recommended by Saldaña (2013) facilitated gaining an organised overview of the data:

- To facilitate data management, as I imported sources into the database, I recorded basic descriptive information about their *attributes*, for example, format (interview transcript/ field note/ report ...) and role or demographic of participants (occupational therapist/ support worker/ person with intellectual disabilities ...).
- To ease identification of individual sources, I *descriptively coded* each individual one, by briefly identifying its contents, for example the topics covered in a particular interview.

5.5.3.2 Open, In Vivo and Process coding

I initially approached all textual data (transcriptions of interviews, field notes, occupational therapy case notes and other documents related to the case, my own memos) in a similar way. I began to code this, sometimes directly within NVivo (the method recommended by Bazeley (2013) as most efficient) and sometimes, usually for practical reasons such as being away from a computer, by adding marginal notes to paper printouts, which I subsequently added to NVivo.

Initially I found I was often naming a code using the actual words of participants themselves, i.e. coding '*in vivo*'. I did this particularly when someone used an evocative phrase or used a phrase repeatedly, as this helped me to pay attention to the language they used and to their perspectives (Saldaña 2013). I identified that a particular code was an *in vivo* code by recording its name in "inverted commas" (such as the code "*Making it individual for each of them*", named using Esther's words). Where I did this, I found the preservation of participants' meanings a valuable starting point in my exploration of the data. Sole reliance on this would however have limited my own interpretation of the data and development of conceptual understanding (Saldaña 2013). From the beginning and increasingly as analysis progressed I also therefore coded more openly, as suggested by Dyson and Genishi (2005), naming the *open codes*, or initial codes (Charmaz 2012) more interpretively using my own words.

As I coded text and re-visited codes so far used, it became apparent that my data was often about actions and processes. The case of occupational therapy that I explored was a process and I therefore needed to understand the on-going actions and interactions in response to events within it. Charmaz (2012) for example suggests that when studying processes, coding often focuses on data reflecting actions and stages of the process and the mechanisms put in place to aid that process. As well as coding topics, I therefore made a point of *process coding* both observable and conceptual action in the data (Charmaz 2012, Saldaña 2013). Examples included where I interpreted participants as explaining, negotiating, adapting, or struggling. Naming those codes using gerunds facilitated this focus on actions and processes (for example the codes "*Demonstrating that people do give feedback*" and "*Using evidence base to justify actions*") and this allowed me to see the sequence of events within the case over time (Braun and Clarke 2013, Strauss 1987).

5.5.3.3 Values and versus coding

As I began to explore the data, two things very quickly became apparent. First, some of the protagonists had very clear perspectives or world views on topics relevant to the case, such as the nature of good support for people with profound intellectual disabilities. Sometimes their values, attitudes and beliefs were overtly

expressed and at other times I saw them implicitly in their actions. To facilitate understanding of meaning and perspective, it often seemed useful to code these values, something suggested to be especially relevant when exploring culture within a case (Saldaña 2013). It was particularly important to be reflexive when coding in this way, as the choice of code was unavoidably laden with my own values and positionality.

Secondly, there were quite a number of obvious conflicts within Cavendish House (some of which I hypothesised were at least partially due to differing values, attitudes and beliefs amongst protagonists). I therefore consciously sought to identify tension and divergence and to code this using what Saldaña (2013) describes as *versus coding*. This involves identifying which individuals, groups, organisations, processes or concepts conflict and considering the stakeholders, issues and opposing positions in such ‘moieties’. I discuss in 7.2, for example, the different positions taken on the subject of leadership and the priority of meeting health needs of those living at Cavendish House.

5.5.3.4 Constant comparison

I again borrowed from constructivist grounded theory, by using a constant comparative technique of analysis (Charmaz 2012), involving me constantly moving back and forth between my codes (and any developing categories and concepts/ themes) and the data. I found myself naturally doing this before realising that I was doing constant comparison and, as this seemed to generate useful insights, began to do this more deliberately. The text search query function of NVivo facilitated this constant comparative analysis, as it enabled me to have some idea of whether, when I created what appeared to be an important new code, this was also relevant to previously coded documents (Bazeley and Jackson 2013).

5.5.3.5 Memo writing

I know from experience that my thinking develops through writing. Gibbs (2007, p.24) highlights the importance of this as part of data analysis, suggesting that one should “write early and write often”. Braun and Clarke (2013) go further and state that it is not possible to do analysis *without* writing. Analysis therefore started as soon as I began to observe and to write my thoughts in field notes. The value of

constantly writing analytic memos is something that is emphasised in (and that again I have borrowed from) constructivist grounded theory (Charmaz 2012) and they have been an important feature of my analysis, helping to ensure that I captured as many thoughts as possible. Braun and Clarke (2013) describe memo writing as the stage between analysis and writing up, but I have very much seen doing this as an essential part of the analysis itself, as the process of writing has been so instrumental in enabling me to develop and refine my analytic ideas.

I have written (see examples in Appendix 12):

- *Data memos* about the content of or my tentative analytic take on individual sources (for example immediate thoughts, prior to transcription, about an interview just completed; or after completing field notes from a particular observation, addressing practical issues e.g. what to observe or interview about next).
- *Code memos* on the meaning of individual codes (or sets of codes).
- More *conceptual memos* highlighting possible patterns in the data, the relationships between codes, or the process of carrying out the research.

NVivo 10 (QSR 2013) makes it simple to link memos to individual codes or data sources, and to code these memos as data, making retrieval of ideas within them straightforward. Adding annotations to specific parts of text in a data source, or adding 'see also' links between related text from different sources were also very useful ways of tracking possible connections between parts of the dataset.

5.5.3.6 Categorisation and mapping of codes and their dimensions – my code book

A large number of codes were needed to capture the complexity of the data. For each one, I generally wrote a definition, sometimes with examples of coded text, which formed my 'code book' (Saldaña 2013, p.24, Braun and Clarke 2013) of some 450 codes, which are listed in Appendix 13. I aimed to ensure that each code was meaningful and informative even when seen apart from the data coded to it and the code book therefore captured the nature of the data and my analysis of it (Braun and Clarke 2013). The following is an example from the code book:

“Making it a project-y thing”

Working with the whole house and staff team rather than individual work

Investing time, working more intensively/ systematically (4.6.13)

Incorporates previous code <working with 5 people together more efficient> (17.6.13)

The outcome of even the early stages of coding of initial data sources, was a simple, but un-organised list, about which it was difficult to make sense. I very quickly realised that I wanted and needed to begin exploring how these codes related to each other and to map possible relationships. I needed, in other words, to introduce some structure to my expanding code book.

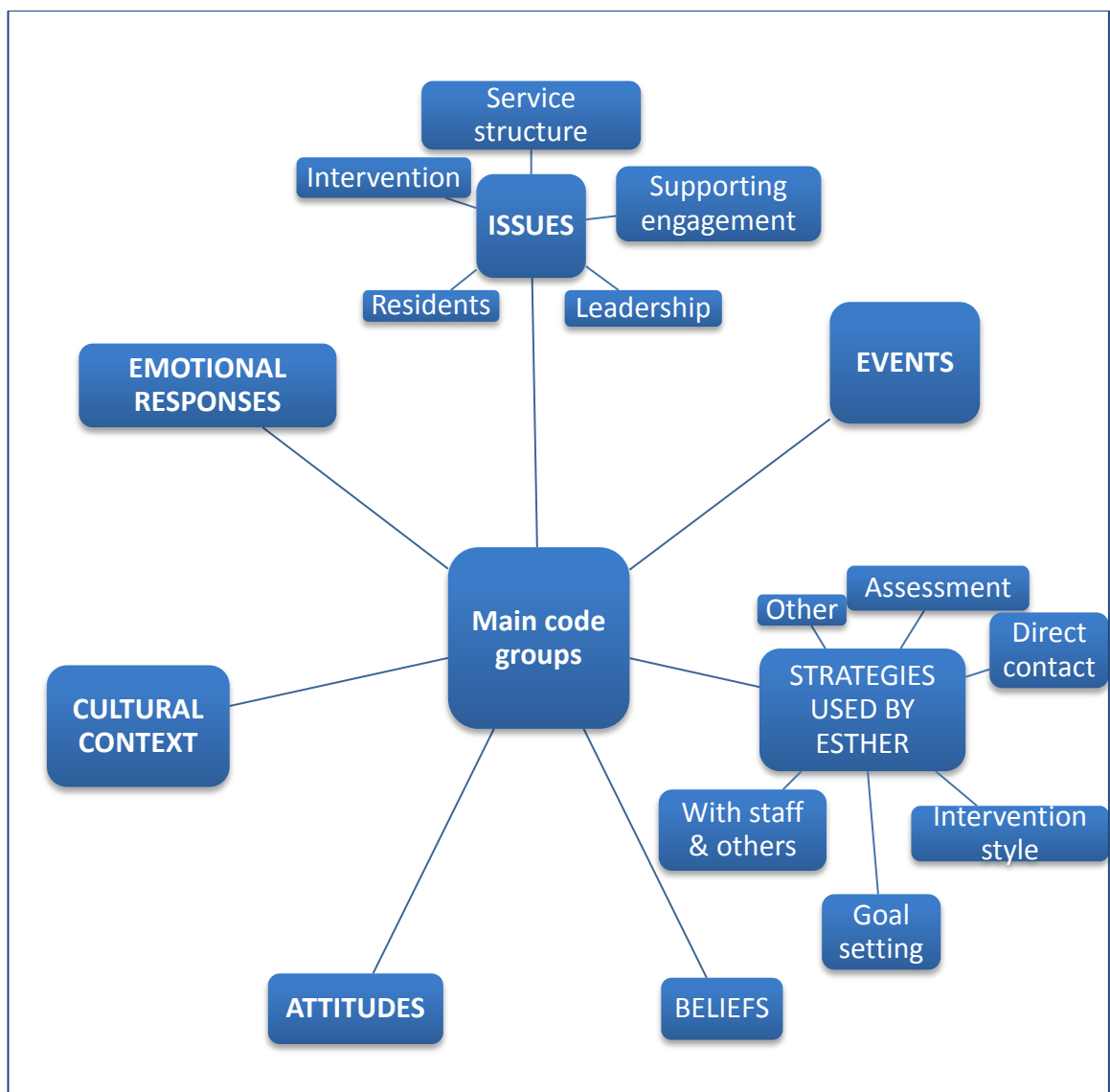


Figure 5.5 Main Code Groups

The distinctions amongst the codes that were most immediately apparent were that some seemed to be about issues or problems, others about the culture(s) within Cavendish House and still others about the strategies that Esther was utilising in her work. Realising this, I began to organise the codes into groups by categorising them (and gradually and continuously re-categorising them) within a framework of trees and branches. I drew on, though very much adapting for my own purpose, the list of code groups suggested by Bazeley (2013) and Bazeley and Jackson (2013) resulting in the main code groups illustrated in Figure 5.4. As I did this I decided that some codes were duplicates and that others contained multiple ideas. This led to me 'coding on' from the codes in the manner described by Bazeley (2013). I lumped codes representing duplicate ideas together and split others into new codes and whenever I made changes to codes, I continuously updated their descriptions in the code book.

Through these processes of coding-on, categorisation and re-categorisation, a framework of trees and branches evolved. The particularly high number of 'issues' and 'strategies' codes were sub-divided into separate 'trees' related to different types of issue, or strategy used by Esther. See, for example, in Appendix 13:

- The 24 codes under "*ISSUES re activity levels and ways of supporting engagement*", relating to perceived problems with the way those living in Cavendish House were supported to engage in occupation.
- The 44 codes under "*STRATEGIES with staff team and other professionals*", relating to the ways Esther worked with the staff team and managers of Cavendish House (and others).

Organising the codes in this way was an initially useful means of understanding ways in which they related to one other, including where they overlapped, or contained multiple ideas which needed to be split. As I deepened my analysis and moved towards development of themes, I began to realise that as well as organising the codes in this way, they could also be seen, as dimensions of wider categories. This is where the 'Sets' feature of NVivo 10 became particularly valuable. Organising potentially related codes from different trees in the coding hierarchy together into sets (or categories) allowed me to reflect on code

meanings and relationships and to deepen my thinking about them. Each time I created and explored a new set of codes, I made extensive use of concept mapping to model the data and emerging themes visually using the 'model' tool within NVivo. I drafted a memo about this set and what its meaning might be. Appendix 12 reproduces an example category of "*Issues with leadership, autonomy, initiative and how valued staff feel*" and includes that set of codes, two memos about this (written 11 months apart) and a concept map illustrating my thoughts at the time about the relationship between those codes.

5.5.4 From codes to themes – second cycle coding and later stages of analysis

Much of 2013, was spent recruiting participants, gathering data and beginning to analyse this data using the first cycle coding methods described in 5.5.3 above. By early December 2013, Esther had completed her work with Matt, Steve, Harold, Becky, and Jane and I had collected the majority of my data. In 2014, I therefore moved into a second stage of analysis. In this phase, I continued to use the coding methods so far described, making increasingly deliberate choices for example to code specific aspects of the data, such as overt or implicit values, attitudes or beliefs of participants; or conflicts between participants. As I proceeded, I gradually realised that I was moving into a different and deeper, more theoretical or conceptual analysis of the data (Braun and Clarke 2013). This is described by Saldaña as 'second cycle coding' (2013, p.207) and by Charmaz (2012, p.138) as a shift to more analytical 'focused coding' of the data.

The ease with which it is possible in NVivo to look at all text coded to a particular code and to organise codes into varying sets (categories), facilitates comparison and contrasting of segments of text to establish similarity and difference. Through undertaking this analysis and re-analysis, the way in which some of the codes could be seen as dimensions of wider categories became clearer. I gradually began to pay more particular attention to broader patterns across the data, and to move towards identifying themes (Braun and Clarke 2013, in their description of thematic analysis), or concepts (Charmaz 2012).

A theme “captures something important about the data in relation the research question and represents some level of patterned response or meaning within the data set” (Braun and Clarke 2006, p.82). In searching for themes I was not trying to explain or represent everything in the data, but selectively was telling a particular story about the case that answered my research question. Each theme has a ‘central organising concept’ (Braun and Clarke 2006, p.82), explaining something meaningful about the case in relation to my research question and the way in which that concept appears within it. In Chapter 7 I have identified two over-arching themes and a number of sub-themes, capturing the patterns in the data most relevant to answering that research question.

These patterns were identified through a continuing process of reflecting on and reviewing the codes in my code book and the data coded to them. Through this I:

- Ensured that these codes reflected the patterning of my data (Braun and Clarke 2013).
- Refined my coding ‘trees’: identifying similarity and overlap and relationships between codes and considering whether they should be divided/split, or clustered/ lumped together to form new codes.
- Searched for concepts to which several codes related and that might therefore be useful to consider as categories (or sets) and ultimately if sufficiently rich and complex to be candidates for themes (Charmaz 2012).
- Continually reviewed and revised provisional themes to determine how well they fitted with the data coded to them and my overall case and whether they told me something meaningful about an aspect of the case in relation to my research question.
- Reflected on whether further data collection, might be necessary to ensure sufficient meaningful data to support themes. Using theoretical sampling, I did gather a small amount of additional data (for example Esther’s views on drafts of the findings and discussion on two occasions).
- Ensured that each theme was coherent and considered whether it might need to be split into two or more themes or sub-themes.

- Considered the possible relationships between overarching themes and how each theme contributed to the story of my overall analysis of the case. Mapping and the modelling within NVivo helped me to see these relationships visually.
- Continued to write increasingly conceptual memos in relation to the developing analysis.

5.5.4.1 Dramaturgical coding

In 5.5.3, I described my desire not to be constrained by a rigid method of analysis and my wish to gain an understanding of the case through a repertoire of appropriate methods. I was interested in on-going actions and interactions in response to events within the case and therefore made a point of coding the *processes* within it (as explained in 5.5.3.2). I found it insightful consciously also to look at dramaturgical aspects of the case. Dramaturgical coding (Goffman 1959) is particularly relevant to case study research and complements this coding of processes (Saldaña 2013). My naturalistic observations of specific vignettes, episodes or stories within the case and the narratives in my interviews can be seen as performance or social drama, particularly where two or more participants act, react and interact. Applying (in a small way) dramaturgical concepts such as cast of characters, monologue, dialogue, soliloquy, scenario, script and plot devices to the data allowed me to see the case in a different way, attuning me to the qualities, perspectives and drives of participants and their objectives, tactics and attitudes. The outcome of my efforts to consider the case in this way are visible in the presentation of the story of the case using vignettes in chapter 7.

5.5.5 A rigorous and trustworthy analysis – evaluating the quality of the study

The somewhat eclectic, but nonetheless systematic, analytical strategy that I have described contains a variety of different methods for attempting to understand the case. I have attempted to achieve a balance of an adaptable and flexible approach that is nonetheless rigorous. Yin (2009) emphasises the importance of doing this where some people need convincing of the value of studying cases in this way. The triangulation of analysis does I feel contribute to rigour and the likelihood of it having resulted in a good understanding of the case. The creative approach to data

analysis that I have taken has enabled me to go beyond producing a purely descriptive account, instead producing a systematic conceptual account.

I have provided in this thesis a clear and transparent audit trail of exactly how I have constructed my findings in order to justify my conclusions. Having every part of the data and my analysis together in one NVivo project file was particularly useful in relation to this audit trail, as with regular backups I could go back to any point in the analysis and retrace my steps. Rather than distancing me from the data, I found that the use of this CAQDAS software enabled me to be *closer* to the data. The ease with which I could return from a coded extract to its source seemed, as suggested by Gibbs (2007), to reduce rather than increase the risk of extracts becoming de-contextualised.

I concur with Simons (2009) that concepts of validity, particularly external validity, are not easily applied to social constructionist case study research and would rather consider the degree to which my analytical strategy has led to findings that are credible and transferable (Guba and Lincoln 1994). Chapters 6 and 7 are therefore intended to provide sufficient information for future readers to judge the authenticity of my findings and to be confident that I have interrogated the data for alternative interpretations and negative instances (Simons 2009).

Although I am not researching from a realist stance and therefore do not suggest that triangulation enables me to get to a single truth of the reality of the case, this concept still has relevance. The triangulation of data, method, analysis and theory inherent in my design allows me to acknowledge and explore multiple perspectives, and the ways in which these converge or diverge (Simons 2009). Beginning analysis early and gathering data iteratively, has given repeated scope to gather Esther's perspective of my analysis, generating further data which I then also analysed.

Key to ensuring the trustworthiness of this analysis is my reflexivity throughout the research process, which has helped me to distinguish between interpretations where my knowledge and background has furthered the analysis, from ones that are biased (Stake 2008) and where, for example I have influenced a participant's response. My prolonged involvement in the case also guarded against reactivity

and respondent bias. I explore these issues of my presence as part of the case further in chapter 8.

Chapter 6. AN INTRODUCTION TO THE CASE

In this chapter, I use excerpts from my field notes and interview transcripts to introduce the setting for the case, Cavendish House, and some of its key players, in particular the people that live there. In Chapter 7, I present my findings in the form of a story of the case that illuminates my research question. I reiterate at this point that all names of people, places and organisations have been changed to ensure the anonymity of participants.

6.1 Cavendish House

My first visit to Cavendish House was two weeks before Christmas in 2012. Some months earlier I had recruited Esther, an occupational therapist, as my first participant in this research and in November we had together identified the potential for her intended work at Cavendish House to be the kind of exemplary case of occupational therapy that I was seeking (see 4.2.3.1). Esther and I were visiting the house on this occasion to begin the process of recruiting those who lived there and to discuss their capacity to consent to participate themselves with assistant manager of the service, Norma. I recorded my initial impressions on this first visit:

“On approach it seems a large building. Glass fronted entrance, parking area outside. Button pressed on arrival and opaque glass sliding doors opened and we walked into a large open high ceilinged airy ‘lobby’ area at (what turned out to be) the apex of the ‘T’ of the single-storey building. Wide corridors (not usual domestic scale) largely clear with minimal furniture. Clean and very warm in temperature (Esther referred to the underfloor heating making your feet hot). Lino on floors, all walls in communal areas painted off white/cream. High wooden window frames, light and airy.” (Field note 11.12.12)

Cavendish House is in a suburban area of a city in the south of England. At the time of my first visit, Matt and Harold (previously introduced in 5.2.2.2) lived there with four other people. Three of them, Steve, Jane and Becky, became participants in my research, along with Mo, who moved into the house early in 2013. Matt,

Harold, Steve, Jane, Becky and Mo all have intellectual disabilities and were supported by a team of support workers, house manager Sue and assistant manager Norma. They also received additional input as necessary from health and social care professionals from the local community team for people with intellectual disabilities and this included community nursing and speech and language therapy alongside Esther's occupational therapy.

The house has a somewhat unusual and unique history. Following the closure of the local inpatient intellectual disability hospital in the mid-1990s and the post National Health Service and Community Care Act (GB Parliament 1990) drive towards care in the community, it was built as a small NHS inpatient "locally based hospital unit" for people with intellectual disabilities and additional complex health needs. A team of intellectual disability nurses and nursing assistants then provided care and support. In 2011, however, in response to policy commitments to re-provide all remaining NHS hospital or inpatient facilities for people with intellectual disabilities (Department of Health 2009), the service had gone through major changes at all levels. This involved support no longer being provided by the NHS, but rather by Futures, a not-for-profit organisation that described their support services for people with intellectual disabilities and/ or autism as following a personalised 'supported living' philosophy (see excerpt from Wood and Grieg (2010), in Appendix 14). Although the team of intellectual disability nurses did still input regularly on an outreach basis from the community team, they were no longer based in, or had any management responsibility for the day-to-day running of the house. Futures and new house manager Sue explicitly positioned the service as "social care" rather than "health".

It became apparent to me very quickly that the existence of this house, its residents and support workers in transition somewhere between two very different models of support, as explained in more detail in 7.2, was an important feature of the case and a major influence on the direction of occupational therapy.

6.2 The people living at Cavendish House

I now invite you to meet five people I consider to be of particular importance in this case, Matt, Harold, Jane, Steve and Becky. As you might expect from my earlier

description of people with severe and profound intellectual disabilities as “heterogeneous”, and as I was to realise as I got to know them, they are five very different individuals whose intellectual disabilities affect them in varying ways. For further detail of Esther’s conclusions about each of their levels of engagement and intentional/ pre-intentional communication, see additionally the excerpts from occupational therapy reports in Appendix 15.

At 35 years old, **Matt** is the youngest person living at Cavendish House. He is very sensitive to noise, as I discovered on my first visit:

“We sat in what appeared to be a lounge area. Matt was sitting there in his wheelchair in front of a Christmas tree with two people that I assumed were relatives ... and I was introduced to them all. Esther was familiar with them already. We were offered tea by one of the staff. Several staff around, one pushing a resident from the adjacent dining room to bedroom. Friendly greetings – seemed to know Esther. Others having a meeting (“handover”) in the dining room. As we talked, Matt’s vocalisations increased and Esther suggested that we move away, interpreting that he was objecting to us all talking around him. We withdrew and sat on the sofa on the other side of the large room and waited for Norma.” (Field note 11.12.12)

Matt has a diagnosis of agenesis of the corpus callosum, leading to profound intellectual, motor and sensory disabilities, including additional diagnoses of spastic tetraplegia and gastric oesophageal reflux. His often self-injurious behaviours are regarded as indicative of something, but can be difficult to interpret:

“He has got a very narrow sphere of communication, I’ll hit myself if I am in pain, if I am unwell, if I am hungry, thirsty, hot, cold you know everything. That’s the only way I can show you there’s a problem, so you can’t say, well the difference in the behaviour shows that this is the problem.... Because of the narrow sphere, you have got to go step by step and eventually you’ll find something that works. We’ll try this, we’ll cool you down, we’ll engage you, we’ll give you Gaviscon, we’ll give you paracetamol, we’ll put you on your bed,

we'll do this we'll do that and you know you'll get your solution in the end."
(Adam 8.3.13)

Harold is in his early sixties:

"He held onto my hand firmly for some time and looked me in the eye. It seemed effortful for him to partially raise his head to be able to see me through his one open eye. Esther greeted him verbally and crouched down to the left side of his wheelchair (his head was slightly turned in that direction). Close to him, she held his hand and talked to him briefly." (Field note 4.1.13)

Harold was described as having severe intellectual disabilities, but with abilities that had reduced considerably (and health needs that had become much more complex) following a cerebro-vascular accident a few years earlier. When I asked about him, respondents would often refer to how he used to be:

"He used to be mobile and he was 'interesting', a challenging gentleman, he used to be a right old tearaway really and he used to laugh a lot and as he has gone on through life he has physically deteriorated to quite a poor physical state now, you know he can't chew, he has a catheter, he is peg fed, one of his lungs doesn't work - about thirty different conditions he has got bless him. And I think none of the staff there now know Harold from years ago ... it is a shame that all that information is lost, how someone used to like to do."
(Adam 8.3.13)

"Well Harold just likes to be involved, he likes to be part of the group, the gang and so for those of us who knew him before the stroke, he was a bugger, he used to cause all sorts of havoc... Yes Harold was always mischievous."
(Norma 23.7.13)

"The way Harold sits, he is very slumped, isn't he, his chin is down to his chest quite a bit and he has got one good eye He has epilepsy, he has seizures so if he has had a bad one, he would be physically tired.... and obviously he has got physical problems.... I think Harold just lies on his bed now and doesn't do much at all." (Sarah 8.3.13)

Jane is in her mid-seventies and this was my first impression of her:

“Doug said Jane’s wheelchair is no longer meeting her needs - apparently she is soon to be issued with a new one. They say she is less able to self-propel in this chair than she used to be able to in her previous chair, though she was able nonetheless to scoot [foot propel] over short distances. She is a large lady and was wearing a striking floral dress.... She independently ate a large bowl of what looked to be pasta carbonara from a built-up dish. Doug and Tracy, another support worker, both confirmed that she loves food and in fact Jane then grasped Tracy’s hand and pulled her towards the kitchen towards what she seemed to know as ‘her’ cupboard. Tracy interpreted from this that she wanted some chocolate from this cupboard and indeed Jane ate this chocolate very quickly. Then when Esther approached her, Jane took Esther’s hand and moved towards a different cupboard, which Tracy stated used to be her cupboard. Jane then appeared to pull Esther towards the doorway from the kitchen to the hall. Olly said “she’s trying to take you to her room. She’ll get you to put her necklace on” (which he said was “an effective object of reference for going out”) “and she will want you to go out with her.” Esther said she therefore wouldn’t go to Jane’s room with her at that point, not wanting to give a mixed message, but that she would love to go out with her another time, including for example to the swimming pool, as Olly had reported earlier that Jane likes water and likes to sit in the Jacuzzi there.”
(Field note 28.3.13)

Jane’s intellectual disabilities were inconsistently described as both profound and severe. Her presentation as someone with more of a sense of her own personal causation, and who makes choices and uses non-verbal communication more actively suggested to both Esther and me that her intellectual disabilities were more likely to be severe than profound.

Steve is in his early-fifties:

“Steve sat in his wheelchair and seemed calm and alert, looking around and making eye contact. Esther greeted him verbally and also touched his hand. Steve seemed very interested in her (Jean said he likes women) and looked at

her face very intently, seemingly particularly fascinated. He also reached for her hair and pulled her close towards him. Esther was at times very proximate to Steve, faces close together, lots of physical contact hand to hand. Lots of eye contact, including waving fingers in front of eyes between them, Steve also did this [I can't remember who started doing it first]. He was holding a soft toy elephant and then subsequently a monkey and felt and pulled at these. Esther interacted with Steve using the monkey and talked about it. Jean mentioned that Steve did not like loud noises [he came across as a very placid and calm man]. Esther ... pulled out a stretchy rubber object that she then looped around his fingers and pulled against him with. I asked her whether or not he was pulling against her and she replied that he sort of was. She also offered a small mouse that had a rough texture, which Steve immediately held onto and also a small toy "Tigger" that vibrated (a less clear reaction to this, though Steve did grasp it). Jean felt that Steve was enjoying the exchange as he was not making any of the vocalisations that might indicate that he was not." (Field note 28.1.13)

I got a sense from a number of respondents that Steve was the person staff found it most difficult to know how to support to engage in activity:

"Because Steve doesn't give you, oh this sounds really awful and negative I don't mean to sound negative, but because Steve doesn't give you that instant feedback does he, when you are doing like a leisure activity or a personal care activity, he is very kind of placid laid back kind of guy, just lets it all go on around him ..., it is very hard to, for want of a better expression, read Steve." (Sue, Manager, 27.7.13)

Steve has profound intellectual and multiple disabilities including dysphagia leading to risk of aspiration. He is very prone to chest infections and needs care to ensure tissue viability and prevent pressure sores.

Becky is also in her early fifties:

"Becky sat in her wheelchair in what seems to be 'her' corner of the dining room facing into the room. Sunny spot, she seemed happy and was vocalising,

repetitive sounds [I admit I find it difficult to hear exactly what she's saying, lots of background noise anyway, but there seem to be words there]. Staff seem to interact with her as though there is meaning in what she is saying e.g. that she was calling someone a "muppet" ("who are you calling a muppet?"). She had a table in front of her, on which she slapped her hand from time to time. For some of the time she was wearing 3D glasses having been to the cinema recently and Doug said she looked like one of the Blues Brothers. Esther sat with her briefly and chatted. Tracy mentioned that it is Becky's right eye that she can partially see out of. I was sitting on that side (i.e. to her right) and did not get a strong sense that she was looking at me out of that eye, her eyes were moving all-round the room, but difficult to know if she was fixing on anything."

"Esther placed the musical objects into Becky's hand and she mainly threw them/ dropped them over her right shoulder. The first time she did this it hit a metal bin, making a quite loud noise and Esther then picked up the bin and caught the object in the bin each time Becky dropped it. [It was very difficult to say whether Becky was rejecting the objects or engaging in a game and Esther later clarified that she was not certain. Becky did persist with this however and there were no signs she was not enjoying it, which leads me to think she was engaging in this as a bit of a game]. This continued for about 10-15 minutes." (Field notes 27 and 28.3.13)

Becky has severe-profound intellectual disabilities (secondary to meningitis), cerebral palsy, scoliosis and epilepsy.

Shortly after Esther had begun to work with Matt, Steve, Becky, Harold and Jane, **Mo**, a lady in her sixties with moderate intellectual disabilities, moved into the house. Esther worked with her and she did become a participant in this research, giving informed consent herself to participate, as her abilities enabling her to understand sufficiently to have capacity to do this. As a woman with *moderate* intellectual disabilities, Mo features in only a small way in this case, interesting though it was to see the way that Esther worked in an individualised way with her.

My research question relates to the ways an occupational therapist supports people with profound intellectual and multiple disabilities to engage in occupations at home. Esther's work with Matt, Steve and Becky is most relevant to this, but I have concluded that many aspects of her work with Harold (who has severe intellectual disabilities, but whose abilities have reduced considerably due to ill health) and Jane (whose intellectual disabilities are severe rather than profound) also illuminate the topic. I have therefore included reference to Esther's work with them.

6.3 The occupational therapy intervention

By the time of my first visit to Cavendish house, Esther had worked as an occupational therapist in the local community learning disability team for about 10 years. I myself had known her throughout that time, occupational therapy with people with intellectual disabilities being a small field and one in which we therefore seek formal and informal opportunities to network for support (Lillywhite and Haines 2010).

Esther had previously worked with Cavendish residents Matt (in 2005-6) and Harold (earlier in 2012). The current referral arose out of concerns that she and the community nurses had about the extent to which they in particular were enabled to engage in activity at home. Additionally, Cavendish House's assistant manager Norma had requested specific support regarding how the team might enable Steve to engage more in activity.

Esther's previous work with Matt and Harold did not seem to have been completely successful at sustaining increased levels of occupational engagement in Cavendish House. Clearly frustrated by this, though nonetheless typically full of energy and enthusiasm, Esther discussed this issue in January once Matt, Steve, Becky, Jane and Harold were part of the study. She recognised the potential of the research to provide an opportunity for more extensive occupational therapy input, not only with Matt, Harold and Steve, but as a project with *all* residents and crucially also with the whole of the Cavendish House staff team:

“I feel like that might be more effective than doing very specific work with each of the people, so what I am thinking I would do is assessment work with each of [them] but then trying to engage the staff in a bit of a project.... I have done this before in other houses where I have only worked with one person, but then I have tried to engage the staff team in changing the way they work generally, and it has impacted on the other people. But the beauty of this is that I will be working with all the people or most of them, so I can help them tweak it for each of those individual people..... It would be really nice if they embraced it and got on board with it.” (Esther 4.1.13)

She hoped this might be more effective at enabling the team to adopt a different way of working and was interested in the potential for improved and more sustained outcomes than she had managed to achieve from previous more typical interventions.

Esther worked with those living in Cavendish House and their support workers for a year from January to December 2013. The main phases of her occupational therapy intervention can be seen in the timeline in Figure 6.1, including

- A period of some three and a half months of assessment in order to get to know the individuals and how they were currently supported and which, in particular, sought to gain a picture of the levels at which they were able to engage in occupation, their likes and dislikes and sensory preferences.
- Preparation of resources (reports, activity session plans, cue cards, lists of suggested equipment to be purchased) to facilitate the staff supporting residents in the way she was recommending.
- A four month period during which the staff team implemented her recommendations, with gradually reducing support, recording activity levels on a daily basis.

Figure 6.2 then illustrates some key moments in the case, which arguably either facilitated the objectives that Esther was trying to achieve, or hindered progress. These included initial resistance, but eventual enthusiasm from manager Sue, varying responses from different members of the staff team, staff sickness and

shortage and key members of the team leaving towards the end of and shortly after the intervention.

Reference is made to the phases and moments on these two timelines in Chapter 7, where I move on to discuss key aspects of the case of relevance to my research question.

The case Timeline 1 – Phases of Occupational Therapy Intervention

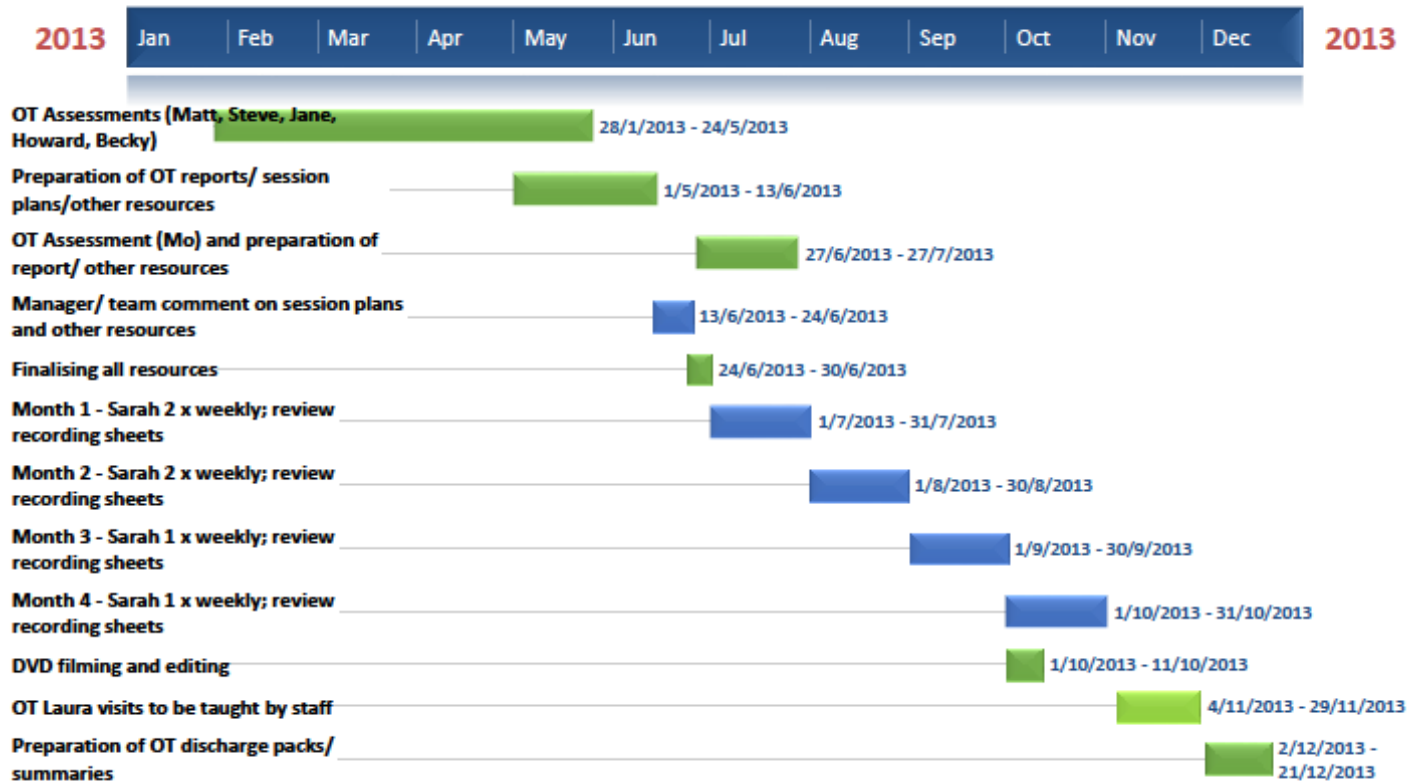


Figure 6.1 Timeline of phases of occupational therapy intervention

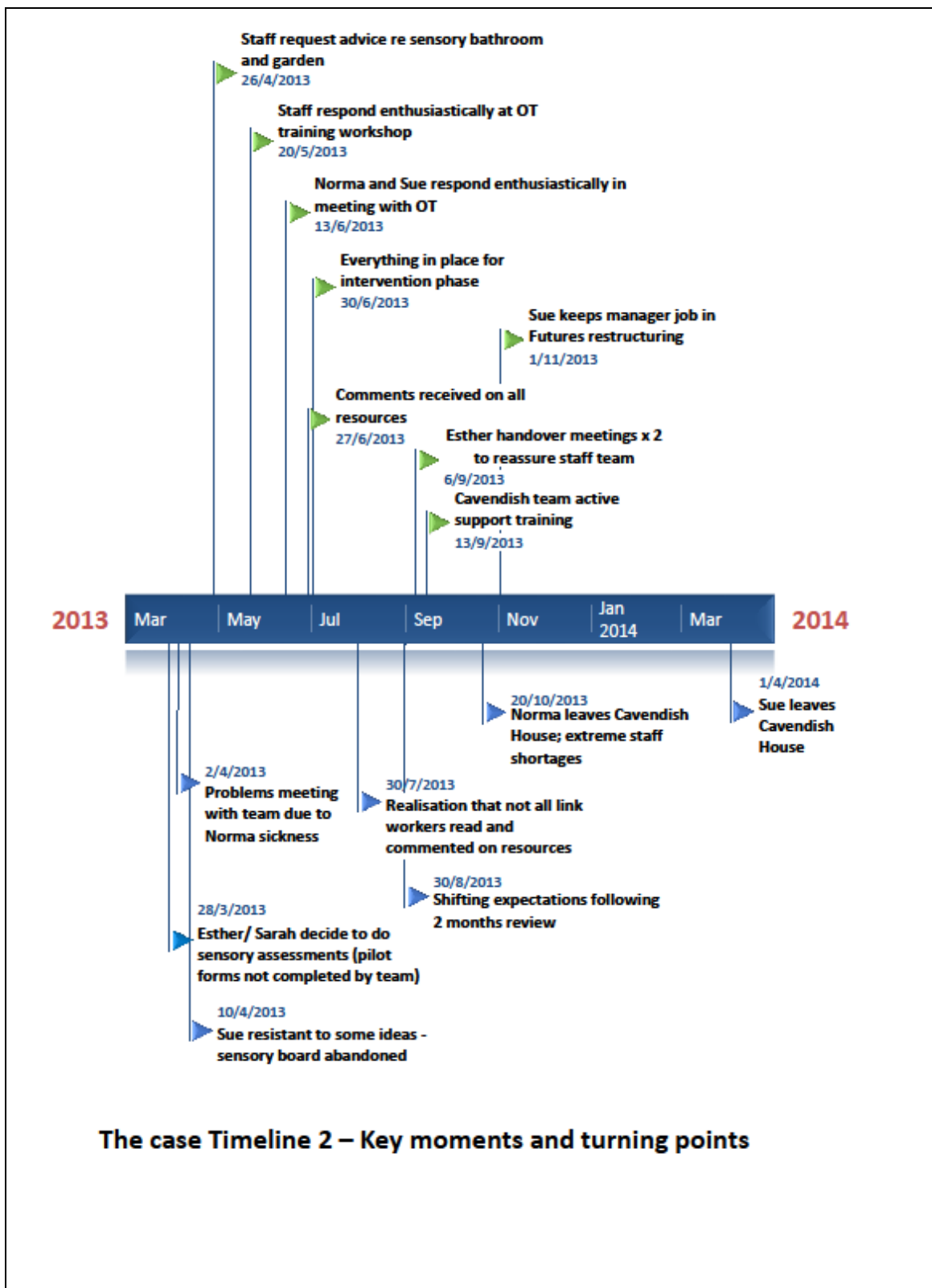


Figure 6.2 Timeline of key moments and turning points

6.4 The boundaries of the case

The bounded system or object of this case (see 5.2.3) can now be described as:

“The occupational therapy that supports Matt, Steve, Becky, Jane, and Harold to engage in occupations at home in Cavendish House.”

Its nature has crystallised gradually and its physical borders, time span and which actors are within and outside it are now apparent. The boundaries of the case, in particular the setting and the various actors, are illustrated in Figure 6.3.

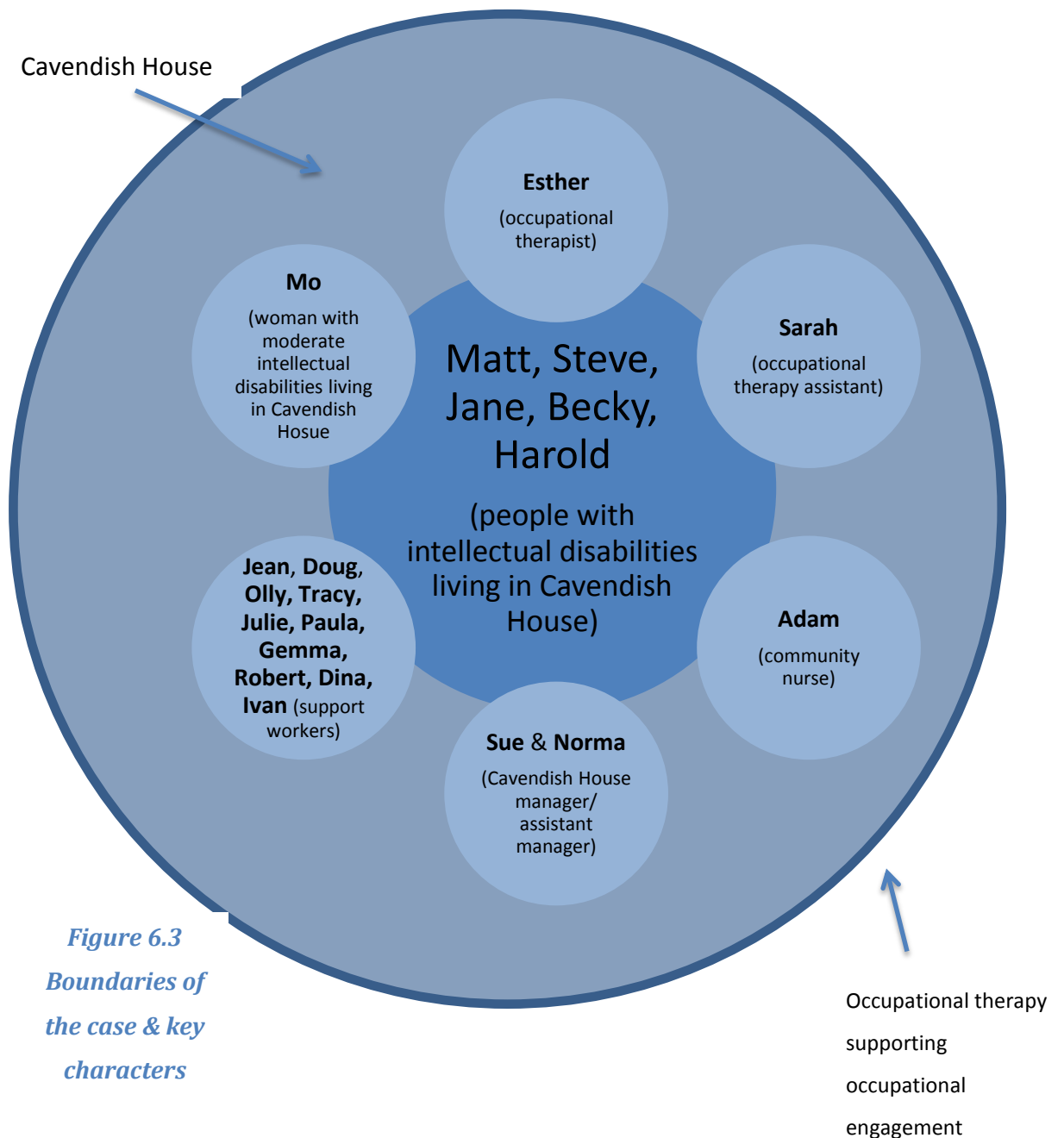


Figure 6.3
Boundaries of the case & key characters

6.5 Themes – patterns in the story of the case

I was mindful of Thomas' warning (2011) that the freedom in case study methodology can result in:

“an undifferentiated collection of thoughts and quotations from interviews with very little in the way of glue to hold the whole thing together.” (Thomas 2011, p.195).

My analysis led to the construction of two overarching themes to be explored: the impact of the shifting cultures within Cavendish House on engagement in occupation by those living there; and characteristics of an occupational therapy intervention promoting engagement. I do not claim that these and their sub-themes explain or represent everything in the data, but each “captures something important about the data in relation to the research question and represents some level of patterned response or meaning” (Braun and Clarke 2006, p.82). In Chapter 7, I use the themes constructed out of my analysis to tell a particular story about the case of Esther's work at Cavendish House that I understand to be relevant to my research question and appropriate for my audience. As implied by the stance I have taken as a researcher, this story is highly interpretive and I use these themes and sub-themes as organisers to explain my interpretation (Simons, 2009), or my translation (Van Maanen 1995).

Whilst mindful of the need to be rigorous, rather than reporting the case cautiously in more traditional formal and structured ways, I have experimented with potentially more vivid ways of telling its story. Bassey (1999) suggests using detailed description to draw a picture of the case setting, or a particular participant or event and I have tried to follow Simons' advice (2009) to weave my data into a coherent story and to "depict experience in real-life cases with such veracity that others will have vicarious experience" (2009, p.158). With their words in mind, I have sought to enrich my reporting to contribute to such vicarious experience, whilst also developing a critically reasoned and evidence-based argument, with a strong story line. Stenhouse (1994) and Simons (2009) emphasise the importance of portrayal to achieve this and I have displayed data in the form of quotations from participants and excerpts from my own field notes, as

well using three vignettes to illustrate different important aspects of the case. Along with the cameos of those living in Cavendish House in this chapter, these aim to bring the participants and case to life for the reader.

Chapter 7 is by nature somewhat descriptive, but in the discussion in Chapter 8, I take a more explicitly critical stance, evaluating the ways in which my story sheds light on the research question and situating it within the wider literature in the fields of occupational therapy and intellectual disabilities (including my own previous research). I use my theoretical framework to explain aspects of this story (Simons 2009) and, in conclusion propose a theory of the case itself (Thomas 2011).

Chapter 7. FINDINGS:

A Story of the Case

In this chapter, I present my findings in the form of a story of the case with two overarching themes. The first of these is the shifting cultures in the setting of the case, Cavendish House. I argue that an understanding of its various and support cultures is important as these impacted on the ways that those living in the house were supported to engage in occupation.

The second overarching theme is the characteristics of the occupational therapy intervention itself. This was an intervention that:

- Aimed to create and sustain cultural change within Cavendish House.
- Had a particular understanding of authentic engagement in occupation.
- Was underpinned by theory.
- Involved getting to know those living in the house well.
- Was creative and flexible.
- Provided resources and ideas.
- Involved working with the staff team and managers in a way that Esther described as similar to working with her service users.

Before presenting the story of the case, however, this chapter begins with three different vignettes which I have constructed from the data with the aim of illustrating in detail how Esther sought to embed a different way of supporting those living at Cavendish House to engage in occupation.

7.1 Vignettes

The following three contrasting vignettes illustrate different aspects of the case and I will refer back to and explain aspects of them in the remaining sections of Chapter 7 and in Chapter 8. I invite you, the reader, to consider and decide for yourself the extent to which I have achieved what Saldaña (2011) suggests is possible: authentic and credible renderings of aspects of my story of the case, revealing something of Esther's objectives, conflicts and strategies.

As an overall depiction of the occupational therapy intervention, I have constructed the first vignette in the form of a monologue, using Esther's words as spoken in various research interviews with me. Although re-ordered, I have otherwise edited her words very minimally, making changes only where necessary for the script to flow and make sense. I have drawn on Saldaña's suggestions (2011) regarding the use of ethnodramatic play scripts as representational or presentational methods for fieldwork, this modality seeming to me to be as potentially effective for illustrating a case as Saldaña argues it is for communicating ethnographic findings.

Vignettes 2 and 3 use excerpts from interviews, field notes and documentary data to illuminate Esther's work with Matt and her collaboration with house manager Sue.

7.1.1 Vignette 1: Embedding sensory activity – Esther's monologue

Scene 1: The project – a journey together

Esther: (speaks passionately) I want to talk about the project. I have come to this point where I am going "no, a project will be better", because it felt that I was dipping in and out with Harold and it wasn't enough to get people motivated and doing stuff. And if I am coming in, swooping in, telling them what to do and then swooping out again and then no one else there is talking about it, then it does look like I am coming in, giving orders, or whatever. But if I go in and I am giving them some resources, I am being helpful and their own service are embracing and are checking it and talking about it all the time, it feels more collaborative, doesn't it?

What I want to do is to get it into the culture, I want to get everyone thinking about sensory activity. I often feel that people don't know what to do when it comes to sensory, so they get lost and then they don't do anything. I often think that. I think there is a culture of not doing stuff and not thinking of sensory and yeah probably coming down from above, this culture that we need things to be functional and we need to make it normal life, like you and I would live.

(Emphatically) Why, why is Steve doing laundry? Because that is not a meaningful activity, laundry for him. If it was sensory laundry or laundry done in a way that

makes it meaningful for him then yes I get that. But if it is just about, if anything Steve being in the room while the staff do the laundry? And, you know, I hear people talking about this age appropriate thing and maybe they have got quite stuck in:

(as house manager Sue) "these are adults and they should be doing adult activities and sensory activities are like children's play."

So somehow I need to put what I am doing into a language that fits with that, cos it doesn't have to be so far apart. Framing it slightly differently, so it feels more acceptable and fits with their philosophy a bit more?

So yeah, I think getting people to think about it more, getting it embedded into everything, giving them ideas, giving them resources and I am hoping that all these things are just going to get them excited about it.

I think to start with there is probably quite a long journey to make before they are thinking about sensory activities every day. Norma needs to be on board, absolutely needs to understand it and be promoting it, as does Sue. I think everybody needs to know what it is about and what I am doing and things like having the board on the wall as the constant daily reminder that we are supposed to be doing that. And some of it is about me going back in there regularly, how are you doing, how are the sensory activities going? Not checking up, but just keeping it on people's agenda. It just gets into the culture that everyone has the expectation that we are working on these activities for people and everybody is thinking about it and talking about it. That bit about getting it into people's psyche!

And it feeling like it is a joint venture and not just the OT coming in and telling us, but everybody is on board, everybody is thinking this is a good thing to do. You have got to get people on side with you. I suppose unconsciously I want to build a relationship with them so they feel comfortable that I am going in and, yeah, we work together on it and it doesn't feel threatening. I suppose I want that to be a supportive process, so they feel like we are on a journey together to improve it. What we do in our training is, we learn to do things alongside other people, so when we do an activity we do it alongside them. And for me that has translated into if I am going to work with the staff team I am going to work alongside the staff team. So it is a way I guess of motivating them to take ownership for what's happening.

(Laughs) yeah, so maybe there is something about that gently educating without looking like you are educating, do you know what I mean, that explaining why I am doing what I am doing almost, I don't know, without going:

(didactic teacher voice) "I am going to teach you about what I am doing, I will tell you all about sensory"

kind of making it more part of the conversation:

(gentler, less didactic voice, as if talking to the support workers) "Well this is what I want to do and this is what I am thinking and why I am thinking it. Am I being clear?"

But I still feel that I might be imparting some knowledge. And maybe that is easier to take?

Yeah if I can win staff over and help them feel like they have got things to offer. So to do a workshop to get everyone on board, a bit of a group session with all the staff and get them to sort of take some ownership by understanding where we are going with it and them telling me what they already know about the guys that live there. I think if you can get everyone signing up to those things and everyone has heard it first-hand sometimes it is better than if you ask a manager to introduce something and it takes a while to filter down and not everyone understands why they are doing it.

(Laughs) My brain is jumping all over the place! I feel like I have all these ideas and I have to bring myself back sometimes otherwise I'll lose the staff!



Scene 2: The bridge

Esther: What we tend to find is that if people are at the earlier Pool Levels [see 3.3.5.1], you know if they are more at the reflex end, then they are more likely to be pre-intentional communicators and if they are right at the other end towards exploratory level of Pool Levels, they are more likely to be intentional communicators, so we used this concept of a bridge with the idea that in order to move your communication skills and your level of engagement forward, you need good quality sensory activities. Some need those very structured and guided and with others you introduce more challenges into those sensory activities, does that make

sense? We might use something like a switch that they'd have to activate to get the sensory reward they were looking for, whereas right at the early part of the bridge we wouldn't expect them to do anything to get their sensory reward, we'd be putting the sensory object in their hand, shaking it and holding it, whereas later on we'd be expecting them to you know, we'd put something further out of their reach so they'd have to go for it.

I actually think that analogy of the bridge and those Pool activity levels is more useful in understanding what is going on than saying "he has a profound learning disability" or "she has a severe learning disability".

And then the next thing is about looking at people's sensory preferences and I'll try to get the staff team to help me with this cos there are so many different types of sensory experiences, it would take me forever on my own. Leaving the form with them, getting the staff to try and work out their sensory preferences. I have tried this once before with Harold, but they didn't fill it in, so (shrugs) we'll see how we get on with it!



Scene 3: No one is really doing anything

Esther: (sighs) (quieter voice, speaks more slowly) *Ummm I have kind of abandoned the idea a bit of them showing me what they do, cos whenever we turn up no one is really doing anything and when you ask them "what do they normally do", they always say "go out", don't they? (rolls eyes) Often. So in a funny way I have abandoned the idea of going in with the hope that I'll see somebody doing something with the guys.*

(pauses)

(decisively) *So, I am meeting with Sarah tomorrow morning and we are going to put together our assessment kit for the sensory preference checklist. Between us we thought we would carry it out because I don't think the staff will, I don't think they'll do it. Ummm but I know that it is too time intensive for me to do on my own, so Sarah and I will use the assessment kit to carry out the assessments between us.*

(frustrated) *And it is proving so hard to get to a staff meeting! It is taking weeks to set this up. Maybe I am pinning too much on meeting them as a whole staff group and I should be going in and speaking to them individually?*



Scene 4: Training with a small 't'

Esther: (speaks excitedly) *I'll tell you about the training I did last Monday, the workshop. You know I wasn't at all hopeful about it! Well it has been cancelled loads of times hasn't it? But it was brilliant, it was really, really brilliant. I wanted to have everyone or as many people as I could, as I think then everyone takes ownership. Well, (shrugs) I got the people who were there on shift at that time (laughs). I was there at half past one because that's the handover time between the morning in the afternoon shifts and it was whoever happened to be on at that time.*

I was thinking of (mimes inverted commas) "training with a small t", a little bit of information giving about how people with intellectual disabilities engage with activities and get them to tell me where they think those guys are functioning. Again so they get a bit of ownership.

I felt really positive afterwards. I explained why we were doing a project and why now and I tried to be quite gentle about:

(empathic voice) *"you know you've all told me that there have been changes and you are not able to do the things that you used to do and how do you feel about it?"*

And everybody it seemed like in harmony went:

(in voice of support workers) *"we haven't got a sensory room any more, that that's what's changed. We haven't got any resources."*

One of the things they came up with was about not having time to make resources, so the fact that it is being provided for them I'm hoping is a way of overcoming that barrier. And I was sort of saying:

(supportive, accommodating voice) *"I've done this, but I'm more than happy to change it and tweak it. You tell me."*

And I really felt like it was a bit of a journey and so I said:

"I've set these goals, are they realistic, you know five activities a day can you do that? Am I just being an idiot?"

And it was a bit jokey and I think I probably made it sound like I was criticising myself a little bit, but I think that's all about getting people on board isn't it? And they said "yes" they did think the five activities per day were realistic, because I was saying they are probably not going to be more than 10 or 15 minutes are they realistically? So that was brilliant!

I said that aside from all of this I would also do an activity file or a sensory ideas file, because (you remember?) I said originally that I wanted a sensory board? I said "I understand that that could be seen as a bit institutional", but they all went 'oh, is that institutional?' and they obviously didn't think that! (Shrugs).

I said that I felt it was really sad that a lot of the time people do activities on their own and was there was scope for them doing more with each other and everyone in the room was saying:

(as support workers) "yeah, it would be lovely if they were able to do things together."

So I thought that was good too, yeah I felt that was a bit of a win really.

Oh yes and then they were all coming up with these ideas and a lot of discussion at the end. And they were saying for Steve they are going to go to the garden centre to get a jasmine plant, which someone had seen that weekend. And then:

(as support worker) "oh but we can't get that for Jane, because she's allergic" but they thought of another plant. The fact that they were even thinking about those practical things made me feel really more confident. So really starting to process and think and get enthused.

It felt like there was some energy and like we were on a journey together which was quite nice. It is about finding allies isn't it? To all of the link workers I said "you are my allies now and I am telling you this because it is your job now to tell everyone else and I want you to kick people up the bum and get them doing it" and they all said "yes!"

Once you've got one person on board and they are talking about it when you're not there, then it starts to spill over and other people start to hear it and it is not just coming from us.



Scene 5: A turning point

Esther: *I think that was a bit of a turning point (laughs)! I had finished my session with Becky and was just about to go and one of the members of staff kind of ran after me and said:*

(as support worker) "hold on, I want to talk to you about something, I need to pick your brains. I really want to make a sensory bathroom for Harold and we need your advice and help about how we are going to make his bath times sensory."

They already had got some ideas, but what was really nice was they were wanting some advice and some support with it. And then she said:

(as support worker) "also we have been doing some sensory gardening with Harold, come out and have a look."

So they took us out of the building and there's like a couple of raised beds which they had planted up with lavender and sage and various different herbs and then I asked "did Harold help you do this?" because I wondered whether they had planted it for him and they said

(as support worker) "oh no, we had him out here and he was holding the pots and he was helping us out with the soil."

It was really lovely and I did feel that there might have been a step further they could've gone in terms of helping him hold the herbs and smell them, I didn't get a real sense that they did that, but they did support him to participate in it and they are thinking sensory!

Yeah it was really, really positive, I think just having a presence there is helping, just being there, yeah, so I think just seeing us there is making them think a bit more about making things a bit more sensory.

I also did an equipment list for each person because I keep getting asked:

(as support worker) "oh you know, Harold has got money, what should he spend it on"

which again I feel so pleased that they're asking me and not just going and buying stuff, or not bothering. So I came up with quite a few things for each person. So I've written lists, which mostly link with, the session plans.



Scene 6: They need to feel like they own it

Esther: *I do think it is a bit of both. It does need to be led from the top – and I feel so positive that I have won Sue over after that meeting, because I think unless she is on board we are not going to get everybody else on board are we? But people on the ground also need to feel like they own it.*

Norma agreed that the lead link workers would review the session plans for their people and give feedback and we also agreed that those link people would review the recording forms once a week. So I think she is invested in making sure it happens. I did wonder whether I would get these session plans back with not many comments at all and that people would glance through and go, yes that's fine. But I have only been through Steve's and Becky's and I have had to revamp four of the plans for Steve! I am really glad that they have circled things, like that I have got a typo there and they have said here that, well I have said that the environment needs to be calm and clutter free and they have made the comment that it also needs to be warm. You know, so they have considered things, it doesn't feel like they are just glancing through.



Scene 7: Teething problems

Esther: *(frustrated) Ohh, days like today I feel really defeated. (pause) I think I have got all these great ideas and it would be brilliant and I can see how all these things would help the people that live there and then I hit a barrier like that and I think realistically is it ever going to happen? Sometimes I feel like I am walking through treacle and nothing ever gets done.*

I feel like it is not filtering down very well and the support workers have got less knowledge about the session plans than I originally thought they had. And that is why I pulled the stuff out about active support and leadership, because I can't do that – I shouldn't have to talk to every single member of staff! To help them remember that it is the session plans that they are following, it is not just about doing personal care, it is about doing personal care in a much more sensory way.

(pauses, thinking) But maybe I am beating myself up because it has only been a month and everything takes a time to get embedded doesn't it? There were bound to be teething problems, there were bound to be people that were a bit more resistant than others. It is not surprising really that they haven't quite got into it. And I get the sense that some people knew what was happening and some people really didn't. Even though I did those two sessions and even though, you know, Sue seemed so on board and Norma knows what is happening, there are definitely people in the team who are going:

(in voice of confused support worker) "I don't know what this is about, I don't know what you are asking me to do."

I feel like there is a risk I could end up getting a little bit defensive and a little bit in a battle, so I probably do need to just sit back and take a breath and go "right".

(pauses) I won't stay defeated (laughs) but today I do feel defeated.

(pauses, thinking) It is on their radar, it's definitely on their radar. But I still think there is a shift to be made before they really take ownership of it. Cos I wonder if I stopped now and didn't do any more recordings and I didn't check anything, would the momentum continue?

Maybe I need to shift my expectation a bit and rather than sort of expecting that everybody does everything, try and hone in a bit more on what people are good at and what motivates them? It is also about playing to people's strengths, because, say, Tracy has done the sensory gardening and maybe it is just about for her nurturing that and you know giving a few strokes about yes you are doing really well with the sensory garden, you should carry on with that. As opposed to pressuring her because she is pushing back against certain other activities you want them to do.

I want to give staff a pat on the back for achieving what they have in difficult circumstances, because they are very short staffed. These are the areas we need to work on next month, let's just keep chipping away at it. Only little tweaks really.



Scene 8: Stepping back – a parting shot

Esther: *I do need to start stepping back from it now I think, I need to make them feel like they are responsible and not think I am going to keep coming in to check. We have backed off quite a lot this month. We can't keep recording it forever.*

I wonder whether this DVD might be my "parting shot". You know, we are going to discharge and this is what we have done, this is the finishing touch. Because I just feel that it has really captured well five people with PIMD with different needs and it kind of pulls out their different individual things, it looks at communication, it looks at activities. I think that is why it will be so useful as a training resource cos you have got a range of different people. It feels having invested all of that time that it all came together and that it is quite a nice summary of the guys and the work. People are more likely to engage with it than a written report.

I am going to do a discharge pack with the DVD in it. One for each person, session plans, discharge summary, DVD etc.



Scene 9: Small steps – it is on their radar

Esther: *Now Norma has left and if we lose Sue, I can't see that it is embedded enough and that really worries me and I don't know what to do about that really.*

I do feel quite torn about it, it has been a very time intensive piece of work and I do wonder how easy it is to justify the amount of time for the outcome we got. I think I have made a real conscious effort to bridge that

(in voice of critical support worker) "You don't know, you've come in for an hour and you don't know"

a little bit and to meet people half way. I don't think we would have got this outcome had we not invested as much time, but I still think we didn't achieve enough. I mean

it is a little bit of that if you aim up here (points high) you get here (points a little lower), because I do think it is on their radar, just the fact that they know when I visit, immediately they are saying “sensory”. If nothing else, I have got it into their psyche.

I think I probably could have engaged with the actual staff sooner, cos I did a lot with Sue and Norma to start with and I lost the staff along the way I think at the beginning, although having said that, it was so hard to get to a staff meeting! So whether it could have been earlier? It was a bit hit and miss wasn't it? Maybe it is about small steps.



Scene 10: The new manager

Esther: *I bumped into Maureen the other day, she is now the new manager at Cavendish House. She said she was looking through all those sensory activity session plans. She asked me about them and sounded really interested. I am going round next week to talk her through them.*

7.1.2 Vignette 2: Supporting Matt to engage authentically in occupation

Data from various different aspects of the case are used in this vignette to illustrate Esther’s understanding of the nature of authentic engagement in occupation for Matt and how she supported the staff team to achieve this.

Esther [discussing previous input with Matt in 2005]:

“And then we just looked at regular things during the day that he could do that were more sensory, more deep pressure, things like foot massage. And also things like making angel delight in a really sensory way. Basically getting all the things ready and taking your time over let’s feel the milk, what does it feel like? Is it cold? Let’s wipe your fingers and scrunch the towel and feel it on your face and spend time pouring the powder over your hands into the milk and what does it feel like, you know all the way through the process and getting him to taste it. And the staff really, like if you go in there now, they will have angel delight in the cupboard and they will talk about angel delight and if they talk about no other sensory activity it will be that.”

Video recording: Esther building a relationship with Matt

Excerpt from my field notes (watching video recording)	Interview with Esther (30.7.13) whilst watching this video recording
<p><i>Matt is in his wheelchair wearing coat ready to go out. Esther is crouched down beside him watching him attentively (Sarah is filming).</i></p> <p><i>Matt makes occasional vocalisations: “khhhhhh” (described as “happy sounds”).</i></p> <p><i>Esther makes Matt's “khhhhhh” sound three times. Matt smiles, turns head towards Esther and goes “khhhhh”.</i></p> <p><i>Continues to smile and puts right index finger in mouth. Esther repeats it back</i></p>	<p><i>Esther: laughs (in response to video).</i></p> <p><i>Lovely! So what do I think is happening? I suppose before that clip he was making those noises, which made me think he was happy and I just wanted to touch base with him really, to make that connection, that I was there, that I was doing the same, you know something that he understood and yeah trying to get a bit of a connection with him.... cos kneeling and chatting to Matt probably wouldn't do that at all would it? He</i></p>

<p><i>and then again: "it's your turn". She repeats it again. Matt removes finger from mouth and turns his head to the right (pensive?). Sarah says "you've gone quiet now".</i></p> <p><i>Esther makes the "khhhhh" sound again and Matt smiles broadly and immediately makes the sound again. Esther repeats immediately and Matt does as well, extending it longer. Turns head towards Esther, finger still in mouth, still smiling, then turns head to right.</i></p>	<p><i>would know that you were there, but you haven't really entered his world there have you? It really looked like he was listening. Lovely!</i></p>
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Norma [in response to "what does engagement mean for Matt?"]

"With Matt he will stop and he will listen, because he moves his eyes when he is listening, so you will know.... because he's blind he tends, his eyes move more and he will take his hands out of his mouth and he will stop the moaning and he will go very still and you will think yeah, you're listening to that and you can tell that he is listening.... It is very subtle, but it is there."

Video recording: in the tea shop

Excerpts from my field notes (watching video recording)	Interview with Esther (30.7.13) whilst watching this video recording
<p>1.</p> <p><i>Esther is to Matt's right, leaning down to his level. Jean is standing to his left. Esther is holding a bag of loose tea, which she shakes close to his right ear. The foil packaging makes a crunchy sound. Matt wrings his hands and makes a moaning sound "mmmmm."</i></p> <p><i>Esther holds the bag under Matt's nose so</i></p>	<p><i>Esther: That "mmmmm" is "I am not really sure about this" and it might tip either way. Because I have seen him go from that to going "khhhh" and really happy. What I am thinking now is that this is an initial reaction against the smell.... I felt like I wanted to persevere a bit with the smell, maybe that is why I</i></p>

<p><i>he can smell it, his vocalisation increases and both his arms go up and he puts his right thumb in his mouth</i></p>	<p><i>was doing the rattling first to engage him and calm him and help him feel safe in that activity....</i></p> <p><i>So I think his initial reaction is always going to be to pull away, but I did sort of want to work through that really just to see whether that was a real reaction, you know whether he really didn't like it or whether it was just I don't know what that is, so get it away from me.</i></p>
<p><i>2.</i></p> <p><i>Esther continues to encourage Matt to smell the tea. He has his right thumb in his mouth and his fingers wrapped round his nose. Esther sniffs the tea herself. Matt makes vocalisation and turns head away.</i></p> <p><i>Jean hands Esther an alternate tea and they swap. Esther "oh that is strong". Matt in the meantime wrings his hands and blows quiet "raspberries". He has his hands up by his face. Esther then approaches him with the second tea and shakes this near his face again. He points his nose towards it. Turns head away and vocalises a couple of times. Esther leaves the tea there for a few more seconds and then takes it away.</i></p>	<p><i>Esther: I was deliberately doing that really loudly, so he could get the sense of you are supposed to smell this (laughs).</i></p> <p><i>DH: There is that change at the end where he starts to look up</i></p> <p><i>Esther: and that for me is him getting used to it now, he is starting to understand what it is about. You can't force it on him too quickly, but equally you have got to gently... Even if he is not [sniffing it], he must be able to smell it just from breathing so closely to it</i></p> <p><i>DH: He hasn't turned his head away from the packet</i></p> <p><i>Esther: I think he is smiling, you can see in his eyes</i></p>
<p><i>3.</i></p> <p><i>Matt stops vocalising, then Esther re-presents the tea and he begins again (moaning noise).</i></p>	<p><i>Esther: I don't know whether that was the smell or whether he was just overloaded by then, we had done too</i></p>

<p><i>Esther shakes bag of tea near Matt's face. He looks towards it and then turns head slightly to the side, possibly a slight smile on his face and he puts his right index finger to his mouth [is this a happy sign, seems to be?]. Esther then shakes it closer to his face to release the smell. He raises his bib to his mouth and then lowers his hands and turns his head towards it. Leaves his head with nose right up to the opening of the bag for some seconds, smiles. Esther gets close and smells the bag with him. Matt looks towards her and blows a "raspberry"</i></p>	<p><i>much all at once. I think I started to feel like that ... we needed to give him a little break....The thing with Matt is you can't always, I mean sometimes he will start sounding like he doesn't like something and then all of a sudden he will laugh or his happy sound, so you can't always be sure.</i></p>
<p><i>4.</i></p> <p><i>Esther is close to Matt, she has some loose tea in her right hand. Matt's hands are clasped together. She scrunches the tea (makes a noise) and then touches the tea against the underside of one of his hands</i></p> <p><i>Matt does not immediately pull away. He allows her to do this for a few seconds and then raises his elbows up and his hand to his mouth - puts bib in mouth. He is quiet at this point, head oriented towards Esther's hands. Esther touches the tea against the underside of his hand again briefly. He then pushes both his hands down into Esther's open hand [is he trying to feel the tea? It doesn't look as though he is pushing her hands away]. Hands held against the tea for several</i></p>	<p><i>Esther: I had some different tea leaves in my hand and I wanted to see if he would respond to the texture, and he didn't like the texture, well he didn't like touching, I don't know if it was the texture</i></p>

<p><i>seconds fingers slightly wrapped around Esther's hand. Then he raises his elbows and hands towards his mouth. Wrings his hands then moves his hands back towards Esther's hand. Chewing on his bib he makes a "khhhh" sound, turns his head in towards his chest and puts his thumb to his mouth. Moves his hands back down towards Esther's hand (not touching). Moaning vocalisation and raspberries. Esther touches the tea against his hand and he pulls away slightly, though not very far away. Vocalisations increase, but he wrings his hands and they touch Esther's hand and the tea a couple of times</i></p>	
<p>5.</p> <p><i>Matt sitting, chin tucked, arms clasped together at chest level. Jean has placed a large (kilo?) foil bag of tea on his lap and she makes a sound by pulling at the foil. She gently takes his right hand and places it on the foil bag, pressing down on it with her left hand. He does not immediately resist, but after a few seconds, pulls his hand away. She holds his hand and strokes his fingers - again he does not pull away immediately but then pulls his hand away after a few seconds.</i></p> <p><i>Jean places Matt's left hand on the top of the bag and encourages his fingers to</i></p>	<p><i>Esther: Jean is really good What I think about that is when I was doing the tea leaves, I think she is more assertive, she is being more assertive than I was ... He is getting the movement from her isn't he? See I wonder if her assertive approach helps him to feel secure. "Oh she obviously thinks it is ok because she is doing it" maybe?</i></p> <p><i>DH: yes "it is safe to try this thing that I am not too sure about because Jean is obviously ok with it"</i></p> <p><i>Esther: and I suppose then that comes down to the relationship you have got with the person doesn't it? See I think when he goes quiet like that and just</i></p>

<p><i>grasp the foil bag. She crinkles the bag to make a noise and then squeezes his fingers to encourage him to do the same. She rubs the side of the bag and then encourages placing his right hand on the side of the bag, rubbing it and then his middle finger against it to encourage him to feel it. She rocks and squeezes the bag so that his left hand (still gripping it) and arm moves. She then continues to encourage him to rub it with his right hand, and squeezes his left hand. Matt is quiet throughout, then raises his left hand and puts his right thumb in his mouth</i></p>	<p><i>listens that is also a positive</i></p>
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Excerpts from Matt's Occupational Therapy report (Esther, May 2013)

"Matt's assessment suggests that he is functioning between the reflex and the sensory level of engagement (Jackie Pool 2002). This means that he is unlikely to take meaning from tasks that we traditionally see as functional. He will not understand the purpose of participating in stages of tasks such as putting laundry in the washing machine or doing the shopping. He will therefore not experience enhancements in self-esteem as a result of these types of activities in the way that people who have more advanced cognitive skills might. He will however enjoy engaging in the sensory elements of day to day tasks if they are brought straight to him and he is given hand over hand prompts and bodily contact to help him engage. By actively participating in sensory activities he is likely to develop a better sense of self and skills which will enhance quality of life....

Matt's level of communication is pre-intentional, reactive which means he will react to stimulus and to his own body but he has little understanding of the impact of his own behaviours on others. The noises he makes are reactions to his mood but they are not intentionally communicative. He is reliant on staff to recognise these reactive behaviours and respond to them...

Recommended interventions will focus on providing facilitated opportunities to participate in a range of sensory activities. The key principles for providing good quality sensory activities are to ensure they are fun (they must centre around his sensory preferences), focus should be on the means not the end, they should be free from rules and should promote active participation (as much as the person can achieve which may just be watching and following the activity)....

Practical resources to facilitate implementation: To support the process of planning activity and achieving a good balance the following system has been recommended.

- Prompt cards: A set of prompt cards have been produced for each day of the week. Staff will carry out two sensory personal care activities a day, one domestic task, three leisure activities and two community activities. These will be reflected on the prompt card for that day. Staff should record which activity they carried out using the sensory activity recording chart which will be in Matt's file. For ease of use, the prompt cards are colour coded as described below:
 - Dark yellow indicating – Stimulating personal care activities
 - Light yellow indicating – Relaxing personal care activities
 - Red indicating – Domestic tasks
 - Dark blue indicating- Stimulating leisure
 - Light Blue indicating – Relaxing leisure tasks
- Session plans: These prompt cards are supported with session plans. Staff will need to build on these.
- Physical resources: A range of resources have been provided as examples of activities that can be carried out. These include discovery bags, sensory stories and sensory boxes. In addition, a list of recommended resources which can be purchased has also been developed. Cavendish House will need to continue to develop resources.

Focus of skill development: At Matt's level of functioning the focus of skills development should be on attention, anticipation and building up active engagement. These will offer sufficient challenge to Matt and will help him develop the building blocks of more complex cognitive skills.

Conclusion: Matt is a gentleman who is functioning between the reflex and the sensory level of engagement. He will be best supported to develop his skills and achieve a good quality of life by being offered a balanced range of sensory activities. Session plans and prompt cards have been provided to help embed and establish this way of working with Matt, however, it is important that his staff continue to develop these activities to ensure they stay fresh and interesting and continue to reflect his skills."

Occupational therapy session plan (Matt) – example 1: angel delight

Planned activity name:	Sensory cooking –angel delight
Activity Goal(s):	To promote shared attention, concentration and active participation
Equipment required:	Angel delight, bowls (small and large), spoons, whisk, milk, spoons and sauces.
Precautions:	<p>Ensure Matt's hands are clean before this activity. Do not allow others to eat the angel delight and make sure you follow the principles of good food hygiene.</p> <p>Do not add items such as sweets which may be contra-indicated by dysphagia.</p> <p>Do not use an electric whisk as Matt does not like these kinds of noisy activities.</p>
Environmental considerations:	Make sure the kitchen is clear from clutter. Select a quiet time to do this activity. Do not do it immediately before a meal.
How to do the activity: <i>How you will support the individual's specific needs & enable them to participate?</i>	<p>Ensure the environment (kitchen) is quiet and not cluttered.</p> <p>Get out a bowl, whisks, spoon, Angel Delight, milk and damp cloth.</p> <p>Check Matt is not hungry, thirsty, needing the toilet or in pain.</p> <p>Before bringing him into the kitchen, place a wheat bag on his knees and allow 5 minutes to 'play' with the vibro tube.</p> <p>Bring him to the kitchen and tell him "we will make Angel Delight".</p> <p>Place the adjustable height table in front of Matt.</p> <p>Wipe Matt's hands with a cold damp cloth, comment on the temperature and feel of the cloth. Then dry them with a paper towel and encourage Matt to feel it/crunch it.</p> <p>Open the Angel Delight and offer it to Matt to smell. Tell him "This is Angel Delight – smell – um".</p> <p>Pour the packet into the bowl – encourage Matt to place his hands in the bowl and feel the powder – you may want to sprinkle some over his hands and say "feel this Angel Delight".</p> <p>Encourage Matt to take his hand to his mouth to taste the powder.</p> <p>Wipe his hand again, comment on the coldness of the cloth.</p> <p>Encourage Matt to feel the empty packet – crunch it – comment on how this feels.</p> <p>Allow 2-3 minutes to explore this.</p> <p>Next encourage Matt to feel or smell the milk – tell him you are pouring it into the powder.</p> <p>Begin to whisk the mix and comment to Matt about the sound. You may want to use hand over hand to encourage Matt to help whisk and allow him to control the sound. Comment "listen to that – you are making that noise".</p> <p>Finish whisking the mix so it is firm.</p> <p>Encourage Matt to put his hands into the mixture and feel the difference from when it was powder.</p> <p>Encourage him to raise his hands to his mouth to taste the mix.</p> <p>Add sauces which should be poured from a height so he can watch the visual effect.</p> <p>Finish by using a spoon to assist Matt to eat some of the mixture.</p> <p>Praise him and comment that he made it.</p> <p>Save the rest for Matt to eat later.</p>

Occupational therapy session plan (Matt) – example 2: tea

Planned activity name:	Discovery bag - tea
Activity Goal(s):	To increase attention and active participation
Equipment required:	Discovery bag – linen bag including: different flavoured teas, builders tea in foil packet, Twinings selection (different teas), loose tea leaves, granulated sugar, white sugar cubes, sweetener, empty carton of milk (for sound), spoon, cup and saucer, tea pot. Thick and easy
Precautions:	Do not allow Matt to hold or touch hot items and assist him with anything that might break if he drops it. Due to Matt's dysphagia all drinks must be thickened as per speech therapy guidelines. Ensure Matt does not eat any inedible items.
Environmental considerations:	Make sure the kitchen is clear from clutter. Select a quiet time to do this activity. Do not do it immediately before a meal.
How to do the activity: <i>How you will support the individual's specific needs & enable them to participate?</i>	<p>Set up the kitchen so it is calm and quiet and make sure you have everything you need to hand.</p> <p>Bring Matt into the kitchen and encourage him to reach into the bag and pull out an item. You may need to assist with this. It does not matter which order items are taken out but below are some ideas about how you might assist him to engage with each one:</p> <p>Builders tea in foil packet – Matt loves rustly noises, encourage him to hold the packet and scrunch it, you may need to help with this to start with. Do not rush because sometimes it takes him a few minutes to fully engage and understand the task.</p> <p>Twinings selection (different teas) – these are in tea bags, encourage him to hold them and explore (although be careful he does not split the bag and eat the tea. Assist him to smell the different tea bags as well.</p> <p>Loose tea leaves – have a wonderful texture which you can encourage him to explore with hand over hand but they also have a much stronger smell so you can encourage him to smell them. You might want to put them in a sandwich bag so he also gets an enjoyable sounds from this too.</p> <p>Granulated sugar – can be placed in a container and shaken to make an interesting sound. It can also be put in a sandwich bag and felt.</p> <p>White sugar cubes – Sugar cubes can be dropped into another container or added into the empty milk carton to make a shaker.</p> <p>Sweetener – The sweetener is a lovely tool for shaking and clicking</p> <p>Empty carton of milk – This can be squeezed to make a crunchy noise and things can be added into it to make a shaker. You may also want to fill it with water and so you have a pouring sensation. Debbie could be encouraged to put her hand under the water as it is poured (ensuring it is a safe temperature).</p> <p>Spoon and cup – Can be used together to bang. Ensure these are not thrown.</p> <p>Tea pot – also makes an interesting sound (although Matt is a little sensitive to high pitched sounds). He might also like the feeling of the tea pot which is metal so may be slightly cool. You could enhance this by putting it in the fridge for a bit before the session. Like with the milk carton you may also want to fill it with water and so you have a pouring sensation too.</p> <p>You could end this activity by washing up the items (see washing up session plan)</p>

7.1.3 Vignette 3: Getting Sue 'on board'

Opening a dialogue

Esther stated that she wanted to work together with Sue and the staff team to enhance and build on what they were already doing. She described her idea of the "discovery bag" and the different sensory experiences that could be had with different flavoured teas. Sue responded warily that she was concerned about the health and safety of Harold or Jane putting the tea in their mouths. Esther quickly responded with a variation to address this issue. She then explained her general aim to develop skills through sensory activity (giving an example of developing Matt's skills of attending to something for more than a few seconds, taking turns and visual tracking). Sue emphasised that she was interested in any form of engagement like this, giving an example of him chopping up a carrot using a vegetable chopper if he couldn't use a knife. After a brief pause, Esther (although not explicitly disagreeing with this) referred to the need to be ensure it was meaningful for Matt, with more of a focus on the process than the end product. Sue said that they would need to make sure that activities were age appropriate, though Esther in response emphasised that they should be developmentally appropriate and that this was not the same as treating people as children.

Esther described wanting to embed sensory activity into the environment so that the team were thinking about it more. She described the idea of a "sensory board" situated in the hallway near the front door on which could be pinned resources and ideas of activities currently being tried by the team (for example sensory cookery or laundry), that could act as a prompt. Sue however felt that this would be too institutional. Esther quickly suggested an alternative idea of placing the prompts that were to go on the board in the shift leader's folder.

[The tone of this meeting was friendly, but Sue's body language and tone of voice and some of her responses to Esther suggested caution and uncertainty and that she either did not understand, or did not fully agree with some of what Esther was proposing. I suspected that Esther was doing her best to hide frustration and observed her frowning at several points during the interview.]

(Field note following observation of discussion between Sue and Esther 10.4.13)

They become my closest allies

Esther: I probably do need to just sit back and take a breath and go right – Sue clearly needs to demonstrate that she is meeting certain needs doesn't she? She needs to prove that she is working on people's skills and she's facilitating independence. So somehow I need to put what I am doing into a language that fits with that cos ... it doesn't have to be so far apart.... I think unless she is on board we are not going to get everybody else on board are we?....

Actually, logically I know that when I have come up against managers like Sue before and I have spent the time to work with them and to gently educate them and come a little bit closer to the way that they think ... they have been my closest allies so ... you never know I might be able to, I don't want to say win her round cos I think eventually it will end up being her coming a bit closer to what I am trying to say and me having to tweak and compromise what I am saying really....

It has opened a dialogue with her. She has seen me, she has talked to me about it, it is on her radar that we are doing a project there, so yes those are the positive things. And she is going to meet us again in a month's time and maybe both of us will have processed it a bit further and you know uhhh I don't know (laughs).

(Interview with Esther following meeting with Sue, 10.4.13)

Functioning at a sensory level

Esther: (Holds up occupational therapy reports) [These are aimed at] staff at Cavendish and probably mainly Sue (laughs). So I've just talked about what we're looking at is promoting quality of life and looking at opportunities for skill development. I wanted to be really clear for her what the objective would be from my point of view, and that it incorporates to some degree her objectives. So I have just given an overview of what the different ... Pool Activity levels are. And then for Steve I have said that I think he is functioning at a sensory level, which means he is unlikely to take meaning from tasks that we traditionally see as functional. He will not understand the purpose of participating in the stages of the task such as putting laundry into a washing machine, doing shopping, so [refers to report]:

"he will therefore not experience enhancements in self-esteem as a result of these types of activities in the same way that people with more advanced skills might."

And the reason I put that is because I think Sue's argument was that people should engage with functional activities because it's good for their self-esteem and self-worth. And I just wanted to be really clear (laughs) that for someone like Steve he won't achieve that by doing activity in that way (laughs). I think yes it's really important to engage in meaningful activity, and that will ultimately improve his self-esteem and self-worth, but I don't think it's about doing functional tasks and then you can see an end product and then you have done a good job and you are being independent. Because I don't think that is how Steve experiences it. I've put:

"he will however enjoy engaging in the sensory elements of day-to-day tasks. By actively participating in sensory activities he is likely to develop a better sense of self and skills which will enhance his quality of life. He does notice motivating sensory experiences in the environment and will reach for them and therefore it is important that opportunities to engage in objects are available to him.... At Steve's level of functioning the focus for skill development should be on attention, tracking, reaching and turn-taking. These will offer sufficient challenge to Steve to help him develop the building blocks for more complex cognitive skills."

What I wanted to be really clear is that for Steve you have to focus on this because until you've done turn-taking and tracking and all that, you can't build and do more functional skills. And I just wanted to be really clear for Sue that there is a sort of hierarchy of how you build skills and if you pitch it up there, he just ain't going to get it.....

Yeah, I do generally feel more positive about how they are going to embrace it. I don't feel like she is actively against it.

(Interview with Esther 24.5.13)

I never knew OTs did this

Esther: *Yeah, do you want me to start from the beginning then and sort of talk about that meeting I had with Sue and Norma? I was happy! I was really happy with it.... I*

brought the folders like I have here and I said, right what I'll do is I'll talk through one person in real detail and I will talk you through the report and the session plans and the goals but once I have done that you will have an idea of the sort of structure and where I am coming from...

What I think was helpful is that I sort of had a bit of an attitude of "I know you already know this but I just want to talk you through the report so that we are all on the same page." So I wasn't trying to make them feel like I was trying to teach them something they didn't know. But I suppose underneath it I thought "you don't know this."

So I talked through the activity levels ... and Sue just went, "Ahhh that makes absolute sense, I can really see where you are coming from now." And it was almost as if a penny had dropped you know? And then I talked about [each individual's] sensory preferences and I did lots of you know "what you do really well is the community stuff and I know it is difficult and you don't always have the resources you need... so I have given you your equipment lists" and they said "oh yeah, we have looked at those and we have started buying stuff."

And then I talked about doing activities with peers and choosing to do activities with other people and that was the first point at which I got the sense that they were pulling back again and sort of going "ohh I don't know about that because you know everybody has their individualised care" and so I did a little bit of umm "most of us choose to do activities with other people" and they said "well the only people that really seem to get on are Mo and Jane" and I just thought I would use that as a window. But then I talked a bit about how could they develop that relationship and move that forward and what activities could the two of them do and then I sort of dropped in "and what about involving Harold?" So I have planted a seed with that I think.

But you know then they seemed to come back round really quickly. I think I was trying to trying to make them see how ... what I am doing sits alongside their philosophy, because what they want is person-centred care, they want people to be meaningfully engaged. They do want that, but I just think they misunderstood how to achieve it..... Umm and then I yeah I talked about the goals I had set and asked if they were realistic and they thought they were.

But Sue sort of ended by saying “this is the most person-centred thing I have ever had, I never knew that OTs did this, I thought they just did baths and grab rails! I have never seen an OT doing anything like this before.” And she could see how it fits together and how it might enhance what they did for their whole service. So I just felt so positive when I left that meeting that I had suddenly won Sue over. Because she will now lead from the top, she will make sure people do it. She is already telling other people who come into the unit that they are doing it. I couldn’t believe that they had invested three hours with me ... and I really felt in that meeting that both Norma and Sue were listening to what I was saying and they were making sense of it in terms of the work that they do and the paperwork they have.

(Interview with Esther 7.6.13)

Keeping it on people’s radars

Esther: *I won’t formally review things until the beginning of September, but what I did do is I picked up the recording forms last week and I have had a little look to see how things are going.*

Sue: *they are not consistent, the recording forms*

Esther: *Ahh there were probably a handful of days in each of them that hadn’t been filled in, but in fairness to everyone, most of the days were filled in, so that was good*

Sue: *It is just me being disappointed (laughs)...*

Esther: *You know I think it is good to have that balance do you know like we need to be positive don’t we, but we also need recognise where the gaps are, so that we can try and move it forward. Which was the other reason really why I thought it would be good to touch base with you so that we can look at what is going well, but also what can we try and work on over the next month so that when we get to our more formal review in September we have kind of pushed things forward.... So you know they each have set some objectives and for most of them it was to do five activities.... So I have just looked at how many times each of those different types of activities were carried out in the month*

Sue: *we have got the flash cards haven’t we, which are informative, there is no doubt about it, but it doesn’t lay it out. This [full session plan] is more of your action plan or support plan or whatever.... That’s exactly what to do and I think that is what my*

team are used to. Even though the flash cards are brilliant because they are the memory jogger ... this lays it out and I think having that as a reference point for people might up this a little bit.... even if we put them all together in a folder, yeah and have them sectioned out for each person and then people can go to.... And I think that will help increase the success rate, yeah because then even if somebody is supported by somebody agency, bank who haven't been here for a while, whatever the case may be, they have still got somewhere to go and say, right ok, got it.

Esther: I'll do that then.... So just my suggestion is that in August we try and get a bit more consistency and try to achieve at least the expected outcomes, so that is five short activities a day, they only need to be ten or 15 minutes.

Sue: It is not a huge ask is it?

Esther: It is not but as you say it is a shift in culture and some of the feedback I have had from people is that they are feeling a bit overwhelmed by it.... Something for you to manage anyway! I have just put thank you to everybody for embracing it and I do feel that people have embraced it, they know why I am here, they know what my job is....

One of the key elements from [active support] is about practice leadership, so the management or senior staff that are there day to day – you probably know all this – making sure that they're pushing.... It is about organising staff as well and it is about someone saying "here are the cards you have to do this today!" I am more thinking for someone to be responsible for knowing, for doing that scouting about and going "how are the session plans going, are you really doing the session plans...?"

Sue: Shift leaders.

Esther: ... I am going to speak to Norma about the practice leadership stuff from active support just as a, you know, she has got a really important role and the shift leaders will too in that day to day chivvying people along, not necessarily nagging, not being massively responsible for it

Sue: Just a nudge in the right direction isn't it every day?

Esther: Yes... keeping it on people's radars! ... but what I don't want it to mean is us [Esther and Sarah] swooping in

Sue: *In fairness I don't think that has been the case and I don't think it is the impression that has been received either, so people have gone "actually this is ok." ... And it is not a negative experience for the staff, but it is about you are absolutely right, me and Norma and the shift leaders ... just making sure people are you know keeping awareness of it really.*

Esther: *And it feeling like it is a joint venture and not just the OT coming in and telling us, but everybody is on board, everybody is thinking this is a good thing to do.....*

(Discussion in meeting between Esther and Sue 27.7.13)

It is truly meaningful

Sue: *I think specifically the work Esther is doing around the sensory engagement stuff for people with profound learning disabilities here is invaluable. I personally have worked in care for the last 18 years with Futures ... with people with learning disabilities - quite a bit with people with profound disabilities.... I have never known anything that is quite so person centred for somebody with profound learning disability and that is really meaningful, truly meaningful, which is a complete difference to the other stuff that I have been involved with and witnessed.... It is tokenistic, you know oh get somebody involved in their domestic skills, well especially for someone with profound learning disability it is a case of they are in the room. Whereas this actually ... gives somebody with a profound learning disability ... a sense of self-worth. And it is very hard, specifically here at Cavendish to know whether that is the case, because people don't verbalise. So you have to go on all the other stuff, you know behaviours, whether people get involved and whether they want to get involved and whether they initiate it, then after a period of time, that is our only measure. So I think it is brilliant, I am really positive about it, I really can't be more positive about it. It is just that it is so individualised, that somebody has come in on Esther's part and taken time to actually do the background study for it, you know. To see what actually engages a person on an individual basis ... and she has used the right tool for the right person and come up with this plan, do you know what I mean? ... Esther has come in and gone, OK we will use this tool, this tool for this person because that is where I see them, this person is different.*

She has got that constant presence I suppose, and if she is not present there is the accessibility to her, and that she is positive about it, because she wants it to work for the people we support ... to see the person as an individual, see what actually motivates them, demotivates them, whatever switches on that little light for them and they go "oh I am enjoying this". She has taken time to do that and then pass that knowledge onto the team.

Other professionals have come in, not at Cavendish House obviously ... and go, well we are going to do this and we are going to do this and this is going to be the outcome. You can't do that when you are working with people, because everyone is different.... But Esther takes her time to make sure it is right, to make sure that people understand it, that they know the thinking behind it, the rationale behind it blah, blah, blah and then she follows it through, she doesn't just go "it is over to you now, off you go."

And ... if it it's not working ... she'll change it or she'll tweak it or whatever the case may be. Whereas other professionals in the past in my experience have gone, well it needs to be done like that, do you know what I mean? ...

It is a case of almost switching that light on for the staff isn't it? Oh it is not rocket science, you are not asking me to do anything extraordinary, you are just asking me to be a bit more thoughtful about the experience somebody has when I am giving the personal care, or when doing domestic tasks, or a bit more thoughtful around leisure activities. One thing that sticks out for me is Steve, you know Steve as long as I have known him has always has these long legged monkeys, cos everyone thought he liked monkeys and loves long arms. Esther's observation and the tools that she has used to assess, it is not about the monkey it is about the length of fabric. He wraps it around his arm ... and you know it could be a scarf it could be anything that is long and that he could play with and experience and feel. So it isn't about monkeys any more and once people have read that and seen that it is "oh I get it now" ... It is not the monkey that is special, it is the fabric, the feel of it....

I see them as building blocks Esther has given us for the staff and we need to build on it and ... not just going that was a piece of work we have done that, we'll put it to one side.

(Interview with Sue 30.7.13)

It is not filtering down very well

***Esther:** And even at the top here of the recording plans it says “please record which session planned activities you completed today.” And below “we are aiming for two session planned (underlined) (laughs). You know so (sighs) I just think they are missing that. I do have some thoughts about how I am going to take it forward. I have printed off all the session plans and what I was thinking ... for Jane’s link worker for instance, I want to book and say I want to sit down and go through every one of these session plans with you and I want you to help me fill in this evaluation so tell me, how are the sensory baths going and I think that will enable me in a not such a confrontational way to go, ok so when you, you know, get the smelly things out that are in this session plan, how does that work (laughs) and then hopefully they might say we don’t quite do it like that...*

Cos I think if I go in and say “you are not doing the session plans are you?” then I will lose them.... Helping them remember that it is the session plans that they are following, it is not just about doing personal care, it is about doing personal care in a much more sensory way....

This is probably overly structured, but you know I think they need it at the moment. I feel like it is not filtering down very well and that is why I pulled the stuff out about active support and leadership because I can’t do that, I you know I feel like I will invest more time and I will go through the session plans with each of the leads and do it in a way in which I am evaluating what their thoughts about you know and it will be important to evaluate it like that. But on a day to day basis, I think Norma and the [shift leaders] need to be checking that people are wearing the cards, asking them how did they do it in a sensory way... when they did the bath did they use the care plan, or did they just do a bath and are they just writing sensory bath because they know they have to? Cos you know on a lot of the forms it says sensory bath but I don’t know whether they are just saying it is a sensory bath or whether they are actually following the care plan.

(Interview with Esther 30.7.13)

Some kind of autonomy in their life

Sue [in response to question about the likelihood that the work Esther has done will be sustained]: *It is extremely likely, extremely likely and I will tell you for why. Futures as an organisation are ... really, really keen on personalisation, we use a lot of person-centred tools.... The staff since last time we spoke have taken part in an active support training day, so they have now got the kind of awareness of the stuff that Esther has been doing and the sensory engagement and also they now know how to make an active support plan to bring that sensory engagement* [Esther's work] *just basically echoes and reflects what our personalisation is about, it is about engaging people, it is about promoting that independence, promoting that choice, giving people opportunity and moving it forward, it is skills teaching as well. It is about all of that and moving it forward for the individual.... We want people to be as independent as possible, even if it is only that they are able to brush their teeth, or they are now able to make a cup of tea or they now make choices about where they go in the community*

DH: *how would that translate to someone like Steve or Matt?*

Sue: *it would probably mean, for people here with more profound disability, that they get actually some kind of autonomy in their life, you know.... With Esther's work and our personalisation, it is about not disrespecting or forgetting the health needs, because if you are not healthy you can't engage or feel reluctant to engage in stuff, but again it is about moving that culture from carer and it is about giving people more autonomy and choice really*

When Esther came to me with the idea of this sensory engagement, I had seen it before and it had always been tokenistic, some people sat in a room while care staff did it.... Well that's not really what it is about ... and I was so like conscious that I didn't want it to be that for people that lived here, because I wanted it to reflect our personalisation stuff and I think it really is doing that in more ways than I even could see in the beginning... No it definitely won't go away and disappear, I mean I see it as a foundation block in a way and we can only build on it and once people acquire these skills or maintain skills, we will just think a bit more creatively about what will be a natural progression.

(Interview with Sue 1.11.13)

7.2 The shifting cultures within Cavendish House

An important part of this story of the case is the context in which it was set.

Participants described their varying perspectives on Cavendish House's unusual and unique history. The way the service developed has, I conclude, had a lasting influence on the cultural setting and a number of different – and conflicting – cultures seem visible within the house, influencing attitudes towards those living there and ways of supporting engagement in occupation.

Versus coding, as described by Saldaña (2013) (see 5.5.3.3), was helpful in enabling me to see where individuals, groups, models of practice and processes within Cavendish House were in direct conflict with each other. Within the cultures in the house, a number of “moieties”, or “mutually exclusive divisions” (Saldaña 2013, p.94), each with polarised positions, were apparent. Naturally, although often perceived or described as binaries, these conflicts were nuanced and participants had multiple perspectives and took their particular positions to varying degrees.

The point when I made my entrance into Cavendish House was approximately 18 months after the transfer of the service from the NHS to Futures (as described in 6.1). The two organisations were described by all participants as having very different cultures and policy and support practice within the house was shifting. Although the house, its staff team and residents had been through major changes, to me they seemed situated somewhere between two different cultures, with different members of staff identifying, to a greater or lesser extent, with one or other of these.

I sometimes found myself thinking about the staff team in the binary terms that my participants often used, in particular, frequent references (by Esther, by Sue and by the staff themselves) to “old staff” and “new staff”. This was seemingly short hand for the core of staff that pre-dated the transition to Futures (some of whom had worked in the house for 13-20 years) and those who had arrived since 2011, each on different (though gradually harmonising) pay structures and conditions. It would be simplistic to assume that each of these groups were homogeneous and thought along similar lines, though some ‘old staff’ did align themselves with the

former 'health' focus of the service and some newer staff with the philosophy of the new organisation. In contrast, however, some longstanding 'old' team members (support worker Olly, for example) very much welcomed the change. What became evident was a staff team that did not feel like a unified whole: there were essentially different 'camps' of staff who either felt they fitted in with Futures and embraced its new ways of working, or did not and for one reason or another struggled with or were resistant to the shifting culture. I would characterise this latter group as somewhat lethargic and lacking in motivation towards their work (see further 7.2.3).

I begin this section by using three of the afore-mentioned moieties to illustrate aspects of the conflicting cultures at Cavendish House. In 7.2.4, we shall then see how this had an impact on the staff team's success at supporting Matt, Steve, Jane, Becky and Harold to engage in occupations at home. In 7.3 I explore Esther's efforts to change the culture within the house in another, different direction. The case illustrates how difficult it can be to change the culture of an organisation, something I will go on to discuss in Chapter 8.

7.2.1 Meeting complex health needs versus supported living

Current house manager Sue described how Futures explicitly positioned itself as a "social care" rather than a "health" organisation, providing support services for people with intellectual disabilities along the lines of a personalised 'supported living' philosophy:

"It was probably just the culture at the time, the culture and the environment of the service, you know then it was NHS you know and ... with the NHS you are more focused on health. People's social interaction, activity, you know community participation and all that might be secondary.... Since we have transferred over you know and we provide the social care ... it is like it has been a shift, it is more about getting people out into the community, giving them presence, giving them a voice and as an organisation, Futures are very good at that." (Sue, Manager 30.7.13)

A large proportion of the staff team, including assistant manager Norma and three of the support workers I interviewed (Olly, Jean and Doug) had been working in

the service since before the transition. This change in the service was referred to every time I interviewed anyone and all voiced strong and varied opinions about it and the degree to which it had been beneficial for those living and working in the house. It became clear to me that, two years on, this transition was in no way complete. The house and its residents and support staff existed somewhere between two very different models of support: a nursing-led, complex health needs-focused NHS locally-based hospital unit model and Futures' particular interpretation of a social care supported living service model. Different cultures and strong conflicts were thus apparent among and between participants, who openly shared their perspectives. This was an important feature of the case and a major influence on the direction of occupational therapy.

People with profound intellectual disabilities do tend to have a high level of, often complex, health needs (see 2.3.1) and certainly Matt, Harold, Becky and Jane all became ill during the course of this research (stomach bugs, chest infections, skin integrity problems). Adam, an intellectual disability nurse formerly based at Cavendish House, now inputting into the house on an outreach basis, expressed pride at the nurses' expertise in meeting these health needs:

"People somehow feel that learning disabilities nurses don't know what they are doing cos they are "well you just know about learning disabilities". Well no, I know specifically about the health needs of people with learning disabilities, the patient group that has got the most severe level of health needs. The epidemiology of learning disabilities is vast." (Adam 8.3.13).

There was, however, a difference of opinion within the house surrounding the extent to which these health needs should be the main focus of attention. Support worker Doug had worked in the house for many years:

"All of their needs, their meds and everything else, because everything you are trying to do stems from that because if those things are neglected, that person is ill and they are not playing skittles or anything.... And all that Esther has put there [points to report] has to come down there [indicates lower priority] you know.... some things must stay because they keep them safe ... and then that keeps them healthy so they can do the other things, because if*

they are ill, they are not going to be doing any of it are they? It stems from that ... because it facilitates the rest. So it is all well and good to focus on you know, so and so went and got a paper, but he is not going to get a paper if he is in [the hospital] is he? At the end of the day the people in here have complex health needs and if you don't meet them, that is where they will go, to the hospital." (Doug 11.10.13)

* Doug seems to identify me with Esther here, i.e. I believe he means "everything *Esther* is trying to do"

Sue, referring back to the period before Futures took over the running of the house and she became manager said:

"And it was like if somebody is ill, that means they can't do anything, you know? If they are in bed, with a temperature, it means they can't watch a film, they have got to be almost molly coddled, because they are ill!" (Sue, 30.7.13)

She seemed to imply that the extensive ongoing input from the nurses from the community team was perpetuating a focus on meeting health needs:

"[There are] high health needs here in the people we support, however they are not really that high in comparison to ... any other residential service. The only thing is, Cavendish House is unique in that we work so closely with the [community intellectual disability nursing] team in providing their healthcare. In our other services, across the country as far as I know, if we have people to support with the same health needs, they would be having district nurse or GP visits. They would be exactly the same as you and me." (Sue 1.11.13)

Assistant manager Norma identified from the transition:

"It is a big change, you have got to suddenly start seeing them as people not patients and some people really found that difficult" (Norma 23.7.13).

Futures had taken over the running of Cavendish House with the explicit intention of doing things differently, espousing a very clear set of values around promotion

of independence and choice, personalisation of support, community participation and individual rather than communal living:

“This is a supported living service, this is not registered care, let’s move away from that because that is where we have always had our heads is registered care. It is not, it is supported living.” (Sue 27.7.13).

These values seemed to be strongly, or at least largely supported by participants, but there was disagreement about the relevance of some ways in which they had been interpreted and some resistance to changed ways of working was clear in interviews with Doug, Tracy and Norma. Participants’ words quoted above do suggest differences of opinion about the priority of the service. I got a sense from some that something many had been proud of (managing complex health needs) had been ‘lost’ in the transition, with the whole of what had gone before now ‘rubbished’ and strengths existing prior to the transition not recognised.

7.2.2 Hierarchy and direction versus autonomy and initiative

A second moiety, also connected with this transition, related to style of leadership and in particular the relative merits of a directive style of management versus a leadership style that encouraged autonomy and initiative.

On the one hand, participants described how leadership had previously taken the form of directive management by nurses, whereby nursing assistants and support workers were told what they had to do:

“You had a nurse, a senior member of staff going to you “you will go and do that, cos that is what we pay you for, I don’t care if you don’t want to do that, cos I am telling you to do that cos I am in charge and you ain’t.” Not in such an abrupt way, but that is the basics of it.... I am senior nurse on duty, I am in charge, so and so who is doing that today, who’s doing that are you doing that? Yeah if no one volunteers, I will pick you, right doing that you’re doing that, you’re doing that, I am doing this.” (Adam, 8.3.13)

Initiative was described as not encouraged or valued and new ideas often ‘knocked back’ and critical responses to mistakes made:

A couple of feedbacks I got from some of the staff re their appraisals in the NHS was that usually in their appraisals they just got bollocked about what was wrong and what they needed to change ... and they walked away feeling defensive, negative and demoralised. (Sue 30.7.13)

On the other hand, Sue described Futures' contrasting approach of a much less hierarchical team in which all staff were encouraged to take on leadership roles. Any one of the five or six support workers working on a particular shift could have the responsibility of acting as shift leader, with the explicit intention of allowing and encouraging initiative. There was less need to get permission to take forward ideas about how an individual might be supported on a particular shift. Sue described recruiting new support workers with "*the ideas, the fresh eyes who can be creative*" (1.11.13). Doug described now working in a different way:

"To a degree I have a greater carte blanche to effect change, because sometimes there were things I wanted to do that I couldn't because I was blocked by a nurse, right? ... Whereas now it is up to me what I do today with Harold pretty much, I have got all the things that I need to fill out and that I need to do, but I can structure and reorder and jiggle a lot more than I could."
(Doug, 11.10.13)

To provide staffing cover of up six support workers at any one time during the day, the staff team is inevitably large. Both approaches recognise the importance of leadership if communication is to be effective and practice to remain consistent. Esther, Sarah and Adam, however, referred repeatedly to a current lack of leadership in the house ("*they don't have the same level of leadership*", Esther 22.2.13). Seemingly situated somewhere between two different leadership models, the team appeared to be struggling with a greatly reduced level of 'top down' leadership. Sue as manager was not based full-time in the house, as she had additional management responsibility for another service. Interviews with both her and assistant manager Norma (who had been working in the house for a number of years under the old system) suggested that the working relationship between them was difficult. Although Norma worked some shifts:

“They don’t have someone senior on every shift. They have a shift leader, but then it takes a very specific type of individual to be able to lead within a team of equals.” (Adam 8.3.13)

Not all support workers seemed to want to (or felt able to) take on this now expected shift leader role. Doug and Jean, two support workers, both differentiated themselves from colleagues who they felt struggled with being creative in such roles:

“Some people want to be led, some people ... want to know 1,2,3,4 what do I do now? ... All of their normal things will be done and that person will be looked after, but nothing will be added ... the person will be fine, but there could have been more.... Some people respond best to something very direct, I would like you to do that, will you to do it? Other people need to be more tootled along kind of thing, so that is another skill of the leader job.” (Doug 11.10.13)

I observed this with Tracy who, despite having worked in the house for many years, nonetheless interrupted the above interview with Doug three times to ask for direction regarding what seemed to me to be straightforward aspects of the support worker role. Clearly different levels of knowledge, skills and confidence within the staff team, contributed to readiness to take on that leadership role.

7.2.3 Passion versus lethargy: feeling valued

A real passion for their work was evident when speaking to a number of participants (for example Sarah, Esther, Adam, Jean, Polly, Olly and Sue). I witnessed examples indicative of real commitment and creativity in the work of individual support workers that were very much supportive of the occupational therapy intervention. This included the ways that Jean supported Matt at the tea shop (see Vignette 2), Olly supported Harold to go to church (see 7.3.1) and what Esther described as Paula’s natural ability to engage Steve.

Passion and creativity amongst the support workers was, however, not always apparent. Adam, Esther, Sarah and Sue all referred at various points to a general lethargy and lack of passion within the staff team, seemingly referring in particular (though not exclusively) to some of the ‘older’ staff members (as explained in 7.2).

In a field note in September 2013, I noted a sense of cynicism and a “*definite low point*” in motivation levels and morale. Participants also reported limited initiative:

“I think within the team I have got naturally creative people anyway, but again I have staff in the team who if it is not written down it don’t get done.” (Sue 30.7.13).

“Activities are quite (hesitates) I wouldn’t say hard but a lot of people haven’t got the forethought to create something that the person can do indoors. Fine taking them out, everything outside for them to do but to have the structure inside, it is the normal just watch a DVD.” (Jean 27.6.13).

“The problem is more staff are coming into the job that don’t want to do it - people who are negative and who don’t want to be in the job.” (Adam 8.3.13).

Those lacking motivation in this way were described as ‘stuck’ in a routine, perhaps more likely to focus on the ‘givens’ that had to be done, such as personal care and meal times. Esther described excuses given for why it was not possible to do the things that she was recommending (lack of resources, no longer having a sensory room, shortness of staff) rather than seeing potential in the resources that *were* available. Esther, Sue and Adam all described creativity as having been stifled by years of following instruction rather than being encouraged to take initiative and, in contrast they saw more creativity, passion and acceptance of new ideas amongst ‘fresher’, newer members of staff.

The way some support workers described and went about their work suggested to me that they did not feel valued in their roles. Every long-standing team member I spoke to made reference to having had their pay reduced and evening or weekend working enhancements removed. This and having now sometimes to work ‘split’ shifts (a few hours in the morning, then a break before further hours later in the day) was a clear source of contention. The house’s sensory room had been removed (see 7.2.1), manager Sue had less of a presence in the house than the team were used to and information often seemed not to flow effectively between Sue, Norma and the wider team. Reference was made by Adam to “*strong and*

influential personalities" (8.3.13) within the team, with passing comments made by others about bullying, though I was never completely clear about who the perpetrators and victims of this were.

Feeling under-valued was, however, not everyone's experience, as some (Olly for example) described feeling *more* valued by a new organisation that allowed them more autonomy and valued their individual contributions more than the old system. I suggest however that a proportion of support workers not feeling valued by their organisation affected the degree to which those people took initiative and put effort and creativity into their work. It may explain some of the resistance to adopting new ways of working, such as those recommended by Esther. In 7.3.5 I discuss how she particularly focused on ensuring that the staff team were aware that she valued the work that they were doing.

7.2.4 A culture which misses opportunities to support engagement in occupation

Now that the reader has some understanding of the cultural setting, we can move to matters more directly related to my research question, namely the extent to which Matt, Becky, Steve, Jane, and Harold were supported to engage meaningfully in occupations at home. Before discussing the generally low levels of engagement in occupation before Esther's intervention, I begin by exploring what the case suggests about the level of understanding and confidence of the staff in their work. In 7.3, I discuss how Esther's occupational therapy intervention aimed to enhance this.

7.2.4.1 Understanding how to support people with profound intellectual disabilities to engage in occupations

Throughout her involvement, Esther expressed a view that a limitation of the staff team was their level of understanding about the work they were doing and specifically their understanding of how to support people with profound intellectual disabilities in ways that make activities meaningful for them. Some of the support workers themselves admitted that they found it difficult to find activities for Harold, Steve and Matt and Norma had specifically referred Steve to occupational therapy because of this:

“With somebody like Steve umm it is very difficult to know what he likes. He lets us know what he doesn’t like, but it is very difficult to find out what he likes and what he is just tolerating.” (Norma 23.7.13).

All three were described as difficult to ‘read’, which I interpreted as meaning that it could not always easily be told from their behaviour whether they were interested or meaningfully engaged in a particular activity (illustrated in the case of Matt in Vignette 2). Not feeling able to judge if someone is engaged in an activity seems to reduce motivation to persist in supporting them, or to result in support without enthusiasm and a support plan being followed in a way that is half-hearted and less likely to be meaningful or successful:

“And [Olly] said “to be honest” and he started talking from other people’s perspective but then he came round to saying “well I feel like this too”, he said “we can’t see a response, we can’t see that Harold is particularly motivated by these things, we feel like we are jumping through hoops” and for me what an eye opener! Of course they are never going to engage in this if they think that they are just jumping through hoops” (Esther 30.8.13).

Video recordings of Esther and Sarah engaging Harold in a game of skittles and Jean supporting Matt to explore the smells and tastes of different teas (see Vignette 2), made it apparent that both did give definite indications when alert and interested in what was happening. These were subtle and easily missed, however, and preferences could be interpreted in varying ways. Esther clarified, for example, that the understanding that Steve liked soft toy monkeys was not strictly correct, for at his developmental level he would be unlikely to recognise his large collection of these as monkeys. Rather, as indicated by his equal interest in her scarf, what he liked were long soft materials that he could twirl and wrap around his arm (see also Vignette 3).

The way staff supported activity (and described doing this) suggested to Esther that they did not always fully understand the level of individuals’ ability, or *“cognitively or developmentally where they are functioning”* (Esther 10.4.13). This, she felt, resulted in a lack of confidence in interacting with or engaging those they were supporting in activity, or to presenting too great a challenge. She argued that

staff were unable to support people in ways that would make activities meaningful, because they did not really understand what it is that makes activity meaningful for someone with profound intellectual disabilities. I explore her particular interpretation of this further in 7.3.1.2.

Futures' philosophy was one of personalisation, independence and choice: people should be supported in individualised, age-appropriate ways to be independent and autonomous adults. Adam suggested that the organisation had a greater level of experience supporting those with less severe intellectual disabilities and it seemed, perhaps due to this, that some could not fully see how this philosophy related to those with severe and (in particular) profound intellectual disabilities they were supporting. There was talk of "making them more independent", but when I asked, without questioning this as a goal, for clarification about what it actually meant for someone like Matt or Steve, responses were vague, suggesting that it was particularly difficult in their cases. Sue, however, in the course of struggling to answer my probing question, seemed to begin to work out an answer for herself (see Vignette 3). In 7.3.1.2 I describe how an important part of Esther's occupational therapy intervention was supporting the staff team to see how her recommendations fitted with and helped explain this organisational philosophy.

7.2.4.2 Low levels of meaningful engagement in occupation

At the time I first arrived at Cavendish House, Esther and occupational therapy assistant Sarah had been working with Harold for a number of months. His referral to occupational therapy a year earlier had suggested that the staff team were struggling to engage him in activity now that his abilities were considerably reduced. Esther and Sarah had modelled ways of supporting him that reflected his personality and his like of what they called "the banter":

"Every time I went I would say it doesn't matter, Harold doesn't actually have to physically participate, he doesn't have to hold that ball and play the balls, because they have a skittle alley. You know, I said, we can do the participating, it is the noises, the environment, the nice atmosphere we create, the banter to include Harold in that." (Sarah 8.3.13)

They emphasised lively things going on around him that he could feel part of and that might motivate him sufficiently to make the great effort that it took for him physically to participate. This recent intervention with Harold did not, however, seem to have resulted in him being supported to do more:

“Yeah I felt frustrated working with Harold, like you said 31st January last year is the first entry and it still feels like he is not doing anything.” (Esther 22.2.13).

Seven years earlier, Esther had also completed a lengthy intervention with Matt introducing specific occupational responses from staff to behaviour (e.g. teeth grinding or hitting his face) indicative of distress. This involved reducing sensory stimuli in the environment, introducing deep-pressure proprioceptive activity (e.g. massage or vibration) and supporting him to engage in developmentally-appropriate sensory activity (see further 7.3.1 below). Adam, who worked with Matt at that time, showed me his analysis of behavioural charts indicating that from the 25 recordings that he was able to interpret, it was this engagement in activity that was most commonly successful in reducing his distress. This was used successfully for some time, but by early 2013 Matt’s levels of distress were described as having increased and the therapeutic engagement techniques from Esther’s previous intervention seemed no longer to be used.

For Esther, this was indicative of a general issue with levels of engagement in occupation in the house: *“whenever we turn up no one is really doing anything”* (Esther 2.4.13). She expressed concern about how many of the activities described on paper (e.g. on individuals’ weekly timetables) really happened and about being often told that an individual was “resting” on their bed. She sensed that people might be spending much of their time at home doing less than ever and that the culture in the house still seemed to prioritise meeting health needs over engagement in occupation. Lethargy had, she felt, led to some of the support staff and in particular those who had worked in the house for some time getting ‘stuck’ doing the same routine things and unable to be creative in their work. This she felt resulted in limited variety and novelty for those living in the house and also to staff

not gaining the motivation that might come from supporting a greater variety of activity.

As well as this occupational deprivation, Esther was particularly concerned about *imbalance* of occupational opportunities with much of the engagement that did happen being self-care activity (washing, dressing, eating). She noted a lack of meaningful engagement in domestic and particularly leisure activity and, citing occupational science theory, argued the importance of increased balance in individuals' occupational lives. She concluded that many of the staff particularly struggled to support engagement in leisure activities, seemingly understanding leisure as 'relaxation' or 'resting', whereas she also had in mind more active or stimulating leisure activities.

Where efforts were made to support engagement, Esther argued that these were often tokenistic or superficial, with opportunities missed to promote more meaningful or authentic engagement, whether due to level of understanding, or lethargy. Matt, Steve, Harold, Jane and Becky were very often present when, for example their laundry was being done or their lunch prepared, but on early visits to the house, I did not see much evidence of them being *involved* in these activities in a meaningful way. Their general presence (e.g. in the laundry room with laundry basket on their lap) indicated a willingness to involve people more, but Esther felt that many support workers lacked an understanding of *how* more meaningfully to achieve this.

7.3 Characteristics of Esther's occupational therapy intervention

It was clear from our many discussions that Esther also had her own understanding of the cultural setting in Cavendish House that she was taking into account as she encouraged the team to support Matt, Steve, Harold, Becky and Jane to engage in occupation in a particular way. As suggested at the beginning of Chapter 7, her occupational therapy intervention had a number of marked characteristics, all visible in the vignettes in 7.1 and I now move on to explore these.

7.3.1 Creating – and sustaining – cultural change

From when we first discussed the possibility of Cavendish House being the setting for the case, Esther recognised that even though her work there was going to be a somewhat larger and more intensive than usual project, it was nonetheless time-limited and would therefore need to end at some point. If change were to be sustained over time, there was no point in working only with those living in the house, but it would rather be necessary to think of the whole system and to work also with the staff team and managers. She spoke of “revitalising” her previous input with Matt and Harold, of trying to change the staff team’s outlook on the way they supported them and their housemates and of embedding a different way of working into the organisational culture. Having worked in Cavendish House and other similar settings previously, however, she was under no illusion that embedding change was going to be easy, or quick. This is illustrated in Vignette 1, Scene 1.

Esther sought to embed a particular way of working into the culture and support practice within Cavendish House in order that those living there might spend more of their time engaged in occupation. She started with an assumption that authentic or meaningful engagement is possible for every individual, but otherwise began with very few assumptions about them. She referred to always being open to being surprised by people, seeing them as having potential, with any conclusions reached about them always being provisional and open to revision. Superficial or tokenistic engagement (which she referred to as “*just jumping through hoops*”) was rejected as in no way representing genuinely meaningful or authentic engagement

and she gave the example of Steve being *present* while a support worker put his sheets in the washing machine, but no effort being made beyond this to engage him in the task.

When talking with both myself and others, she tended to use the term “sensory activity” as a shorthand for this particular way of working she had in mind. I have concluded that when using this deceptively simple term, Esther was referring to a specific understanding about what meaningful activity (i.e. occupation) is for someone with severe or profound intellectual disabilities, and what *authentic* engagement in such occupation might mean and look like. It was apparent that this implied engaging in ways that are different from the ways we might typically engage. In this section, I explore how this case illuminates what it means for someone with profound intellectual disabilities to be meaningfully or authentically engaged in occupation. This is also illustrated in the opening scenes of Vignette 1 and in the description of Esther’s work with Matt in Vignette 2.

7.3.1.1 Authentic engagement means “doing regular things in a very sensory way”

A particular focus of Esther’s work reflected her recognition that developmentally, Matt, Steve, Becky, Jane and Harold were “*functioning at that very sensory level*” and she therefore overall sought to embed an approach into the culture of Cavendish House of:

“Doing regular things in a very sensory way ... making the environment more sensory.”

Esther saw individuals as having varying levels of alertness and ability to concentrate and attend, affecting the level at which they could be expected to engage in activity. This would likely mean that engagement would require maximal support, take time to happen, be partial and very likely only achieved in short bursts. She encouraged the staff team to seize opportunities to adapt ordinary everyday personal care, domestic and leisure activities around the home to make them meaningful, arguing that their meaning to these individuals lay in their sensory aspects. This meant supporting activity with maximal attention to these, with the *process* being more important than the end result. Esther explained that

fundamental skills of attention and interpretation of sensory experiences needed to be built before developing more complex skills.

This focus on “sensory activity” can be seen throughout the three vignettes and is illustrated in the following two further examples:

Becky, unlike both Steve and Matt, loved life to be as noisy as possible, though she was very reluctant to hold anything in her hands for very long:

“You know with Becky it is not so much about getting the washing up done, it is about clanking things round in a bowl and throwing them or transferring them into another container and it making a lovely noise! ... Dina said she had tried it and Becky wasn’t interested, because she didn’t want to put her hands in the water and I said that is absolutely fine don’t worry about her not wanting to put her hands in the water, because you can still put things that make noises into there, you can hand her things out of the water that she can chuck into a bucket and it will make a lovely crash and you can still make it enjoyable and rewarding.” (Esther 30.8.13).

Steve always had a mid-morning hot drink and Esther developed this into an activity that was both longer and more sensorily stimulating for him and therefore something in which he could more authentically engage. This involved him being supported to explore the contents of a “discovery bag” which contained the items needed to make the drink (see the session plan for a similar activity for Matt in Vignette 2).

As previously mentioned, the staff team often complained of the loss of Cavendish House’s multi-sensory room, though Esther saw this as less of a problem than they did, as she felt that its existence may in the past have contributed to sensory activity only happening there, rather than being embedded more generally into the way the staff team worked. It was also potentially somewhere for people to be placed while staff did things elsewhere.

I feel that Esther made some progress in developing the team’s understanding of this kind of approach to supporting activity, leading to some increases in the

amount of meaningful engagement within the house. Even towards the end of her intervention, however, I noted some members of the team still not fully understanding what she meant when referring to engaging people at a sensory level. Support workers seemed to manage to incorporate this approach better when supporting with personal care (sensory baths and showers using different scented soaps, different textured flannels and sponges and so on), but found it harder to translate it to other sorts of activities and leisure activities in particular. This was notable when I spoke with support worker Olly:

“There can be rather an over-dependence on scented bath products and things like that which umm a lot of the guys here have very sensitive skin. Certainly we introduced one thing that was perhaps on Esther’s list for a sensory bath and the guy came up with a rash and had to go to the doctors. So we have to be careful of not putting too much reliance on scented products.” (Olly 2.8.13).

What I found surprising in this interview, was that Esther had previously reported a conversation with Olly in which he had described supporting Harold to go to church in a way that had suggested that he really understood the approach that she was trying to get the team to adopt:

“The way he described it was so sensory and such a lovely session. You know they sit outside in this sort of like a little sheltered area just outside the church when they first arrive and they light incense and a candle and then they listen for a bit. And then they go into the church and it feels lovely.” (Esther 30.8.13).

7.3.1.2 Reinterpreting independence, choice and personalisation

Some of the confusion about what Esther meant by “sensory activity” and consequent initial resistance from Sue and some support workers to her suggestions seemed to stem from an incomplete understanding and a somewhat overly-rigid interpretation of concepts of personalisation, choice and independence in the context of those with severe and profound intellectual disabilities. Some of these interpretations did not seem consistent with an aim of

promoting authentic engagement and the following are examples that Esther challenged:

- Promoting “independence” within Cavendish House had been translated into a focus on functional activity, such as enabling someone develop the skill of cleaning their own teeth (as referred to by Sue in Vignette 3). Esther on the other hand pointed out that Matt and Steve, for example, were not going to gain enhanced personal causation from being able to do this, or from being involved in preparing their own meals, as they would be unlikely to associate any steps they were involved in with the end result of clean teeth, or eating dinner. Focusing, however, more on the *process* than the result of preparing a meal, they could gain meaning from using meal preparation as an opportunity to explore the different tastes, textures, smells and sounds of ingredients, packets, utensils and kitchen appliances. Preparing the meal could be an opportunity to learn to express preferences and perhaps to effect some control over the environment, for example using switches.
- There seemed to be a “rule” in the house that if Harold, for example, fell asleep on his bed in the afternoon following personal care support to change a continence pad, he was not to be woken up as he had “made a choice” to go to sleep. Esther, challenged this assertion and questioned whether Harold had *really* made a choice. Might he not have become bored and fallen asleep? Would he really have understood the alternative activity he might be missing by falling asleep, an understanding she argued was necessary in order for that to be an informed choice? Knowing what we know about Harold, might we suppose that his preference might then be to be woken up?
- Futures placed an emphasis on individualised activity, an explicit rejection of overly-communal models of service provision which were more typical in the past for many people with severe and profound intellectual disabilities. Whilst applauding aims of individualisation and personalisation of support, Esther challenged whether this need

necessarily result in individuals now seemingly almost never doing activity with their peers and housemates?

- Everyone I spoke to (with the exception of Esther and manager Sue) bemoaned the loss of the house's multi-sensory room, which had been removed at the time of transition. This was described as a much-used resource, but being communal in nature (and shared by all who lived there), it was regarded as too institutional and 'health' focused and not something that would be expected in the 'ordinary' house that Cavendish now aspired to be.

Part of Esther's approach seemed therefore to be to promote a reinterpretation of independence, choice and personalisation and she highlighted how her recommendations not only fitted with these organisational aims of Futures, but were in fact the way that they could meaningfully be achieved for people with severe and profound intellectual disabilities.

"I was trying to trying to make them see how this work, how what I am doing sits alongside their philosophy" (Esther 21.7.13).

Authentic engagement seems to require going beyond simplistic literal understandings of (and merely paying lip service to) independence, choice and personalisation. It requires a more nuanced, real understanding of what they mean for people with severe and profound intellectual disabilities and how these aims can be achieved. Despite her initial resistance, this was something that Sue came to understand and excitedly embrace, following lengthy discussion with Esther (illustrated in Vignette 3).

7.3.1.3 Engagement is observable (if you know what to look for)

Some members of the staff team had expressed a particular difficulty engaging Matt, Steve and Harold in activity. This was due to these individuals' extremely limited communicative repertoires and the consequent difficulty knowing whether or not they were engaged in and/ or liked a particular activity. Esther considered that this impacted on motivation to persist in attempts to support engagement.

Esther's strong belief that, through interpreting behaviour as communication, there *were* observable signs when all three were meaningfully engaged, is illustrated in Vignette 2. She argued that their behaviour could potentially communicate something about their mood, feelings, response to the activity and wishes. These signs of engagement were observable by those who knew them well enough and if looked for deliberately. A need to demonstrate this was one of the main reasons for her decision to produce a DVD with explanatory subtitles for the service, showing examples of each person engaged in activity. This highlighted, for example, the very subtle body language indicating when Matt was alert and attending to something (see Vignette 1, Scene 9 and Vignette 2).

7.3.1.4 Authentic engagement comes out of relationships and communication

Esther described both Steve and Matt as needing engagement in occupations "*to be brought to them.*" My interpretation of this was that they were very unlikely to engage in anything (other than perhaps self-stimulatory activity, including self-injurious behaviour) unless others made opportunities available and gave effective encouragement. Authentic engagement in occupation for people with profound intellectual disabilities therefore seems to come out of a creative and responsive relationship between the individual and the person supporting engagement. There was a genuineness and natural warmth for example in the way support workers Jean and Paula supported Matt and Steve and the nature of the relationships both Esther and Jean had with Matt can be seen in Vignette 2. Both were creative in the way they supported him, responsive to him as an individual and able to take initiative rather than only working in prescribed ways.

I noted Esther's deliberate positioning of herself, referring to her tendency to "*climb over things*" to "*get right in there*" and place herself where she was most likely to develop relationship with individuals. With Harold for example, she was always very close to him, to his left and at a low level. This ensured that he could see her and what she was doing through his left eye, despite his narrowed field of vision from a closed right eye and flexed neck. She was also then in a position to see any responses that he might make.

Esther's interpretation of engagement was broad and she saw it, for example, as possible for someone authentically to be engaged in an occupation without necessarily physically participating in it. Her approach was often to do activity adjacent to someone, ensuring that there was sufficient going on around them from which they might gain stimulation and thereby opportunity to try things. With Harold for example, for whom any physical movement had become effortful since his stroke, she proposed having lively activity going on around him that might motivate him to join in. Playing a game of skittles, she emphasised the importance for him of creating a sufficiently exciting atmosphere with lots of lively encouragement ("*the banter*"). I saw this eventually succeeding in maximising his volition sufficiently for him to make the huge effort required to roll the ball off his lap. Even prior to this, however, it was apparent (if careful attention was paid to the movements of his left eye) that Harold was watching what was going on around him and arguably very much engaged in the activity – and, as Sarah put it "*part of the gang*" – long before he physically participated.

By way of contrast, Matt's auditory defensiveness meant that gaining his attention through liveliness and banter would be ineffective and in fact distressing for him. Esther therefore used alternative approaches to build relationship with him and was adept for example at using intensive interaction (Coia and Handley 2008, Nind 2009; see 8.2.2) to "*bring him out of his own world*" of self-stimulation, meaningfully engaging him in a conversation of sorts, both as an end in itself, and as a precursor to supporting engagement in other activity. In the interaction described in Vignette 2, Matt's pauses, thoughtful expression and sudden beaming smile are all suggestive of her having caught his attention and built a trusting relationship. Having his attention, it was then possible to support him to engage in a subsequent activity which involved him experiencing the smells and tastes of a number of different varieties of tea.

The approach assumes that authentic engagement is most likely to result from relationships in which things are done *with* people rather than *to* them, and that value doing activity together. Although many of the activities Esther encouraged involved one-to-one sessions between an individual and their support worker, she also emphasised the importance of individuals doing activity with their peers. This

was particularly important with someone like Harold whose liking of social situations meant that group activities, such as the skittles game involving lively turn taking, were most likely to catch his attention.

7.3.2 An intervention underpinned by theory

Esther often explicitly referred to theory from, for example occupational science, to underpin her work in Cavendish House and support the recommendations that she made (and in Chapter 8, I will discuss additional theory to which she did not explicitly refer, but on which I conclude that she was also drawing). Much of this theory she referred to only in interviews with me, but some of it she made a point of sharing with the Cavendish team and in particular with manager Sue, who became very interested in it. Used in this way, theory seemed very much to facilitate an understanding of occupational therapy aims and the needs of those the team were supporting.

In her recognition of Matt, Steve, Becky, Harold and Jane's paucity of authentic engagement in occupation, in emphasising the importance of them being supported to increase such engagement and in her intervention's particular focus on enabling more of a *balance* between self-care, productivity and leisure occupations, Esther was both explicitly and implicitly drawing on occupational science theory, as previously discussed in section 2.3.5 (though see my critique of her use of this theory in 8.3.1.1). With her previous work with Matt and her experience elsewhere in mind, she referred to a conviction that having insufficient things to do had negative impacts on physical and mental health, distress and agitation and on levels of self-injurious and sensory self-regulating behaviour.

Esther's work explicitly aimed to address this lack of occupation and occupational imbalance and reference to this and other occupational therapy theory can be seen in the wording of her reports, such as the following excerpt from Becky's:

"Achieving a balance of meaningful activities: We all need a mixture of active and passive tasks during the day. On an average day we experience things that are relaxing, exciting, things that give us an opportunity to interact with others and develop our skills. Regardless of what level of engagement people are functioning at, it is important that we offer, and plan, opportunities that

allow for a balance between stimulation and relaxation. Rodges and Ziviani (2006) explain that stimulation helps promote opportunities for learning, for testing one's own abilities and exploring the environment, whilst relaxation is an important counter to allow people to recover from the challenges of engaging.

Becky should be supported to engage in a range of the following activities"
(Becky's Occupational Therapy Report by Esther 28.6.13)

The most striking use of theory within Esther's work, however – and one from which the staff team seemed to gain a lot of understanding – seems to me to be her use of the metaphor of a bridge to illustrate to the staff team the varying levels of ability of those they were supporting and to explain her slightly different proposals for each of them. To do this, she drew on two theories:

- **Pool activity levels** (Pool 2012) (previously referred to in 2.3.2): illustrating the different reflex, sensory, exploratory and planned levels of ability to engage in occupation that those with a cognitive impairment may have and the varying support needs at these different levels.
- **Levels of intentional/ pre-intentional communication** (Coupe O'Kane and Goldbart 1998): reflecting the fact that those with profound intellectual disabilities may developmentally only be able to communicate at one of three pre-intentional levels (reflex, reactive and proactive) and the ways communication partners assign significance (i.e. that communication and meaning was intended) to individuals' responses to stimuli.

The way that Esther drew on this theory to illustrate the abilities of those living at Cavendish House is illustrated in Vignette 1, Scene 2 and the excerpt from Matt's report in Vignette 2. She used it to explain her plans in meetings with Sue and Norma (see Vignette 3) and with groups of support workers. These discussions were turning points in the intervention in terms of understanding of and enthusiasm for what she was hoping to achieve.

Many of Esther's strategies for implementation of her plans drew on theory from person-centred active support (see 3.4.1). She referred also to how theory from sensory integration had informed her previous assessment and intervention with Matt (which involved understanding his ability to cope with sensory input and the over sensitivity of his system) but distinguished this from her current "sensory activity" approach, which she explained as drawing on a developmental understanding of how people gain meaning from activities.

7.3.3 Getting to know Matt, Steve, Jane, Becky and Harold really well

Esther emphasised how she wanted to get to know each of the individuals living at Cavendish House well and that gaining a real understanding of how to support each of them to engage meaningfully in occupation was essential to be able to make informed recommendations:

"You can't just come in and say "we are going to do x" – you need to take the time to get to know people." (Esther 30.7.13)

Prior to my first visit to Cavendish House, Esther had previously worked with Harold and Matt and had also met Jane, Steve and Becky in passing. I therefore did not witness how she might make an initial approach to someone she was meeting for the first time. The considerable effort that she put into getting to know each of them well over multiple visits particularly between January and April 2013, but also throughout the year-long period of the case, was however apparent from my observations, our interviews and her clinical notes. There were similarities in the ways that she went about getting to know each person, but she individualised her approach each time. She described wanting generally to understand skills, strengths, needs and interests, but notably focused in particular on understanding their relative abilities to engage in activity and their auditory, olfactory, proprioceptive, tactile, vestibular, visual and gustatory preferences.

Much assessment was through informal observation and Esther was particularly keen to observe the staff team's day to day work interacting with and supporting individuals, for example during personal care, at meal times, when out in the local community and in particular when supporting people to engage in activity around their home. The latter, however, proved particularly difficult to observe,

ostensibly due, for example, to staff shortages and miscommunications about timings. It seemed to me that this difficulty also however reflected the limited degree to which this type of support was at that time being achieved in the house, and perhaps the confidence levels of some staff in supporting such engagement (and in being observed doing this).

Much information gathering came from speaking to members of staff working on the days Esther was there and she made a particular point of meeting with the “link” support workers (Jean, for example, being link worker for Jane, with a particular responsibility for co-ordinating how the team supported her). She also met on a number of occasions with assistant manager Norma and manager Sue, and had discussions with her own colleagues in the community team, some of whom had known those living at Cavendish for many years.

Reflective perhaps of the paucity of occupational therapy assessment tools relevant to those with severe and profound intellectual disabilities (see 3.3.5) much of Esther’s assessment was informal, but she did use two standardised assessments. The Residential Environment Impact Survey (Fisher et al. 2008) informed her understanding of the impact of the environment at Cavendish House on the occupations of those living there and the Pool Activity Levels (Pool 2012) were incorporated into the sensory preference assessment forms she had devised (see 7.3.3). Esther’s original intention was for support workers to complete these forms, on the basis that they knew the people they supported and were in the best position to provide this information, but also as part of her wish demonstrably to value their knowledge and opinions. By April, however, with these forms only partially completed by the team, Esther concluded that co-operation and knowledge levels were insufficient to gain the necessary information through this route. She therefore decided (see Vignette 1, Scene 3) that she and occupational therapy assistant Sarah would gather the remaining information to complete the forms, discussing the information collected and conclusions reached in supervision afterwards.

Trial and error was apparent in this work getting to know each person and particularly noticeable in the assessment of individuals’ sensory preferences.

Sometimes Esther and Sarah would try a particular stimulus in a seemingly spontaneous and informal way and at other times this might be planned in advance, for example by visiting with one of a number of “assessment boxes” containing a variety of tactile, visual, auditory or other sensory items, used gradually to work out individuals’ preferences and dislikes. Within each individual’s tolerance levels, they got close to them, making sure they were positioned so eyes and hands could be seen. They interpreted behaviour in response to various stimuli as communication, and indicative of, for example mood, interest, disinterest, preference, tolerance or intolerance. Particularly important were examples of the ways in which each individual indicated preference and showed they were alert to and engaged in what was going on (see 7.3.1.3).

Some of this assessment was carried out by simply doing something in the vicinity of someone in order to see whether there was a glimmer of interest or whether they might be persuaded to join in perhaps in some small way (for example the skittles game with Harold).

7.3.4 A creative and flexible intervention encouraging creativity in others

In the context of an at times arguably somewhat lethargic culture, Esther’s occupational therapy input was itself creative and designed to facilitate creativity amongst those working in Cavendish House. She wanted the team to understand how important creativity was to their support work and how they could “*take educated guesses*”, be experimental and creative and try new things to see how individuals responded. Helping them to be more aware of the subtle signs indicative of engagement facilitated taking this “trial and error” approach to supporting engagement and was intended to motivate the team to continue working in this way.

Gaining a new perspective and new ideas from someone outside the team appears to have been valued by some:

Personally, I think it's great that ... little bit extra of an outsider coming in, you miss out on certain points and seeing Esther with them and doing stuff it's like "oh, yeah, perhaps" and it does sort of knock on effect to the staff members who think "oh I'll try that" Obviously we know the guys, we automatically get into our routine of "what's next, what's next, what's next" ... you just automatically get on with it. Whereas ... getting the ideas from somebody else as well, using the different tools that she uses as well is really good. The creativity, I think that is fantastic and I like to see the enjoyment that comes back from the people we support as well. (Jean 27.6.13).

Sue's appreciation of this creativity is illustrated in Vignette 3 as is her recognition of Esther's notable willingness to shift where necessary in relation to obstacles, or events not turning out the way that had been expected. An example that I feel is typical of a flexible approach seemingly lacking in stubbornness and defensiveness and evolving in response to events, is Esther's willingness to compromise on a key aspect of the means of delivering her plan, the "sensory board" on which details of activities in which staff were seeking to engage the residents were to be displayed for inspiration. Although frustrated when Sue "blocked" this aspect of the plan as being too "institutional", Esther very quickly came up with an alternative, more acceptable solution. She clarified how, although not prepared to compromise on the overall goal of embedding sensory activity in the house, she would be as flexible as necessary with the means of achieving this.

Esther's own persistent, problem-solving, flexible, compromising and above all optimistic approach to working with the staff team mirrored the creative and responsive way in which she wanted the staff team to work with those who lived in the house. This can be seen throughout the vignettes and is explored further in 7.3.5.

7.3.4.1 'Providing them with resources' and ideas

Although the idea of the sensory board was abandoned, Esther created a number of other resources to support the staff team carrying out activity with Matt, Steve, Jane, Harold and Becky in the ways she recommended and which she hoped could

be inspirational “*constant daily reminders*”. Her creativity is also reflected in the time she spent ensuring these resources were of good quality. These included:

- Detailed guidelines, or “session plans” for specific personal care, leisure and domestic activities, some relaxing and others stimulating (two of Matt’s are included in Vignette 2).
- More succinct “prompt cards” on key rings that the worker supporting the relevant person could carry around during their shift.
- A number of “discovery bags” containing items needed to complete specific activities (for example Steve’s mid-morning hot drink).
- Recording sheets for support workers to complete, allowing her to monitor how and how often the activity plans were being followed.
- A DVD illustrating how she hoped they might support engagement in occupation.

These resources were “*building blocks*” for the staff team to use and then to develop further themselves using their own ideas for activities.

7.3.5 Supporting the staff “in the same way as our service users”

Esther herself described working with the staff team in a similar way to how she might work with people with intellectual disabilities and this comment highlighted for me the parallels evident in the case between her work as an occupational therapist with those living and with those working in the house. In particular, she made efforts to be more collaborative than directive, in order to support the staff team to feel that they were in control and ‘owned’ the intervention, rather than having it imposed upon them. This section explores these ways in which she supported the staff.

7.3.5.1 Building unthreatening relationships

The relationships Esther had with individual staff members at Cavendish House generally seemed to support the progress of her intervention. From recent work with Harold, she and Sarah were both familiar to many support workers and from my initial visit, I noted Esther’s friendly greetings and efforts to maintain and build relationships with them. Following a visit on 21.6.13, I noted how their behaviour

suggested that regular visits and attendance at some handover meetings had led to her presence in the house seemingly to be accepted and unthreatening to those working on that day. Recognising, I concluded, that different communication styles might be more appropriate with different support workers, she adjusted her approach, for example being more formal with Olly, than she was with Doug.

Aware that the team did not fully understand her intervention, Esther seemed to take the approach of not being overly self-consciousness or worried about appearing foolish – “*I do just sort of bound in*” she said. She demonstrated that supporting those with whom the staff team were working did not necessarily need to be serious and that engaging Harold, for example, in activity might require a fun and excitable approach to create sufficient “*banter*” to stimulate him. Sarah was particularly successful at encouraging people to join in her skittles activity with Harold and I discovered that she and Esther were known within the staff team (affectionately, I think, though it is difficult to be certain) as “*the mad ladies*”.

7.3.5.2 “Training with a small t”

Part of the role that Esther took was to educate Norma, Sue and the staff team about reasons for supporting engagement in the ways she advocated. As illustrated by her words in Vignette 1, she made efforts to make this educative role informal, referring to this as “*educating gently*” and “*training with a small t*”. She produced extensive written materials to explain her recommendations (for example reports and session plans), but rather than relying solely on these, also took time verbally to explain her proposals in detail. She did this both with individual staff members, but also in informal workshops with groups of support workers and in a meeting with Sue and Norma. Her cautious language suggested an attempt not to highlight gaps in individuals’ knowledge too explicitly (see Vignette 1, Scene 4).

Although in the early afternoon there was a brief handover meeting between early and late shifts, there did not seem to be a regular routine of team meetings within the house, which meant that Esther’s eventual group discussions with support workers happened much later than intended. At the time, she felt this was a disadvantage, but later on conceded that it did at least mean that she could speak

about Matt, Harold, Jane, Becky and Steve from a position of greater knowledge having had longer to get to know them.

In order for the team to see the way Esther hoped they might support engagement, she and Sarah also modelled how following the activity session plans might look. With a large staff team, it proved difficult to do this for everyone, though the plan was for Sarah to visit three times per week in July and August, modelling supporting activity according to the session plans in the first month and gradually letting staff take the lead in this whilst giving feedback in the second month.

7.3.5.3 A collaboration

Esther emphasised how the staff team were key to the sustainability of her intervention. As illustrated in Vignette 1, Scene 1, she was keen not to be an outside person telling them what to do, but rather to take a more collaborative approach. She made efforts to get the staff team on her side and to give them some ownership over the intervention, which she felt would make it more likely to succeed. This collaborative approach had a number of distinctive characteristics (see also Esther's own description of the intervention in Vignette 1):

- The scale of this ambitious project aimed to create some excitement within the staff team and therefore to generate some momentum. Although remaining clear in her mind that her aims were realistic and attainable, Esther took care to empathise with the challenges of the support worker role and to ensure that they knew that she appreciated the efforts they made:

"I think this is a way of saying to the staff 'I value what you do with these people.'" (Esther 27.6.13).

- This was evident in the amount of time she put into the intervention, the care she took to create quality resources and her efforts to give regular feedback on progress. Analysing completed recording sheets and comparing the number of self-care, domestic and leisure activities supported each day in her recommended way against individuals' goals, she quantified progress in the form of percentages of expected outcome.

This seemed to help some of the team (in particular, Sue) to see how well they were supporting engagement and appeared to contribute to motivating some team members.

- Recognising some of the previously described issues with dynamics within the team, Esther hoped that her intervention might have the effect of pulling the staff team together behind commonly agreed objectives.
- Mindful of the history of leadership within the house and criticisms from some support workers about being told what to do by qualified staff, Esther tried to avoid being perceived as imposing a set of recommendations. She described making suggestions rather than telling the team what to do and, in staff meetings and discussions with individual workers, she checked whether there was agreement with what she had concluded from her assessments, for example regarding individuals' sensory preferences. Our discussion in one interview highlighted for me her awareness of the constant risk of being defensive when faced with disagreement and how this could turn into a "battle", but she demonstrated that she was willing to make adjustments in response to feedback from support workers (for example when receiving feedback that a sensory bath product she was going to recommend for one person was unsuitable due to their sensitive skin). Concerned that support workers might disengage from her if she was overly critical, she was nonetheless able (gently and cautiously, though assertively) to challenge:

Esther: That's why I braved it a little bit to say "but I have come in and your staff haven't been [doing what I suggested]"

DH: You said it in a nice tentative way, with a little warning flag "I am going to say something controversial here" and actually [Sue] agreed with you

JB: She did! (laughs)" (Esther interview 10.4.13)

- Mirroring the way she saw each person living in the house as an individual, Esther also highlighted the differences amongst the staff team in terms of strengths and motivators. Some support workers like Jean and Robert seemed to particularly take to the style of support that she

was recommending and Esther saw them as her allies, who could champion the way of working and take on a key role in passing it on to others. Jean was more confident, in her role as Jane's link worker, in leading this, whereas less-confident Robert took a less overt leadership role, but was still able to model this way of working to the rest of the team merely by doing it.

- Esther's plan was gradually to step back and to let the staff team take more of a lead with the intervention and to build on her ideas (see Vignettes 1 and 3).

7.3.5.4 Getting managers 'on board'

Esther already knew assistant manager Norma from previous work with Matt some years earlier and had met manager Sue briefly a couple of times whilst working recently with Harold. Emphasising the importance of leadership if she was going to be successful in embedding a new way of working into the culture in the house, she felt that she needed Sue and Norma to embrace what she was trying to do, so that they could "*lead from the top*" alongside her most motivated allies amongst the support workers (see Vignette 3).

Esther met with Sue and Norma on several occasions, on two of which I was also present. Feeling that without them in agreement, there was little chance of changing practice in the house, she took time to explain in detail what she was trying to do, including running through and explaining the reports and recommendations for each individual in a meeting with them both that lasted three hours. In a previous meeting, when it was apparent that she and Sue were thinking in very different ways, she spoke of previous experience of hostile managers becoming close allies once she had put time into explaining her plans fully. Interestingly, this was to prove prophetic, as that three-hour meeting with Sue was a turning point in the intervention. Sue came to really understand what Esther was proposing and seemingly to realise how this fitted in with her own goals and those of Futures for the people who lived at Cavendish House.



Those then are my findings: a story of the case told using two overarching themes of a cultural setting impacting on support to engage in occupation; and an occupational therapy intervention seeking to create and sustain cultural change in that setting. In the next chapter, I discuss the implications of these findings.

Chapter 8. DISCUSSION

Building on the rich description of the case provided in Chapter 7, there are many aspects that I could go on to discuss in this chapter. I have been mindful, however, of the need to contain discussion to matters particularly pertinent to my research question: “*in what ways does an occupational therapist support people with profound intellectual and multiple disabilities to engage in occupations in ways they find meaningful at home?*” I became fascinated, for example, in the setting of the case and the organisational and support culture in Cavendish House, but contained discussion of this to where it directly impacted on support for engagement in occupation and on Esther’s occupational therapy intervention.

Developing the two overarching themes of shifting cultures and a characteristic occupational therapy intervention that I have used to tell the story of the case, I explore in this chapter a conceptual framework of four ideas, or concepts. Key to the above research question, they are summarised in Table 8.1.

1	Thinking in stories: using narrative reasoning (8.1)	Telling stories
		Creating stories
2	A specific understanding of what authentic engagement in occupation is for those with profound intellectual and multiple disabilities (8.2)	Engagement is observable
		Close relationships: engagement in co-occupations
		Engaging in occupation ‘at a sensory level’
3	Addressing occupational injustices (8.3)	Low levels of meaningful engagement in occupation: occupational injustice for people with profound intellectual disabilities
		Risk of burnout and other occupational injustices for those supporting people with profound intellectual disabilities
4	Empowering support workers to sustain a different way of working (8.4)	Facilitating implementation fidelity
		Working with support workers ‘like we work with our service users’

Table 8.1 Conceptual framework to be discussed

Beginning with '*Narrative reasoning: thinking in stories*', I discuss the ways that the case evolved as Esther reasoned through telling and creating stories about the lives of those living at Cavendish House. Secondly, I consider how the case has developed our understanding of what '*authentic engagement in occupation*' is for those with profound intellectual disabilities. The final two concepts concern two particular aspects of occupational therapy in the case: how this sought to *address occupational injustices* for those living – and working – in Cavendish House; and how this sought to *empower the staff team to sustain a different way of working*.

8.1 Thinking in stories: using narrative reasoning

Case study methodology has enabled me to gain a deep understanding of Esther's work in Cavendish House. Observing and discussing her practice at length in many interviews was a particularly effective way of gaining some insight into her clinical reasoning. This was the process by which she made practice decisions in the case (Higgs and Jones 2008), directed, performed and reflected on her work (Schell 2009) and achieved the goal of seeing disability through the eyes of those experiencing it, thereby understanding its meaning for them (Chapparo and Ranka 2008). I had experienced this knowing in action, or tacit knowledge (Schön 1991) as somewhat elusive in my previous research with occupational therapists, conducted using focus groups (Lillywhite and Haines 2010) and hoped that case study methodology and in particular use of participant observation alongside interviews, might make it more visible.

Clinical reasoning has been conceptualised in different ways, with Schell and Cervero (1993) describing components of scientific, narrative and pragmatic reasoning and others (for example Mitchell and Unsworth 2004) developing Mattingly and Fleming's depiction of procedural, interactive, conditional, and narrative reasoning from their ethnographic study of occupational therapists (1994). Drawing on these conceptualisations, Carrier et al. (2010) were able to highlight six dimensions within the tacit knowledge of community occupational therapists' clinical reasoning. Before discussing in detail how Esther's use of narrative reasoning was especially visible in the case, I will briefly summarise my understanding of these six interacting dimensions as follows:

- *Procedural reasoning* involves problem solving through reasoning around diagnosis, by recognition of patterns and testing of hypotheses (also referred to as scientific reasoning (Schell and Cervero 1993), or paradigmatic reasoning (Crabtree 1998)). Esther, for example, drew on her existing theoretical and experiential knowledge of intellectual disabilities and developmental theory to provide an idea of the kinds of activities *potentially* relevant for those living in the house.
- This is contrasted with understanding an individual's story using *narrative reasoning*, a "deeply phenomenological mode of thinking" (Unsworth 2005, p.32). Unlike in procedural reasoning, goals are set and treatment is individualised in response to what really matters to an individual, turning them into an actor as opposed to a "mere 'body' acted upon by others" (Mattingly 1998, p.137). Narrative reasoning can be seen in a broad sense of understanding the individual's story or their occupational history (Neistadt 1998), the way, for example, Schell and Cervero (1993), Brooks (2006), and Caeiro et al. (2014) seem to understand it. This broad sense seems, however, to encompass three more specific dimensions of clinical reasoning identified by Mattingly and Fleming (1994), namely:
 - *Interactive reasoning* – the interpersonal process (Crabtree 1998) of developing a shared understanding of someone as a person and individualising their treatment (Fleming 1991).
 - *Conditional reasoning*, the most complex form of reasoning (Fleming 1991), involving creating meaningful wholes (Unsworth 2004), such as when Esther considered and made sense of everything she found out about Matt, Steve, Becky, Harold and Jane.
 - *Narrative reasoning* in the more specific sense of thinking in stories, the foundation for the above interactive and conditional modes of reasoning (Fleming 1991). This is the way in which I understand and use the term in this discussion.
- *Pragmatic reasoning*, the process of reasoning in context (Schell and Cervero 1993) that I explore further in 8.4.1.

- *Ethical reasoning* – the restrictions placed on reasoning in the real world involve considering ethical questions (Crabtree 1998). Ethical issues of occupational justice considered by Esther, are explored further in 8.3.1 and 8.3.2.

Mattingly's particular understanding of narrative reasoning (1991, 1998) was, as described below, particularly visible in the way Esther worked. The term was coined by Bruner (1990), who described the fundamental place of narrative in living our lives. He contrasted thinking in stories to paradigmatic thinking through propositional argument (procedural reasoning in the framework I have just presented), whereby Matt or Steve might be seen as instances of a general type of "person with profound intellectual disabilities". Narrative reasoning is less concerned with diagnoses and more with particular experiences of living with those diagnoses. Narratives can be drawn on to better understand what is important to people (Finlay 2004) and the story that they are living (Fleming and Mattingly 2008) and thus to personalise their occupational therapy. An aspect of the theory of narrative reasoning is the concept of 'emplotment'. Drawing on the ideas of Ricoeur et al. (1990), Mattingly described this as the process of "rendering and ordering of a succession of events ... into parts belonging to a larger narrative whole" (1991, p.1002).

I will now use this theory to explore how, through telling and in particular *creating* stories about Matt, Steve, Jane, Harold and Becky, Esther built emplotted narratives in the form of a prospective treatment story that guided her intervention. This, I feel, played an important part in carrying forward her work with them. It is an example of the complex clinical reasoning in which occupational therapists are suggested by the findings of my literature review to engage.

8.1.1 Reasoning through telling stories

Mattingly (1998) noted that the occupational therapists she was observing and interviewing reasoned narratively not just by eliciting stories of the people they were working with, but by thinking and reasoning through literally telling stories of their clinical experiences to themselves or others. This was apparent within the

case when I observed Esther in discussion with Sarah, with other colleagues and with her manager at the community team offices. These were informal conversations, in which she updated her colleagues on progress at Cavendish House, particularly notable at times when she reported how she was struggling to make progress and was trying to make sense of seemingly anomalous events. Mattingly suggests (1998) that narrative is most needed to guide intervention where the therapist is confused about the motives behind a client's actions, or more pertinently in this case about the motives behind the actions of those working in and managing Cavendish House.

Where Esther's narrative reasoning through telling stories was particularly striking, however, was in her interviews with me. These interviews provided many opportunities for her to talk to me about her work in Cavendish House, and to tell stories – to me and in many ways also to herself – about this work. The excerpts from our interviews in Vignette 3 and the first two additional excerpts in Appendix 16 are illustrative of her telling stories in this way.

An especially salient aspect of the case's narrative and one that is visible in the above quotations, was the social domain and temporal context of Cavendish House, with its specific history, including the transition from the NHS to Futures. Through foregrounding these aspects as she constructed and told stories about her work, Esther was able to critique and understand the cultural context. This facilitated exploration of the motives behind puzzling actions, such as when Olly and Sue exhibited resistance to working in a different way, potentially making their resistance more reasonable or at least comprehensible. Mattingly (1998) explains how this is an important part of how therapists reason about the kind of story that they want to bring about. Telling stories therefore allowed Esther to work out what kind of story was desirable – or even possible – and how she would need to act in order to bring this about.

Esther herself acknowledged a number of times that her ideas developed through talking at length in this way with me about the unfolding story of her intervention. She highlighted how this facilitated reflection, likening it to extensive clinical supervision (and arguably thereby supporting the importance of such supervision

for occupational therapists and other health professionals). Mattingly (1998) highlights how when reasoning through telling stories, the teller invites contributions from others, who may ask questions and offer stories of their own. In a similar manner, discussions developed when Esther told stories to myself and to her colleagues. The original story thus develops and becomes a co-construction in collaboration with those to whom it is told. The ways that participating in this research altered and perhaps even enhanced Esther's practice are explored further in the context of social constructionism in 8.6.4.

8.1.2 Reasoning through creating stories

Telling stories is thus the first way in which narrative can be said to have directed action in the case. Mattingly (1991, 1998) also describes a second and more subtle form of narrative reasoning, which involves *creation* of stories. This I also saw in Esther's consideration of Matt, Steve, Jane, Becky and Harold's lives and her imagining of where they could be in the future. Mattingly's participants (1991) described picturing future images of who their patients could be. Esther's words (see examples in all three vignettes and additional interview excerpts 3-7 in Appendix 16) suggest that she had very clear images in mind of what life could be like, vivid pictures of potential futures for the five of them and how they might be supported.

Esther's images give a sense of an ending that could be strived for – a future where sensory activity is embedded into everyday life in the house. They formed a “prospective treatment story” (Mattingly 1991, p.1001), an optimistic forward-thinking narrative, which drove the intervention in the form of an “unfolding story” (Mattingly 1998, p.64). Esther's thinking became organised around this story, which was gradually constructed throughout the case and which she overtly described as ambitious. Her work can be seen as oriented backwards from her imagined ending, with narrative reasoning used continuously to judge how to act and how to direct others' actions in order to further the plot and reach that ending (Mattingly 1998). This judgement was particularly necessary when Esther realised that the images others held of the future for those living in the house seemed to have been different to and in some ways inconsistent with her imagined ending.

Although familiar with Matt and Harold from previous work, in the early stages of the case Esther had less direct knowledge of Becky, Jane and Steve. Mattingly (1991) and Crabtree (1998) describe how prospective treatment stories may start out relatively stereotypical in nature, drawing on and guided by procedural reasoning and prior experience. The plot of a narrative is inevitably influenced by such pre-understandings (Chapparo and Ranka 2008). Prospective treatment stories evolve, however, and become more fine-tuned to individuals with future images more like the actual people as intimate knowledge of them develops. This can be seen in the way that Esther constructed personalised stories for each person, by spending a considerable amount of time getting to know them individually and creating activity session plans for each of them reflecting their distinctive sensory preferences. Kielhofner (2008) describes how an individual's occupational narrative is shaped by the events and circumstances of their life, the culture of their home and wider society and the extent to which they participate in occupations that provoke a depth of passion or feeling. Through focusing on Matt, Steve, Becky, Jane and Harold authentically engaging in occupation, Esther sought to enable their occupational narratives to take shape.

Naturally, there was some distance to travel between the start of the case and the ending Esther imagined might be achieved. Mattingly (1998) describes this gap between where people are and where one hopes they might be as providing impetus for moving forwards. As with all good stories (Mattingly 2007) the plot of this case contains: strong desire for change and investment in bringing this about; conflict, obstacles and suspense about whether the uncertain ending will be reached; and in the end, a (partial) transformation. I have described how throughout the case Esther needed to work flexibly, to improvise and be creative and prepared to change strategies to ensure the co-operation of Sue, Norma and the support workers. Elements of the case – extensive assessments of each individual; breakthrough moments such as Sue's sudden understanding and support for the project; disappointments such as realising that activity session plans had not been shared with the wider staff team in the way that had been hoped – can be seen as episodes in a larger unfolding drama that became meaningful as they were structured by Esther into a coherent plot. They can be

seen as her efforts to preserve the plot line and to maintain the possibility of reaching the hopeful imagined ending.

More than this, however, I think Esther was also trying to create a prospective story that others also could share, with a similarly meaningful vision of the future that they too could imagine. This shared story included how Matt and Steve might authentically engage in occupation; why lively banter was necessary to gain Harold's attention; the small ways in which independence and choice could be possible; and a general portrayal of people who were more than just patients with complex health needs and who could be enabled to be human actors, capable of desire and motive and with occupational narratives with agentic rather than victimic plots (Kelly and McFarlane 2007). The extensive illustration in this thesis of narrative reasoning through creating this prospective treatment story is relatively novel in both the occupational therapy and intellectual disabilities literature. This focus on narrative elements of the case evolved as the case progressed and was not something I was particularly expecting. Although I was open to the possibility of including narrative coding within the overall data analysis strategy described in 5.5, I did not in the end do this. I wonder now what further insight may have been gained from a deliberate narrative analysis of the case and have in mind the possibility of returning to the data to do this in the future.

8.2 A specific understanding of authentic engagement in occupation

The significance or importance of an activity or occupation to someone – that is its meaning – affects motivation to engage in it (Creek 2003). When supporting someone with profound intellectual disabilities, understanding what is meaningful to them enables us to make activity sufficiently motivating for engagement (Mencap 2011). In this section, I explore the ways that the case develops our understanding of what occupation (or meaningful activity) means to people with profound intellectual disabilities and therefore how they might engage in occupation in an authentic, as opposed to tokenistic, manner.

The findings suggest that without an understanding of what makes activity meaningful and the level of engagement people are likely to be able to achieve, it is not possible to support authentic engagement in occupation. An absence of this understanding may be at the root of low levels of engagement in activity. A unique contribution of this thesis is to highlight and illustrate the following specific understanding of occupational engagement by someone with profound intellectual disabilities, one that others seem not necessarily to hold. I relate this understanding to the literature, both from within occupational therapy and from active support.

8.2.1 Engagement is observable

The challenge, when attempting to understand what occupations mean to people whose severe cognitive impairment results in limited ability to self-report, is that this has to be interpreted in other ways. Esther's narrative for those living at Cavendish House assumed that it was possible to gain some understanding of what was meaningful to them from observing and interpreting their behaviour, which supports the conclusion of my literature review that indicators of engagement are observable. Supported by theory of volition (Kielhofner 2008), occupational therapists commonly gain understanding of people's motivation for occupation (their interests, values and personal causation) from observation. This is either carried out informally, or formally using observational tools such as the Volitional Questionnaire (de las Heras et al. 2007). Observation is commonly used in studies researching the degree to which people with profound intellectual disabilities are engaged in activity (Felce and Emerson 2004). An individual's degree of responsiveness, curiosity, investigation, discovery, anticipation, persistence and initiation are suggested to be indicators of engagement within the Department for Education Specialist Schools and Academies Trust (2011) Engagement Profile and Scale (see Figure 2.2. in 2.2.4).

A particularly important finding is the case's strong suggestion that engagement does not necessarily require physically doing something, implying, for example, that definitions of engagement such as "actively manipulating an item (activity) presented" (Klatt et al. 2000, p.496) are therefore far too narrow. Mansell's suggested definition (2002) as the extent to which an individual is involved in

directing or carrying out their activities of daily living, acknowledges the possibility of engagement in an activity in which one is physically unable to participate. Certainly, when efforts were made to include him, Harold seemed to enjoy and to feel part of activity going on around him. Indications intimating that Matt was engaged, such as the slight changes in facial expression and vocalisations illustrated in Vignette 2, were subtle and easily missed.

This finding emphasises that engaging can potentially involve cognitive actions alone and if, in the light of this, one re-examines occupational therapy definitions of engagement previously reviewed in 2.2.1, it is striking that these make no reference to physical actions. Mahoney and Roberts (2009) concluded that engagement is demonstrated not merely by doing activity (or initiating action), but by positive affect and focused attention and Wood et al. (2009) judged the level of interest and engagement of people with Alzheimer's Disease from the degree of focused attention to people, things and events they exhibited in response to immediately available activities. The fluctuating levels of alertness of Matt and Harold in particular were very much evident from their behaviours, their responses to those attempting to support them to engage in activity and how hard Esther, Sarah and the support workers had to work to achieve often very short bursts of engagement.

Naturally, there is subjectivity in interpreting potential signs of engagement, as Ware (2004) cautions. Differences of opinion regarding the meaning of behaviours can be seen in the case, for example in Vignette 3, where Esther clarifies how her understanding of Steve's apparent love of monkey toys is different to that of some of the staff team. The importance of knowing the person whose behaviours are being interpreted well, and underpinning such interpretations with theory seems important to minimise subjectivity and to make such interpretations meaningful.

8.2.2 Close relationships: engagement in co-occupation

I concluded in chapter 7 that authentic occupational engagement is most likely to result from very close, creative and responsive relationships between people with profound intellectual disabilities and those supporting them. Mahoney and Roberts (2009) have previously suggested that such relationships are co-

occupations, within which there is both engagement and reciprocal interaction, resulting in *meaningful* activities both for the person providing support and the person with intellectual disabilities being supported. Mahoney et al. (2013) concluded that people with severe intellectual disabilities engage in occupation more actively and with increased volition when doing it with someone else. Relating this theory of co-occupation to the case, it can be seen as providing a particularly clear illustration of this type of close relationship.

Drawing on her own experience as a mother and research with mothers and children, Pierce (2003) described a continuum of social involvement from solitary occupations, to those which are parallel and shared and then “co-occupations”, her term (originally coined in 1990) for those which are most highly interactive:

“A synchronous dance back and forth between the occupational experiences of the individuals involved, the action of one, shaping the action of the other in a close match” (2003, p.199).

Each party (including the infant in the mother-child dyad) actively participates in the co-occupation and influences the other’s interactive responses and “the occupational performance of one member depends on the other” (Humphrey and Thigpen-Beck 1998, p.837).

Pickens and Pizur-Barnekow (2009) suggested that in addition to interaction, co-occupations are characterised by shared physicality, emotionality and intentionality, in other words, degrees (depending on the complexity of the co-occupation) of reciprocity of movement, emotional tone and intention or purpose. Through this reciprocity, meaning emerges and there is shared experience. Although Pierce (2009) does not agree that shared physicality, emotionality, intentionality or meaning, are necessarily required in this “dyadic interplay” (2009, p.204), she does concede that they are often present. Pizur-Barnekow and Knutson (2009) found statistically significant variations in observable behaviour – such as upper body movement, facial expression, conversation and laughter – when comparing students playing a game of Yahtzee on a computer with those playing as part of a group, which supports the existence of two of these components in a co-occupation – shared physicality and emotionality.

The latter study implies that it can be evident to an observer when an occupation is in fact a co-occupation and I feel that co-occupation is visible in many aspects of my case. An example is Esther's 'conversation' with Matt using the technique of intensive interaction illustrated in Vignette 2. Drawing on developmental theory and reciprocal mother-infant interactions (Coia and Handley 2008, Nind 2009) intensive interaction is one of the two most widely-used communication interventions by speech and language therapists with people with profound intellectual and multiple disabilities in the UK (Goldbart et al. 2014). The way that Esther uses this to respond to and build on Matt's vocalisations and how both she and Jean support him in the subsequent tea tasting activity, illustrate degrees of shared physicality, emotionality and intentionality:

- Shared physicality can be seen whenever Matt is given physical support (for example to explore the feel of the bag of tea), but also generally in the way that Esther and Matt and Jean and Matt are positioned and move in response to each other.
- There are attempts to construct shared intentionality, in terms of the ways Jean and Esther: work to understand Matt's motivations and the intentions behind his behaviours; ascribe meanings to these behaviours even though uncertain that these are present; and help him to feel sufficiently safe to try new experiences.
- The importance of shared emotionality comes across particularly strongly, with the need for Jean and Esther to make second by second interpretations of Matt's limited repertoire of vocalisations, arm movements and facial expressions, his pauses, thoughtful expression and sudden beaming smile. From these interpretations they reach conclusions about his responses to what is happening. Does he like the smell, or not? Is he merely unsure, or is the smell over-stimulating? Should they continue or not? These can be seen as efforts to build a shared – if not necessarily mutual – emotionality.

In building a relationship with an individual with profound intellectual disabilities, the importance of remaining 'in step' seems evident here. The way Esther built her relationship with Matt was very different from how she drew Harold into playing a

game of skittles through lots of lively activity and banter that sought to generate a reciprocal level of excitement sufficient to motivate him to engage (see 7.3.1.4). The importance of fun in interactions with people with severe and profound intellectual disabilities, including comedic interaction and banter, is a prominent part of theory regarding social interaction developed by Johnson et al (2012) from data gathered through observation and interview.

This shared emotionality is reminiscent of affect attunement that is said typically to occur in mother-infant dyads, where the mother immediately recasts the affect of the infant with emphasised facial, vocal, gestural, or postural behaviours (Stern 2007). A recent specific theorisation in the context of communication dyads involving one person with profound intellectual disabilities views attuning as an active process with fluctuating levels of closeness along two continua of empathy and co-operation:

“In essence, how people attune to one another is manifested in the degree to which they empathise and cooperate with the other” (Griffiths and Smith 2015, p.7),

The striking similarity between attunement and co-occupation has been noted by Whitcomb (2012) and by Forster and Iacono (2014) who concluded that these attunement behaviours might underpin good quality interactions. A depressed mother was, for example, observed to miss cues that she could have used to adjust how she fed her son, thus impacting on this co-occupation (Olson 2006). Forster and Iacono (2014) observed support workers interacting with people with profound intellectual disabilities and found many very short episodes of attunement behaviours in most (though not all) support dyads. The possibility of evaluating these affective and reciprocal interactions using tools designed to evaluate parent-infant dyads has been demonstrated by Hostyn et al. (2011).

It seems to me that all the activities in which Esther wanted the staff team to engage (Matt’s sensory angel delight making, Steve’s sensory bath, Becky’s sensory washing up and so on) were intended to be co-occupations. Even if different parties may inevitably be experiencing the meaning of the activity differently (Mahoney et al. 2013), shared experiences intended to be meaningful to all are

apparent. Without the cognitive ability to occupy themselves, authentic engagement in occupation for people with profound intellectual disabilities comes out of creative and responsive relationships between them and whoever is supporting engagement and I suggest that they are likely only to be able to experience authentic occupational engagement through engaging in co-occupations. The case supports Mahoney's previous assertion (2009) that co-occupation may be necessary for them to experience occupational engagement and thereby occupational justice. Occupational therapy can therefore be seen as facilitating increased opportunities for co-occupation for people with profound intellectual disabilities and those supporting them, thus, arguably, improving the occupational lives of both (see further 8.3). This finding also supports the suggestion from my literature review (see 2.2.2) that for people with profound intellectual disabilities who are unlikely to be able to engage in occupation outside of a social context, engagement is synonymous with participation.

8.2.3 Engaging in occupation 'at a sensory level'

Within such co-occupations, the level at which someone is able to engage needs to be recognised. A key feature of Esther's work with Matt, Steve, Becky, Jane and Harold was her emphasis on recognising the sensory level at which she considered they were functioning and how this impacted on the level of engagement in activity they were likely to be able to achieve and what they were likely to find meaningful. It reflects a similar emphasis in Mencap (2011) that meaningful activities for people with profound intellectual disabilities are ones that "recognise that many people ... experience the world largely on a sensory level and take this into account" (2011, p.40). In this section, I explore what the case suggests that Esther and Mencap meant by this and how this helps further our understanding of occupational engagement.

Occupational therapy theory suggests that occupational engagement is complex and multi-dimensional (Creek 2010, Kielhofner and Forsyth 2008). Creek's consensus definition (2010) suggests that someone engaging in an occupation will experience a sense of involvement, choice, positive meaning (that is, significance or importance) and commitment. She clarifies, however, that engagement is not an absolute concept and that individuals can engage to different degrees in different

occupations at different times, experiencing different levels of intensity of meaning. The case implies that those with profound intellectual disabilities are likely to sense this involvement, choice, positive meaning and commitment when engaging in occupation to different and perhaps more limited degrees and that the meaning of engagement is constructed individually. Those who may struggle to engage in occupation without support can nonetheless be enabled to engage and to gain meaning in their own ways. With support, they can still experience at least some of the dimensions of doing in the Model of Human Occupation depiction of occupational engagement (see Figure 2.1 in 2.2.1), in particular perhaps exploration and expression of choice or preference.

This emphasis on the *meaning* of occupations, both personally and socio-culturally, to those engaging in them is consistent across definitions of occupation and engagement from within occupational therapy (for example those cited in sections 1.2.6 and 2.2.1 above). Fisher's definition of "activity that is both meaningful and purposeful to the person engaging in it" (2003, p.2) is particularly clear on this. The findings support the conclusion from my literature review that occupational therapists' key focus with people with intellectual disabilities is on promoting *meaningful* engagement and that they have a particular role in connection with this with people with profound intellectual and multiple disabilities (Tannous et al. 1999, Perez et al. 2012). What this research adds, however, is more detailed understanding of the ways in which occupation may be meaningful, thus allowing those with profound intellectual disabilities to engage in ways that may be authentic rather than tokenistic.

Esther used theory to help Sue, Norma and the team of support workers to understand the abilities of Matt, Steve, Becky, Jane and Harold. She used the Pool Activity Levels (Pool 2012) to support an understanding of the levels at which, developmentally, they were able to engage in occupation and, in collaboration with a speech and language therapist, the Levels of Intentional/ Pre-intentional Communication (Coupe O'Kane and Goldbart 1998) regarding their abilities to communicate intentionally. Using the metaphor of a bridge to illustrate their relative levels of ability was something that some participants (notably Jean, Sue and Norma) found particularly enlightening. Her recommendations regarding how

to support engagement varied for each person, though there were some common themes which are illustrated in excerpts from occupational therapy reports drawing on these theories in the vignettes.

Taking into account the developmental level of someone with profound intellectual disabilities in this way seems to require paying maximal attention to the *process* rather than the end result, with the outcome of an activity of less importance than it might typically be. For example, Becky may not realise that she is washing up and Matt may not understand that the bag he is scrunching contains tea that is going to be used to make a drink. Focusing on the process and taking time to explore different tastes, textures, smells, vibrations, temperatures and sounds that are potentially part of those activities does, however, potentially enable them to gain some meaning from them. It allows for surprise and, through exposure within comfort level to new sensations, may encourage curiosity and opportunity to exert autonomy by expressing preference.

In seeking to embed sensory activities into the culture of Cavendish House, Esther encouraged the team to seize opportunities within ordinary everyday personal care, domestic and leisure activities around the home and to adapt these activities emphasising their sensory aspects. This holistic approach is in contrast to one that compartmentalises the activity most likely to be meaningful to people with profound intellectual disabilities to happen mostly within specialist facilities, such as Cavendish House's former multi-sensory room. It requires recognising everyday opportunities for this kind of activity and consciously making them available. Engaging people at a sensory level may happen in the bath and shower, using different scented soaps, textured flannels and sponges and so on, but 'sensory activities' are about more than personal care, which was something that some support workers struggled to understand. The approach is also and importantly about domestic, productive and leisure activities, such as Becky's washing up, Steve's mid-morning hot drink preparation and Harold's church attendance.

The occupational therapy approach in this case echoes, but also develops the emphasis on readily available ordinary daily activity in active support (Mansell

and Beadle-Brown 2012). That similarly aims to ensure that activity becomes part of the support culture. 'Real' activities, as opposed to childish or special therapeutic ones are regarded as preferable due to their variety and ready availability and the opportunities they provide for people with intellectual disabilities to demonstrate that they can engage in generally valued activities (Ashman et al. 2010). The case suggests, however, a further reason for favouring supporting engagement at a sensory level using ordinary daily activity as opposed to using, say, a bubble tube in a multi-sensory room: it provides structure and has the potential to be more motivating for those providing support. It is potentially, therefore, something that support workers might be more inclined to persist with for longer and to try more frequently.

8.3 Addressing occupational injustices

The five clearly very different individuals living in Cavendish House illustrate the heterogeneous nature (to use Nakken and Vlaskamp's (2007) previously cited description) of people with severe and profound intellectual disabilities. Many of the characteristic cognitive and physical disabilities and complex health, sensory, communication, and behaviour needs described in 2.3.1 are visible. The case highlights how we may often not know with absolute certainty the classification of an individual's intellectual disability and how, as a label, this is in any case merely a starting point in getting to know them and their needs. Matt and Steve both have clear diagnoses of profound intellectual and multiple disabilities, Becky is said to have "severe-profound" intellectual disabilities and Harold and Jane are both said to have "severe" intellectual disabilities (though Harold's abilities are described as having reduced since his cerebrovascular accident).

I have referred extensively in my findings to Esther's work with Matt, Steve and Becky, as the three individuals living at Cavendish who most clearly have the diagnosis of profound intellectual and multiple disabilities referred to in my research question. Although Harold and Jane do not have profound intellectual disabilities, I have nonetheless still referred to Esther's work with them, as many aspects of this were interesting examples of her overall approach and in particular were useful to illustrate how she varied this as she sought to enhance each of their occupational lives.

The 24-hour support provided in the house by 5 or 6 support workers during each daytime shift reflects the suggested extremely limited ability to engage in activities of daily living without support (Vlaskamp and Nakken 1999, Mansell 2010). This high staffing level of 1-1 support did not, however, equate with high levels of authentic engagement in occupation. This supports my conclusion in 2.3.3 and 2.3.4 that to achieve occupationally rich lives, the support provided to people with profound intellectual disabilities needs not only to be extensive, but also of good quality. Futures, the organisation now running Cavendish House, explicitly rejected the 'hotel' model of care where people are inactive whilst those who support them cook and clean (Jones and Lowe 2005, illustrated in 2.3.5.3). Their publicity materials, including their website, described how they supported participation in ordinary activities at home such as cooking, cleaning, gardening and individuals' own self-care. Some of their services had adopted active support (see 3.4.1), though the support workers at Cavendish House only began to receive training in this towards the end of the case. On paper at least therefore, priority seemed to be given to engagement in activity at home, in contrast to the omission of reference to this in some key policy documents (for example Mansell 2010).

Many of the support workers I interviewed expressed their keenness for those living at Cavendish House to have opportunities to be present in and to participate in their local community. I saw, or heard reference to, a number of potentially meaningful examples of this, for example Jane's weekly use of the Jacuzzi at her local leisure centre and Harold's regular attendance at services at his local church. Despite this however, the reality of a large number of waking hours spent at home mirrors the findings of Mencap (2011) and supports my conclusion from reviewing the literature that opportunities for participation in activities at home are all the more important for those who may spend extended periods of time there. I previously concluded that a paucity of opportunity to develop through occupational engagement and poor quality of support to engage can lead to secondary disability and occupational injustice. In the next section, I consider the extent to which those living in Cavendish House might face such occupational injustice and the ways in which occupational therapy sought to address this.

8.3.1 Low levels of meaningful engagement in occupation: an occupational injustice?

Esther's occupational therapy intervention emerged out of her own concerns (and those of some of her community team colleagues) about how effectively Futures supported Matt and Harold, in particular, to engage in activity at home. It was also a response to a specific request for advice from assistant manager Norma about how the team might best support Steve to achieve this. Adam referred to a generally low level of activity in the house and Esther described rarely seeing anyone living in the house doing anything when she visited. She expressed frustration in particular at how her previous work with Harold the year before had had very limited impact on the amount that he was supported to do.

This low level of engagement in occupation by people with profound intellectual disabilities mirrors the conclusions from my literature review (for example, Emerson and Hatton 2008, PMLD Network 2009b, Mansell and Beadle-Brown 2012). The case suggests that occupational therapists may have a particular interest in how people spend their time and engage in occupation at home (as opposed to elsewhere), something not particularly evident in the occupational therapy literature. This interest matches the emphasis on activity at home in the literature I have reviewed from active support, but it is otherwise not very prominent in intellectual disability policy and research.

Matt, Steve, Becky, Jane and Harold required a significant amount of support to engage in occupation, but seemingly achieved low levels of authentic engagement for the reasons outlined above. Viewed through occupational justice theory, their support can be seen as not adequately upholding their occupational rights (Townsend and Wilcock (2004), see 2.3.5), consequently placing them at risk of injustices of occupational deprivation, occupational alienation, and occupational marginalisation. Esther's year-long 'project' to increase occupational opportunities for them and generally the content and tone of her interviews all strongly suggest a purpose of addressing these occupational injustices, though this was not language that she explicitly used:

- **Right to experience occupation as meaningful and enriching.**

If the only activities available do not offer meaningful or enriching occupational experiences then individuals may become alienated from their occupational nature and at risk of institutionalisation, isolation and lack of identity (Townsend and Wilcock 2004). In proposing a different understanding of what it means for Matt or Steve authentically to engage in occupations around their home and in arguing that the absence of this understanding meant that much of their engagement was superficial or tokenistic, Esther promoted their rights to experience occupation as meaningful and enriching. Her intervention thus sought to address *occupational alienation*.

- **Right to develop through engagement in occupations and to exert autonomy through choice of occupation**

Human brains constantly need stimulation in order to develop and such stimulation is achieved through the range of occupations in which we engage (Wilcock 1995). Where the support available to Becky or Harold was generally ineffective in enabling authentic engagement in occupation, they were precluded from engagement due to factors outside their control. This *occupational deprivation* (Whiteford 2000) meant that they missed out on stimulation and opportunities to develop. Partial, though meaningful, participation in the activities in the way proposed by Esther provided opportunities for them, in small ways, to develop basic skills, such as ability to express preferences and exert some control over their environment. Active support (Mansell and Beadle-Brown 2012) similarly recognises how meaningful engagement in ordinary activity around the home can provide opportunity for skill development. It additionally promotes the occupational right to (learn to) exert autonomy through choice of occupation (Townsend and Wilcock 2004).

- **Right to diverse participation in the typical range of occupations of a community**

If the support available to Jane and Steve does not promote inclusion in society as citizens and if it does not enable them to engage (in a way that they find meaningful) in a wide variety of occupations consistent with cultural norms, they are arguably at risk of occupational marginalisation

(Townsend and Wilcock 2004). Conscious that large parts of their days involved self-care activity (such as washing and dressing, eating and medical, or health care), occupational therapy emphasised the importance of them having a balance of occupational opportunities. In encouraging meaningful engagement in leisure activities and domestic activities, such as cooking or laundry, it sought to address occupational imbalance, but also *occupational marginalisation*. Successful engagement in occupation and development of competence can change the perceptions of others, including importantly the perceptions of those providing support (see virtuous circle of positive interaction and empowerment in 3.4.1 (Jones and Lowe 2005)).



The case lends support to the conclusions in my review of the literature that low levels of engagement in occupation may risk people experiencing occupational deprivation, alienation and marginalisation and demonstrates that occupational justice theory can be a useful framework for considering the occupational lives of people with intellectual disabilities.

In the following sections, I explore two contributory factors in the low levels of engagement and occupational injustices I have identified: the knowledge and confidence of members of support workers in enabling authentic engagement and aspects of the house's organisational culture.

8.3.1.1 Gaps in understanding and confidence in supporting occupational engagement

The findings suggest that despite the way that Futures marketed their support services, there were gaps in the knowledge and skills of the support workers at Cavendish House and generally a lack of understanding about how to support engagement, impacting on the quality of support provided. Cross and West (2011) make the point that interventions cannot be any more effective than the skill level of those implementing them. Support to engage in activity seems often to have been at a superficial or tokenistic level, with opportunities missed to support more authentic engagement. Gaps were highlighted in the staff team's level of

understanding about the work they were doing and specifically concerning the points discussed in 8.2: the nature of authentic engagement in occupation for people with profound intellectual disabilities and how to support such engagement. It was an important realisation for Esther that some staff did not fully understand Matt, Steve, Becky, Jane and Harold's developmental levels and cognitive abilities, and that they needed convincing that the narrative of authentic engagement in occupation that she proposed was both possible and observable. This supports my conclusions from reviewing the literature that the social environment, namely the quality of support available, impacts on the extent to which people can engage in occupation and that support workers and service managers may not always have a good understanding of the impact of severe and profound intellectual disabilities on this.

Norma's request for support from Esther regarding how to engage Steve and the admission by Olly that he found it difficult to 'read' Harold both suggest that at some level the staff team were aware of these gaps in their understanding. Storey et al.'s participants (2012) appeared anxious about their abilities and complained early on in interviews about their lack of experience or training working with people with complex needs.

A critique of Esther's intervention and something that, on reflection, I consider may have impacted on the degree to which she was successful in fully engaging the staff team in her vision, surrounds her partial use of the occupational justice frame of reference (as explained in the previous section and 2.3.5). In her discussions with the team and in her activity session plans and reports, she emphasised the importance for Matt, Steve, Becky, Jane and Harold's wellbeing of promoting their occupational balance. By this, she meant a balance between self-care, productivity and leisure occupations. Whilst not disagreeing with the general theorisation (Townsend and Wilcock 2004) of the potential for occupational imbalance to pose a risk to health and wellbeing, I do question Esther's prioritisation of this particular occupational risk factor on this occasion. In the case of people who (as I concluded in the previous section) are at high risk of occupational deprivation, and, notably, of occupational alienation through not being supported to engage in occupation in ways they are likely to find meaningful, an imbalance in those

occupations that they *do* engage in is arguably not the greatest concern. If, as I have argued in 8.2.3, meaning is gained from the *process* of activity rather than its end result, I question whether it is of any significance to Matt, Steve, Jane, Becky, Harold and others like them whether an activity might be seen as self-care, productivity or leisure.

Perhaps for these reasons, the idea of occupational imbalance did not appear to be one that particularly caught the staff team's attention. Whilst still using occupational science to frame and explain her intervention, Esther could alternatively have explicitly demonstrated how the intervention sought to address risk and injustice from a paucity of opportunities to develop through engagement in occupations (occupational deprivation) and to engage in occupation in ways likely to be meaningful (occupational alienation). This alternative framing of the intervention might have been more convincing to and more likely to motivate the staff team than occupational balance did.

8.3.1.2 Organisational culture impacting on occupational engagement

Esther's intervention had some success in supporting the staff team to increase their knowledge and understanding, but other aspects of Cavendish House organisational culture remained problematic. The organisational culture within such services seems therefore to impact on whether or not and how occupational engagement is supported. Schein (2010, p.18) defines organisational culture as:

“A pattern of shared basic assumptions learned by a group as it solved its problems of external adaptation and internal integration, which has worked well enough to be considered valid and, therefore, to be taught to new members as the correct way to perceive, think, and feel in relation to those problems.”

It can be seen in organisational structures and processes and in the organisation's espoused values, but values and actions ultimately come from less overt, and much harder to expose, beliefs, perceptions, thoughts and feelings of those who are part of the organisation. I have described how the service in Cavendish House had been through a significant organisational change with the transition to Futures some 18 months before the start of the case. Ramifications from this change were still far

from settled by the end of the case and Killeth et al. (2012) observed, in their findings from case studies in elderly residential homes, the way in which extensive organisational restructuring from outside can impact on the quality of care.

Bigby et al. (2012) sought to conceptualise culture within group homes, especially those with poorer outcomes in terms of engagement in domestic activities and participation in the community. Secondary analysis of ethnographic and action research data on quality of life outcomes for people with severe and profound intellectual disabilities living in five homes suggested a number of dimensions of culture and norms that appeared to affect occupational engagement. A number of these dimensions (Bigby et al. 2012, p.462) seem particularly relevant to understanding engagement levels in this case: the extent to which those holding power within the support team's values align with those espoused by the organisation; whether those being supported are seen as 'like us' or 'other' and the perceived purpose of the support role; and whether there is a resistant or open orientation to new ideas and change. To these, I have added a fourth dimension of culture that was evident in Cavendish House, also recognised as important (Beadle-Brown et al 2014 and 2015): planning and leadership.

a. Alignment of power-holders' values with organisation's espoused values.

Within Cavendish House there was arguably a powerful clique of longer-standing members of staff whose values were not fully aligned with those of Futures and those promoted by Esther. I feel that this misalignment is partially explained by a lack of clarity about the ways in which such values were relevant to those with very complex needs they were supporting. I explore the role ambiguity arguably experienced and how Esther sought to address consequent opposition and obstruction in 8.3.2.1 below.

b. 'Not like us'

Matt, Jane, Becky, Harold and Steve all had complex health needs, including epilepsy, skin integrity problems, respiratory problems (causing recurrent chest infections), gastric reflux and dysphagia. There remained differences of opinion and a tension within the staff team between those, such as Sue, who advocated a broad focus on quality of life and who saw partial participation in household

activities as possible and important and those for whom this was not a priority, due to the extent of individuals' complex health needs. Support worker Doug's description in 7.2.1 of the team needing primarily to focus on meeting physical health needs reflects previous descriptions of the impact of medical conditions on engagement in planned activities (Zijlstra and Vlaskamp 2005a) and the risk of activities being "lost in the whirl ... of physical and nursing care" (Vlaskamp and Nakken 1999, p.108).

Doug expresses theoretical support for the idea of Harold doing more activity, whilst emphasising that in practice, this cannot be done unless these health needs have been met. This is reminiscent of the "practice/ principle rhetorical device" discourse identified by Jingree and Finlay (2008, p.715) in support workers' discourses regarding choice and control. Identifying Matt, Steve, Becky, Harold and Jane as individuals whose complex health needs preclude them from being offered opportunities to engage in occupation implies that they are 'other' in that they are 'too disabled' to be offered them. It is suggestive of a 'hotel' model of care and reminiscent of two of the dimensions of culture Bigby et al. (2012) identified in homes with poorer outcomes (*regard for residents* and *perceived purpose of role*). Crucially, it situates any occupational deprivation, alienation and marginalisation (see 8.3.1) firmly within individual pathologies. An alternative social model of disability perspective would construct people as capable (Jingree and Finlay 2008) by considering how we might work to find ways to offer opportunities to engage in occupation *despite* their complex health needs. This was what occupational therapy sought to achieve, supporting the relevance of the social model of disability, as highlighted in my literature review.

In a later study consisting of three qualitative case studies, Bigby et al. (2014) went on to observe that the practices and discourses of staff in group homes that had *more* success in supporting engagement were suggestive of higher positive regard for those being supported. Support workers in those homes seemed to be constructing those they were supporting as more 'like us'.

c. Support for innovation

The extent to which members of the team were open to change and supported innovation and their attitudes towards outsiders like Esther had a particularly striking impact on implementation fidelity (see 8.4.1). Resistance to new ideas and challenges from outsiders to the status quo of practice, has been found to be a dimension of the culture of group homes 'under-performing' at supporting engagement (Bigby et al. 2012). Killett et al. (2012) reviewed the literature and carried out case studies in eight elderly care homes and concluded that aspects of support systems that are "fragile" (2012, p.32) and thus likely to preclude delivery of good quality, person-centred care are more easily restored to robust states in staff teams that demonstrate openness and have the capacity to adapt.

Esther's ambitious goal was to embed "sensory activity" into the fabric of the way that the staff team worked and she hoped that this would have the effect of pulling the staff team together behind commonly agreed objectives. This level of change requires a staff team to believe that the intervention is necessary and that it will work (Graves 2007) and then to be willing to take a "leap of faith" (Lewer and Harding 2013, p.80) in completely supporting it. The willingness of Sue and some of the support staff (Jean, for example) to take this leap of faith was important, but it did not prove possible to facilitate the whole team doing this. Although some support workers were clearly passionate about their work and able to work in creative ways, lethargy and lack of passion and creativity amongst some was apparent to me and noted by Esther and Sarah, by nurse Adam, by support workers Jean and Doug and by manager, Sue. Esther and Sarah's experiences matched some of those reported by Bigby et al. (2012), including excuses (the person being supported was too unwell, or resources or staffing were insufficient), cynicism, belittling of ideas, teasing (superficially good natured, but nonetheless perceived as undermining) and half-hearted adoption of recommendations.

These are recognised as common responses to perceived role ambiguity and role conflict (Thompson and Rose 2011), which are explored further in 8.3.2.1, highlighting the importance of Esther's efforts to improve the team climate by addressing them. Significant correlations have been established between the attitudes of care staff towards professionals and both team climate and staff

psychological wellbeing: better team climates correlate with more positive attitudes towards outside professionals (Anderson and West 1996, Rose et al. 2007).

d. Planning and leadership

An aspect of organisational culture that is visible in the case, not reflected in Bigby et al.'s findings (2012), though recognised elsewhere (Beadle-Brown et al. 2014 and 2015), is leadership. Cavendish House's leadership culture had shifted from being very directive, to one in which individual support workers had a higher degree of participation in decision-making and where decisions about engagement in activity were left more to the initiative of those on shift. The structure became much less hierarchical, with all members of staff encouraged to take on leadership roles. Some (Olly for example) experienced this as empowering and felt more valued because it allowed them more autonomy and valued their individual contributions more. Others within the team, on the other hand, seemed to struggle with the expectations of (as Adam put it) "*leading within a team of equals*" and overall it seemed to result in less advance planning of support. Zijlstra and Vlaskamp (2005a) found that despite skilled support being available, activities tend not to happen in the absence of such planning. It is perhaps not surprising that where those expected to plan occupational engagement lack understanding and confidence in providing this kind of support, as was sometimes the case in Cavendish House, planning of it should be found difficult.

Leadership which focuses on how well quality of life is supported, which allocates and organises support in accordance with needs and which helps improve support over time is emphasised in active support (Mansell and Beadle-Brown 2012), A combination of good quality management and day-to-day practice leadership seems important in enabling staff to support engagement (Beadle-Brown et al. 2014). Good practice leadership (in terms of the extent to which it organises and allocates support, focuses on quality of life of those supported and reviews quality of support provided) can result in better active support and has been found to be significantly positively-related to the amount of time those supported spend engaged in meaningful activity (Beadle-Brown et al 2015). Cocks and Boaden (2011) concluded from reviewing literature on personalised support that someone

needs to have a vision, to demonstrate ideas and to lead the creation and embedding of new ways of working. This echoes what Northouse (2007) describes as “transformational leadership” (p. 185) where a leader, perhaps with a charismatic, motivational personality, is an agent for change and good role model and inspires others to achieve higher standards by articulating a clear vision. This person was arguably Esther in the early stages of the case, but she was clear that she needed someone else to take on this role. She saw manager Sue, assistant manager Norma and the ‘link’ support workers of each person living in the house as potential allies and leaders in sustaining sensory activity in the long term. I have described the extensive efforts she made to bring this about. The importance of support and leadership from manager and wider service is stressed repeatedly in the literature (for example, Bradshaw et al. 2004, Firth et al. 2008, Totsika et al. 2008, Killett et al. 2012, Lewer and Harding 2013) and Sue’s eventual enthusiasm for what Esther was hoping to achieve was an important turning point in the case.

A number of factors contributed, however, to an arguable leadership vacuum, impacting on the outcomes that were ultimately possible. These included the nature of Sue and Norma’s relationships with each other and the rest of the staff team, consequent communication issues between the team and them, the team’s struggle to adjust to very different management and leadership styles and the eventual departure of both Norma and Sue towards the end of the case. I have described in the findings a number of examples of ineffective passing on of information within the team and how difficult it was for Esther to meet with the whole or substantial parts of the team due to infrequent meetings. Others have also reported how communication problems within teams can affect the quality of care, for example, Windley and Chapman (2010) and Killett et al. (2012).

8.3.2 Risk of burnout and other occupational injustices for those supporting people with intellectual disabilities

I conclude, therefore, that occupational therapy sought to address occupational injustices faced by those living in Cavendish House. An interesting aspect of the case, however, is the way in which Esther seemed to acknowledge and address an additional power imbalance, resulting in occupational injustices arguably faced by those *working* there. In recognising a link between the quality of support workers’

working lives and the quality of support they could provide, part of her intention seems to have been, directly or indirectly, to address some of the occupational risks to them.

There is a substantial body of research into stress experienced by those supporting people with intellectual disabilities and in particular into 'burnout' as a key indicator of such stress (Hastings et al. 2004). Burnout is classically defined (Maslach et al. 1997, Maslach and Goldberg 1998, Maslach et al. 2001) as a psychological response to chronic and uncontrollable work stress, where support workers experience: *emotional exhaustion* (feeling over-extended and depleted of emotional and physical resources); *depersonalisation* (detachment, and impersonal, unfeeling responses towards those being supported); and *lack of perceived personal accomplishment* (not feeling competent in their work role). Extreme burnout would be suggested by high emotional exhaustion and depersonalisation and low perceived personal accomplishment. Although not necessarily higher than in other human service sectors, there has been evidence over the years of moderate levels of burnout amongst those providing direct support to people with intellectual disabilities (for example Aitken and Schloss 1994, Chung and Corbett 1998, Boumans and van den Berg 2000, Skirrow and Hatton 2007, Rose et al. 2011, Hickey 2014). High levels of stress and burnout, unsurprisingly perhaps, have been found to influence the quality of care (Innstrand et al. 2004), including by reducing support workers' interactions and the amount of support they give (Rose et al. 1998) and by increasing absenteeism and staff turnover (Jenkins et al. 1997, Mills and Rose 2011, Kozak et al. 2013). I am not privy to the reasons for Norma and Sue leaving Cavendish House, but do wonder whether there was a link with stress and burnout. High levels of stress can lead to reduced support for innovation (see 8.3.1.2 above), as staff may seek to protect themselves and avoid burnout by resisting change.

The concept of burnout amongst those providing support to people with intellectual disabilities has been theorised in varying ways in the literature, notably focusing on the fit between support worker and environment and on interactional 'demand-control' models (Thompson and Rose 2011). Innstrand (2002) highlights how individual, interpersonal, demographic and organisational

factors may contribute towards staff stress and burnout. Organisational factors, such as those described above in 8.3.2.2, seem particularly to affect levels of emotional exhaustion (Vassos and Nankervis 2012). Thompson and Rose (2011) systematically reviewed the literature relating to burnout and organisational climate, defining this as “the collective perception and behaviour of individuals within an organisation based upon the values of the organisation” (p179). This seems similar to the definition of organisational culture in 8.3.1.2, which I have established as important within this case. This caused me to question what impact this might have on levels of risk of burnout amongst staff.

I observed levels of stress, motivation and lethargy at Cavendish House to fluctuate over the course of the year-long case, adding some credence to Thompson and Rose’s overall critique of the evidence (2011) that it is largely based on cross-sectional studies, with few longitudinal studies. If organisational variables contributing to stress and burnout are dynamic in nature, ‘snapshots’ may not capture the whole picture of the situation in a particular setting. I will now discuss how investigating this case over a period of a year enabled two particular aspects of workplace stress induced by the organisational culture in Cavendish House to become visible and the way that occupational therapy sought to address this.

8.3.2.1 Role conflict and role ambiguity

Much of the literature on burnout draws on interactional models, in particular Payne’s model of workplace stress (1979) which sees this as a function of the interaction between the constraints of the working environment, the perceived demands and the supports available. Dyer and Quine (1998) considered their findings in intellectual disabilities services to be consistent with this model.

The following factors, which I concluded to be contributors to limited success in supporting authentic engagement in occupation, seem to me to be striking examples of role conflict and/ or role ambiguity, two of five workplace stressors highlighted by Payne (1979) and Dyer and Quine (1998):

- Conflicting attitudes towards leadership and towards the relative priority of meeting the health and wider occupational needs of those living in the house;

- A lack of understanding by some of how to support people with profound intellectual disabilities to engage in occupations at home; and
- Generally an uncertainty about how familiar neoliberal mantras of personalisation, independence and choice, espoused by Futures and national policy are applicable to those with particularly complex needs.

Staff are said to experience role conflict when they perceive workplace demands to be incompatible with each other, organisational expectations to be unrealistic, or that they work on unnecessary things; and role ambiguity when there is a lack of clarity regarding an aspect of their role, or where they perceive organisational values to be incongruent (Thompson and Rose 2011). The clarity of the employing organisation's overall philosophy, direction and goals is closely linked to role conflict and, more particularly, role ambiguity (Dyer and Quine 1998). The evidence from a number of studies in, for example, the UK, Australia and Spain strongly suggests that both these stressors correlate with high levels of emotional exhaustion and depersonalisation and thus with burnout (Hatton and Emerson 1993, Aitken and Schloss 1994, Gil-Monte and Peiró 1997, Blumenthal et al. 1998, Dyer and Quine 1998, Hatton et al. 1999, Vassos and Nankervis 2012). Vassos and Nankervis (2012) found role ambiguity and role conflict to be the only significant predictors of emotional exhaustion.

Thompson and Rose (2011) concluded that ambiguous roles particularly risked staff burnout when there were changes in service provision and socio-political context. Boumans and van den Berg (2000) had previously concluded that those working to person-centred rather than institutional models tended to have greater clarity about their roles (and reduced levels of burnout), but interestingly, this role clarity was not reflected in Cavendish House. With the shift to a person-centred supported living model, Futures' organisational policies now explicitly described support workers' role as "*increasing independence*" (Futures website). A dominant discourse of values and goals of empowerment, independence and choice was reflected in the day-to-day language used and seemed generally accepted, or at least unquestioned. It seemed not, however, well understood. When asked what independence meant when supporting Matt or Steve to engage in occupation at home, manager Sue gave the somewhat irrelevant (in the context of what I have

said about authentic engagement) example of them using a vegetable chopper if they could not use a knife, but otherwise struggled to give examples. Support workers, for example Olly, also seemed to find it difficult to see how the general philosophy of personalisation, independence and choice fitted when supporting these particular people in this particular context. Sue's interpretation of "personalisation" seemed to imply those living in the house never doing any activity with their peers, which I would argue is an over-reaction to historic emphasis on congregate care and arguably devalues peer relationships. This lack of clarity created a tension between the support workers and Futures, similar to the one identified by Forster and Iaconno (2008) where the age-appropriateness of support workers' playful interactions with the people with profound intellectual disabilities they were supporting was questioned by their employing organisation.

Such misunderstandings may be due to policy documents, such as Department of Health (2009) and mission statements of organisations like Futures, making goals of empowerment, personalisation and choice for people like Matt, Steve, Becky, Jane and Harold appear superficially straightforward (Finlay 2008) and failing to explain them sufficiently. Misconceptions of such principles have been described elsewhere (Race 1999) and in addition to increased knowledge and skills, support workers have been found in other studies to need support to understand service values and philosophy (McVilly 1997, Dobson et al. 2002, Graves 2007). Esther's efforts to clarify exactly how these goals might meaningfully be realised by those in Cavendish House, demonstrates their complexity, particularly if we are to move beyond mere illusion of empowerment.

Lethargy and lack of passion evident in the work of some (see 7.2.3) may therefore be partially rooted in role ambiguity and conflict. The case suggests that if, when supporting someone to engage in activity, one does not feel able to judge the extent of engagement achieved, motivation to persist with that support may reduce. Alternatively, or additionally, this may lead to supporting engagement without enthusiasm or in a half-hearted way with less likelihood of meaning or success. A positive outcome for the individual with intellectual disabilities was suggested by occupational therapists to be influential in motivating support workers to follow recommendations (Lillywhite and Haines 2010), but Zeedyk et al.'s participants

(2009) were reticent to support participation in activity because they struggled to recognise signs of enjoyment. This may encourage a gravitation towards routine and non-negotiable tasks, such as personal care and meal times, where there is potential to follow habitual patterns in ways demanding less creativity. If support workers are aiming to achieve “independence” in activities of daily living and they don’t or can’t see how this can be achieved, this tension may lead them to rejecting it as unachievable or irrelevant to those they are working with, or perhaps to feeling that they are failing by not being able to achieve it.

It seems therefore that the way in which changes in service provision are introduced may determine whether or not this leads to reduced or increased role clarity (Rose et al. 1998). Support workers – and managers – need a lot of support to understand new ways of working and the extensive efforts made by Esther to explain the reasoning behind her recommendations can be seen as an attempt to reduce role ambiguity and promote role clarity. In one interview, she referred to how the theory she drew on, for example the Pool Activity Levels (Pool 2012), gave support workers “*permission*”, highlighting, I believe, the way this new knowledge empowered them to do their jobs differently.

8.3.2.2 Equity: reciprocity in relationships

A second, equally relevant, theory used to explain high levels of job burnout is that of equity theory and reciprocity in relationships (Thomas and Rose 2010). This theorises that, in common with other social relationships, support workers compare what they bring or give to their relationships with their employer, their colleagues and those they are supporting with what they receive. In comparing the inputs and outputs, or outcomes, they thus evaluate the equity of such relationships (Disley et al. 2012).

Relatively high proportions of staff working with people with intellectual disabilities have been found to perceive a mismatch of inputs and outputs in their work-based relationships, for example in terms of pay, benefits, security and monotony (Thomas and Rose 2010). This makes them arguably inequitable again potentially contributing to burnout (Disley et al. 2012). The way support workers in Cavendish House described and went about their work suggested that not all felt

valued in their roles. It was notable how often they referred to changed terms and conditions of employment since the transition to Futures. This was clearly perceived as inequitable when weighed against their own inputs to their employer, co-workers and those they supported.

Outcomes from employers such as these are clearly important contributors to the perceived equity of working relationships, but also of relevance are outcomes from the people being supported themselves, including overt behaviours such as appreciation and staff satisfaction from having had a role in other people's achievement (Disley et al. 2012). Hickey (2014) emphasised how prosocial motivation, the desire for one's work to be beneficial to others, can have a moderating effect on burnout, in particular on the association between emotional exhaustion and depersonalised behaviour. Harold, Matt and Steve, however, were all described at different times as being difficult to 'read' (see Vignette 2), meaning that it was not always easy to tell from their behaviour whether or not they were interested or engaged in a particular activity. If support workers cannot see if their actions are beneficial, motivation may be reduced generally and prosocial motivation reduced in particular. In the light of equity theory, Esther's efforts using filmed examples on a DVD to demonstrate that Harold, Matt and Steve *did* give feedback and that it *was* possible to observe when they were interested and authentically engaged seem particularly important. Koski et al. (2010) found, for example, that once staff were more able to interpret the expressions of those they were supporting, they then understood how choice making was possible and gave greater priority to communication.

Not recognising beneficial outcomes for Harold, Matt and Steve means that these cannot be included in support workers' input/ output calculations, increasing the possibility of working relationships being perceived as inequitable and increasing risk of emotional exhaustion, depersonalised working practices and therefore burnout. Understanding how to support authentic engagement in occupation and how to recognise when this has been achieved, not only improves outcomes for those supported, but also means that support workers gain more from their work through seeing that they have made a difference. Poor employment terms and conditions amongst the intellectual disabilities workforce remain an issue to be

addressed, but in promoting this understanding, occupational therapy can nonetheless begin to re-balance the equity equation through mitigating against these other inequities in the relationship and reducing occupational risks such as burnout.

8.3.2.3 Conclusion: risks of occupational injustice for those working in Cavendish House

I am deliberately not drawing an explicit conclusion that members of staff at Cavendish House were experiencing burnout. What I am saying, however, is that the house was clearly experienced by some as a stressful place to work, which was seemingly a contributing factor in decisions to cease working in the house, Norma for example specifically referring to this. I have presented evidence within the case that points to some of the risk factors for burnout: existence of role conflict and role ambiguity; a lack of clarity about leadership and how the staff team were expected to participate in decision-making; and an increased risk of staff seeing their support relationships as inequitable due to their changed terms and conditions along with the fact that they were not always able to tell when their input was effective. This had resulted in an ambiguous and conflicted role for many of the staff, resulting in what I conclude to be real risks to their occupational wellbeing.

The importance of addressing these issues is apparent from the passing comments that were made in interviews with support workers and Esther to “bullying” within the house. Although I was never completely clear about the nature of this and who the perpetrators and victims were, it is potentially indicative of the depersonalisation component of burnout. At an extreme level, depersonalisation can lead to the kind of brutal support practices witnessed in Winterbourne View (Department of Health 2012).

The use of an occupational science and occupational justice frame of reference when considering the support workers’ actions is a unique contribution of this thesis. It is helpful in allowing us to see them not as being ‘difficult’ for not leaping to follow Esther’s recommendations, but rather as being in some way occupationally alienated, due to carrying out their work in a way that limited the

meaning and motivation that might be gained from successfully supporting a greater variety of activity. In striving to enable the whole staff team to experience (like Sue) a development in understanding regarding how people with profound intellectual disabilities engage in activities and the ways in which independence, choice and personalisation are applicable to them, occupational therapy addressed occupational risks faced by the staff team. Although Esther could not influence salaries and terms and conditions, her intervention did have the potential to improve the quality of support workers' daily lives, reducing occupational alienation and promoting occupational justice for them, at the same time as increasing their engagement with her intervention and improving the quality of support for those living in the house. It seems to fit with two aspects of leadership theory: the idea of "servant leadership" (Northouse 2013, p.219), where a leader focuses on addressing injustices, attends to followers' needs and empowers them to develop skills; and "path-goal theory" (Northouse 2013, p.137) where others are motivated to be productive and satisfied in their roles, by the leader seeking to understand and attend to their needs, by making goals meaningful, guiding, coaching and removing obstacles and by providing support in person. Leadership of this type, informed by an understanding of the ways in which support staff may be occupationally alienated in their roles, may be an important way of countering mistreatment and neglect within intellectual disability services, such as practices highlighted at Winterbourne View (Department of Health 2012) and improving the quality of support provided.

8.4 Empowering support workers to sustain a different way of working

Therapeutic outcomes cannot be achieved without the active involvement of those who spend the most time supporting people on a daily basis (Dobson et al. 2002) and Esther's intervention, as we have seen, focused on changing the way that the staff team supported engagement in occupation. The case thus provides a detailed example of current professional practice that is generally described elsewhere as increasingly consultative and indirect, rather than directly with people with intellectual disabilities themselves. This has been illustrated, for example, in the case of speech and language therapy (Graves 2007, Parrott et al. 2008, Lewer and

Harding 2013, Goldbart et al. 2014), physiotherapy (Carr et al. 1995, Stewart et al. 2009) as well as occupational therapy (Lillywhite and Haines 2010). Particularly noted in the findings of our latter study was a consultative role promoting the importance of occupational engagement and enabling support workers to develop their skills in engaging people with intellectual disabilities in activities and occupations.

A recent best practice briefing paper (National LD Professional Senate 2015) described five essential roles of those working in community intellectual disabilities health teams (such as the one in which Esther worked). The case provides a clear example of three of these roles: (1) enabling others to provide effective person-centred support; (2) quality assurance and service development in support of commissioners of services; and (3) direct specialist therapeutic support for people with complex needs.

The difficulties that Esther faced working with the team to embed a different way of working into the culture in Cavendish House are also very much evident in the findings of other researchers. Maes et al.'s review (2007) concluded that it is challenging to create good support and that there are often issues in support workers maintaining and generalising newly learnt practice. Issues regarding "implementation fidelity", the degree to which recommendations are followed as intended (Cross and West 2011 p.19), are commonly described. Studies have investigated, for example, the fidelity of implementation of speech and language therapists' recommendations regarding food and drink modification, meal time positioning and pacing and prompting to reduce risk of aspiration and choking (Chadwick et al. 2006, Graves 2007); and the implementation of behaviour support plans (Reynolds 2013). Speech and language therapists (Graves 2007), occupational therapists (Lillywhite and Haines 2010) and physiotherapists (Stewart et al. 2009) seem uncertain how to ensure that support workers correctly follow guidelines and recommendations, with Stewart et al.'s physiotherapists reporting sometimes having to repeat training and advice to the same staff groups. Reports of feeling disheartened (Lewer and Harding 2013) and frustrated, or powerless (Graves 2007) at limited changes to practice achieved are reminiscent of the emotions expressed by Esther at several points in the case.

Graves' findings (2007) regarding speech and language therapists' indirect interventions with support staff led her to wonder if the skills required to make collaborations succeed were sometimes under-estimated, with insufficient emphasis perhaps placed on how recommendations were to be implemented. Hornby and Atkins (2008) emphasised the need for human relation skills and an understanding of the complexities of the relationship between those making recommendations and those it is hoped might implement them. Aspects of both of these are evident in Esther's efforts to embed a new way of working in Cavendish House and in this section I discuss how the case develops our understanding of the ways professionals can promote their recommendations being implemented faithfully by support workers, as well as also some reasons for all too common low implementation fidelity.

8.4.1 Facilitating implementation fidelity

In many ways, Esther's approach to embedding her recommendations into the work of the team fits with the findings of other research exploring implementation fidelity. Her idea of a lengthy "project" involving a considerable amount of input reflects the conclusion from my review of the literature that personalised support requires "considerable ongoing time and effort" (Cocks and Boaden 2011, p.727). Engagement in activities only increases when efforts are taken to develop support procedures well and embed them in the service (Bradshaw et al. 2004).

Support workers have been found to express a strong preference for training by people who have detailed knowledge of the particular individuals they support (Bradshaw and Goldbart 2013) and they seem not to value as highly more general training, which needs then to be applied to specific situations. Esther's extensive assessments, which involved spending time with each person over a number of months, exploring their preferences and observing the ways they were supported, meant that she could be said to have known those living at Cavendish House very well. It is interesting, however, that despite this, she seemed to have more credibility with some support workers than with others: Jean, for example, was very much in favour of the idea of sensory activity and commented on how well Esther had got to know each person; whereas Esther had less success in convincing

more resistant Olly that, despite being an outsider, she had the required local knowledge for her recommendations to be valid.

The way support workers think influences their interactions with those they are supporting (Ager and O'May 2001) and implementation fidelity is promoted by seeking to change thinking habits as much as actual practices, thus making practice more reflective (Koski et al. 2010, Bradshaw and Goldbart 2013). In seeking to reduce ambiguity about goals of personalisation, empowerment, independence and choice (as discussed in 8.3.2.1) and in using theory such as the Pool Activity Levels (Pool 2012) and the Levels of Communication (Coupe O'Kane and Goldbart 1988), Esther encouraged the Cavendish team to think differently about those they were supporting. She sought to enable the team to recognise signs of interest or engagement that she believed to be observable. Acknowledging that such signs are easily missed, she recognised that increased external rewards such as praise and support are required (Stewart et al. 2009).

In asking the staff to change their thinking, Esther encouraged them to shift their assumptions about those they were supporting. I have described some of the assumptions underpinning her intervention in 7.3.1, for example, that all humans – including people like Matt and Steve – are driven to engage in occupation; and that it is possible for them to acquire roles, of cooking, cleaning and so on, that are typically valued around their homes. Seeing her work with the staff team through an occupational justice lens as described in 8.3.2, she also seemed to approach the staff team with a number of assumptions, in particular that they were doing their best and wanted to improve the quality of the lives of those they were supporting. Support workers have described this as their primary aim and that they most enjoy their work when they feel able to facilitate it (Windley and Chapman 2010).

8.4.1.1 Tension between prescription and compromise

Finding a way to empower a staff team, whilst at the same time encouraging fidelity to a particular approach, involves complex clinical reasoning on the part of occupational therapists and others. I have highlighted the evolving nature of the story of the case and how the unfolding narrative was constantly revised, for example in terms of the speed at which it was possible to proceed and in response

to the realisation that not everyone shared the same narrative. Esther also demonstrated responsiveness in adjusting some of the activities following feedback from support workers. Crabtree (1998) described therapists revising treatment stories when they realised that there was a misfit. These are examples of Esther using pragmatic reasoning (Schell and Cervero 1993) alongside other modes of reasoning (Unsworth 2005). This draws on the theory of situated cognition, which emphasises the context in which cognition occurs (Schell and Cervero 1993), including in this case Futures' organisational policies, the support cultures and history of the service and the knowledge, skills and attitudes of support workers.

Throughout the case, Esther's pragmatic reasoning was evident in her realism and willingness to compromise. This partially reflects our previous findings (Lillywhite and Haines 2010) where occupational therapists described how their work was often a compromise requiring realism about staffing levels and skills of staff teams. Throughout the case, however, Esther kept the prospective treatment story and its imagined ending of sensory activity embedded into daily practice in Cavendish House firmly in mind. That aspect of the narrative was something on which she did not compromise, even though she was flexible and responsive in terms of the plot and how this might be achieved. As she said when I discussed this with her:

"I do believe I was only flexible within certain parameters I had in my head. I don't think I would have compromised my professional opinion on the needs of the guys" (Esther e mail, 13.1.15).

Where she did reluctantly, but pragmatically in the end compromise was on the extent of embeddedness that was ultimately achievable, for example accepting fewer examples of authentic engagement per day than she would ideally have liked the staff team to have achieved.

8.4.2 Working with support workers 'like we work with our service users'

Esther described her work with the staff team as similar to how she might work with people with intellectual disabilities themselves. This seemed particularly reflected in efforts to be collaborative rather than directive, in order to support the staff team to feel that they were in control and 'owned' the intervention, rather than having it imposed upon them. Those seeking to empower people with intellectual disabilities need first, it is suggested, to feel empowered in their own roles (Zakrajsek et al. 2014). This supports my conclusions from reviewing the literature that occupational therapists have an important consultative role in facilitating enhanced quality of support and that collaboration in this is important. It highlights for me the parallels between the occupational therapy approach with those living and with those working in the house.

Aware that input from outside can be perceived as criticism or interference (Potts et al. 1995) and of the history of very directive leadership within Cavendish House, Esther was mindful of how she was perceived by the team, not wanting to be seen as imposing her interventions on them. Avoiding an overly formal approach, she built on existing relationships, used humour to contribute to being perceived as unthreatening and named (to me) what she was doing as "educating gently" and "training with a small 't'". Whilst clear about what she wanted to achieve, she took efforts not to put Sue or staff members in positions where lack of knowledge was highlighted too explicitly (see Vignette 1, scene 4). A collaborative approach in which the team participated in decision making about the sensory activities that were appropriate for each person might, as Anderson and West (1996) suggested, have contributed to investment from the team.

Support workers need to feel involved and supported (Reynolds 2013). As previously explained, work stress can result from an interaction between job demands, workplace constraints and available support (Payne 1979), but a supportive working environment (in terms, for example, of available resources, training and personal support) seems positively correlated with job satisfaction and negatively correlated with burnout (Dyer and Quine 1998). Social support in particular has been found to moderate how job demands impact on stress (Rose et

al. 1998) and personal and organisational supports are suggested to increase perceptions of personal accomplishment and reduce emotional exhaustion (Mutkins et al. 2011). A respectful relationship between professional and team, with negotiated and jointly agreed goals (Lewer and Harding 2013), recognition of support workers' skills (Goodman et al. 2009) and the conceptual and emotional pressures of their role (Wilson et al. 2009) are all emphasised in the literature and visible in the way that Esther worked. She made efforts to recognise the different strengths individual team members brought to their work and sought to ensure that they were aware that she valued the support they provided to Matt, Steve, Jane, Becky and Harold. She tried to empower them and make their jobs more interesting by allowing them the motivation that might come from supporting a greater variety of activity.

Being present in the house frequently provided opportunities for ongoing support, progress monitoring and feedback. These have been found to be important in other studies (Stewart et al. 2009, Cocks and Boaden 2011, Reynolds 2013), including the active support literature (for example, Mansell and Beadle-Brown 2012). For three months, she asked support workers to complete recording sheets every time they carried out one of the activities on Matt, Steve, Becky, Harold and Jane's session plans. Wanting support workers to know there was a purpose to filling these in, she was particularly frustrated to find out that extensive feedback she had given Sue regarding these records had not been communicated in detail to the wider team as she had hoped. This then prompted her to attend handover meetings the following month in order to feedback to the team directly so that the work they were doing could be acknowledged. Investigating predictors of burnout, Vassos and Nankervis (2012) found that effective mechanisms for job feedback were positively related to support workers' sense of personal accomplishment, which suggests that Esther was right to emphasise this.

Graves (2007) highlights how, despite efforts to be collaborative, such relationships between professionals and support workers are not egalitarian with equally shared power, for there is a disparity of knowledge, expertise and perceived status. At the end of the day, despite making efforts to be collaborative, Esther did have a particular way of working in mind that she strongly felt that the

team needed to adopt, in the same way that speech and language therapists place importance on their recommendations to ensure safe eating and drinking being followed to reduce risks of aspiration, chest infections and choking (Chadwick et al. 2006, Tredinnick and Cocks 2014). A tension can therefore be seen in the case and in the consultative role of professionals generally, between a wish to empower the staff team and a wish for implementation fidelity. Esther seemed able to come closer to a relationship of equals with some support workers (e.g. Jean), than she was able to achieve with others (e.g. Olly and Doug), though with significant effort, she managed to achieve a particularly collaborative relationship with Sue, the manager of the service. She sought to change practice through creating a visionary story of sensory activity embedded into Cavendish House (see 8.1.2) and through working as what could be seen as a transformational leader (8.3.1.2.d), but perhaps achieving more would have required being even more collaborative. Her vision was not shared by everyone in the case and arguably she could have either adapted this vision to incorporate more of the values, expertise and goals of the support staff, or made it more explicit how such values, expertise and goals were already incorporated into and represented in this vision.

As well as explaining the desired approach to supporting engagement (verbally and in the session plans and reports) Esther and Sarah modelled this in the house, with Sarah in particular doing so repeatedly over a number of weeks to ensure that it was witnessed by as many of the team as possible. Training by example in this way by outside professionals like Esther, has been found to be more effective than theoretical training alone (Graves 2007, van der Linde 2014), potentially increasing both staff confidence (McDonnell et al. 2008) and knowledge (Chadwick and Jolliffe 2009). Jones et al. (2001a) suggest that working with staff and service users *in context* to support implementation is key and the importance of in situ interactive training, consisting of observation, structured feedback and coaching, is emphasised in the literature on active support (see for example Totsika et al. 2008). Informal on the job learning from observation of more experienced staff and trial and error has been found to be the principal mode of learning in intellectual disabilities services (Bradshaw and Goldbart 2013, Windley and Chapman 2010). Esther's DVD recording of examples of each person being

supported to engage in the way that she envisaged is regarded as a good medium for promoting changes in thinking (Dobson et al. 2002).

What Esther seems to have been aiming for in seeking to embed her vision of sensory activity was to develop a sustained community of practice in Cavendish House (Wenger et al. 2002), in which the support workers were actively involved and which could shape their collective learning. Bradshaw and Goldbart (2013) found that the knowledge development practices most valued by support workers were characteristic of such communities of practice, something also noted by Rayner et al. (2014) in the collective reflection, guiding and mentoring that supported three support workers' intensive interaction training and practice. Those support workers emphasised the importance to them of training being experiential and described powerful shifts in thinking and a deeper understanding of those they were working with, both reminiscent of learning described by manager Sue and support worker Jean.

Despite Esther's efforts, the case seems to have fallen short of achieving the fully interactive training recommended in active support and/ or a complete community of practice, in particular due to the limited success in finding opportunities to provide feedback to support workers on directly observed performance. Esther's plan had been for occupational therapy assistant Sarah to visit three times weekly over a two month period, modelling following the plans with Matt, Steve, Jane, Harold and Becky for one month and then observing staff doing the same the following month, in order to provide feedback. Although some observations under live supervision in this manner were possible, for example of Jean and Polly, staff shortages, communication difficulties, management changes and motivation levels impeded some observations and feedback. Had more observation, feedback and supported reflection been possible, the outcomes may have been improved. Dobson (2002) for example, highlights the benefits in increased self-awareness and culture of reflection that can come from staff commenting on video recordings of themselves following recommendations of professionals like Esther and identifying their own areas for development.

8.5 Occupational therapy supporting engagement: a summary

Having discussed Esther's intervention at length in Chapter 7 and in the preceding sections of this chapter, I now draw together the different approaches she used, in order to summarise what we can conclude about the nature of occupational therapy supporting people with profound intellectual disabilities to engage in occupations at home. I have cross-referenced to the sections where detailed discussion of each point can be found. Later in this chapter (8.7-8.9) I make the contribution to knowledge and limitations of this thesis explicit and propose some implications for practice and recommendations.

Occupational therapy assumes that it is possible for people with profound intellectual and multiple disabilities to engage authentically in occupation (8.2), in other words in a way that we can be reasonably confident is meaningful to them. It sees low levels of such engagement in occupation as occupational injustices, risking occupational alienation, deprivation, marginalisation and imbalance (8.3.1) (7.3.2).

Supporting this authentic engagement requires close, responsive relationships and communication and getting to know people with profound intellectual disabilities very well (7.3.3). In addition to an understanding of individuals' sensory preferences (7.3.3), this detailed knowledge requires awareness of the levels at which they are likely to be able to engage, and the extent to which their communication may be intentional, or pre-intentional (7.3.2). Although it can be difficult to interpret an individual's communication, if we have taken time to get to know them sufficiently well, we can make reasonable interpretations that their behaviour suggests that they are authentically engaged (7.3.1.3, 8.2.1).

Authentic engagement seems to emerge in particular through (and possibly requires) engaging in co-occupations with people with profound intellectual disabilities (7.3.1.4 and 8.2.2). Relating to people using intensive interaction and attuning seems important for engaging in such co-occupations and the occupational therapy approach to facilitating them, recognising developmental levels, was described here as "sensory activity". This involves paying maximal attention to the *process* rather than the end result or outcome of an activity, taking

time to explore tastes, textures, smells, vibrations, temperatures, and sounds potentially part of it, in order for an individual with profound intellectual disabilities potentially to gain some meaning (7.3.1.1, 8.2.3). The approach shares a number of characteristics with active support, including an emphasis on recognising and promoting opportunities for engagement in readily available ordinary activity around the home (7.3.1.1, 8.2.3).

As occupational therapy intervention seems almost inevitably to be time-limited, its focus needs to be on creating and sustaining cultural change in the organisation providing day to day support (7.3.1). This involves facilitating faithful implementation of recommendations regarding how to support authentic engagement (8.4.1). To do this, occupational therapy seeks to empower support workers to sustain a different way of working (8.4), regarding them as “service users” in a similar way to the people with profound intellectual disabilities who are the ultimate beneficiaries of the intervention (7.3.5). Implementation fidelity seems more likely to emerge from collaborative and unthreatening relationships with support workers and managers (7.3.5) and from creative and flexible interventions that provide resources and ideas and encourage creativity in others (7.3.4). Empowering support workers may require recognition of occupational injustices that they may face (8.3.2), including risk of burnout from, for example, role conflict or ambiguity where goals of independence, choice and personalisation are not fully understood (7.3.1.2, 8.3.2).

In seeking to embed a different way of supporting engagement in occupation, it is helpful for an occupational therapist to themselves take on the role of transformational leader (i.e. an agent for change and good role model who can inspire others to achieve higher standards by articulating a clear vision), while at the same time encouraging one or more of the support workers and managers to take on this role. This is an additional way in which occupational therapy shares characteristics with the active support approach, with its focus on practice leadership (8.3.1.2.d), including organisation and allocation of support, focus on quality of life of those supported and review of quality of support provided.

8.6 Reflexivity – the influence of epistemology, ontology and methodology on the case

Before summarising my conclusions and theory of the case in 8.7, I reflect in this section on the various ways in which a qualitative case study, from a social constructionist research stance, ontologically leaning towards relativism and using ethnographic methods, has allowed me to gain understanding in this research. In some ways this understanding was different to that anticipated, with my findings focusing even more than expected on Esther's role with Sue and the team of support workers, rather than on her work directly with those living in the house.

I will begin by highlighting some particular areas in which this study's design facilitated development of understanding, focusing in particular on this single case of occupational therapy as a social construction. I also reflect on some of the challenges I found in using participant observation to gather data.

8.6.1 An occupational therapist's reasoning

Through using a case study methodology I aimed to gain a detailed understanding of an occupational therapist's work and clinical reasoning when supporting people with intellectual disabilities to engage in occupations. With an alternative methodology, I might have limited data collection to interviewing Esther (perhaps several times) about her work. A substantial part of my data collection was in fact carried out in this way, but what I additionally gained from using ethnographic methods was contextual insight. I spent time in Cavendish House, met Matt, Steve, Harold, Jane and Becky and those who supported them and managed their service and saw Esther's work for myself. I could better make sense of her descriptions of her work in Cavendish House, because I had experienced the environment myself and knew the people she was describing. What I feel that the findings provide is a story of the case that is rich in detailed description and which allows, in particular from the use of vignettes, vicarious experience for the reader. It is, to my mind, a much fuller and more detailed depiction of support designed to enable people with profound intellectual disabilities to engage in occupation than otherwise exists in both the occupational therapy and wider intellectual disabilities literature.

Case study methodology has been particularly successful in providing an example of seemingly elusive narrative reasoning. Although in her ethnographic research Mattingly (1991, 1998) identified occupational therapists telling and creating stories about the people they were working with, it is notable how infrequently narrative reasoning in this sense has been described in the findings of other studies. Often, when researchers do identify narrative reasoning (for example, Schell and Cervero 1993, Brooks 2006, Caeiro et al. 2014) they seem to be using the broader definition of this concept and in fact noting *interactive* or *conditional* reasoning. Reviewing the literature, Carrier et al (2010) make reference to occupational therapists telling stories, but not to *creating* them in the sense described in 8.1.2. Unsworth (2004, 2005, 2011) referred to narrative reasoning in Mattingly's sense in the introductions of three research articles, but in interview analysis did not code this as a separate form of reasoning. She coded instead for interactive and conditional reasoning, seemingly because she viewed the entire research interviews as 'stories' of their therapy sessions. Alnervik and Svident (1996) and Lyons and Crepeau (2001) similarly did not code for narrative reasoning and furthermore, it was not evidenced in Munroe's study (1996) of the reasoning of community-based occupational therapists, nor in Ward's research (2003) on mental health group work intervention.

Although it might be concluded from this that occupational therapists (and others) do not often reason in the narrative way suggested by Mattingly, it rather leads me to wonder whether certain research methodologies and methods that have been used to investigate clinical reasoning (for example using single interviews, or focus groups) are less likely to produce insight into narrative reasoning. I suspect, for example, that therapists interviewed about their responses to written case studies by Mitchell and Unsworth (2005) were insufficiently involved in the situation for them to reason narratively in the way that they might in real life. An ethnographic case study on the other hand (Park 2012) exploring in detail interactions in sensory integration-based therapy sessions between occupational therapist Chloe and Dylan, a child with autism, allowed for thick description. It enabled Park to show how an integration of procedural and narrative reasoning led to changes in Dylan's engagement in these sessions.

Mattingly (1991) notes how narrative reasoning is visible in thickly described actual cases from practice, that are rich in context (Stake 1995) such as those in her ethnographic research. Perhaps only methodologies that are likely to produce “experience-near stories” (Mattingly and Garro 2000, p.27) of occupational therapy and which provide vicarious experience for the reader are likely to evidence occupational therapists’ narrative reasoning? In describing this case thickly, I have created a sufficiently experience-near story for Esther’s use of narrative reasoning to become evident.

8.6.2 The lives and occupations of people with profound intellectual disabilities

A second aim was to gain something of the perspective of people with profound intellectual disabilities themselves. Beail and Williams (2014) note how, in a field dominated by quantitative studies, qualitative research is beginning to increase our understanding of the experiences and lives of those with intellectual disabilities. By using a research design that has allowed me to place them centrally in this thesis, I do feel that Matt, Steve, Jane, Becky and Harold are more visible and alive in the case than people with intellectual disabilities typically seem to be in the dissemination of research about them. Observations, including (importantly) repeated observations of video recordings of Esther and others engaging with them in co-occupations, have provided some insight into what is important and meaningful to them, the ways in which they might engage in occupation and indicate that they *are* engaged and into how they construct their world. The cognitive and communication disabilities described in 2.3 mean that it is inevitably challenging to gain such insight and I would argue that what has been gained is (and can only be) partial. Having this partial understanding is, however, a useful starting point for flexible and responsive support of authentic engagement in occupation.

8.6.3 A critical understanding of organisational culture

I have described my methodology all along as qualitative case study, though in 4.2.4.1, I noted how I had considered describing it as an *ethnographic* case study, aspiring to understand the socio-cultural aspects of a case (Simons 2009). Looking back now on my findings and discussion, I realise the extent that these relate to

aspects of the organisational and support culture in Cavendish House. My findings highlight occupational injustices that may be present in settings like Cavendish House (both for those with profound intellectual disabilities *and* also for the arguably marginalised group of those supporting them) and how occupational therapy sought to address these and empower both parties. I have ended up taking a more critical stance, in the sense of political purpose (Thomas 1993), in my exploration of issues of unfairness or injustice within the lived domain (Madison 2012) of Cavendish House than I realised I was going to. I feel that I can now justifiably describe my research as a critical ethnographic case study.

8.6.4 Socially constructed stories in a socially constructed case

Despite not carrying out a narrative enquiry, nor formally analysing my data using narrative analysis, my methodology has been particularly effective at allowing certain narrative elements of the case, the narrative reasoning of an occupational therapist for example, to become visible. These narrative elements link with the social constructionist epistemology of my study.

Narratives are suggested to be socially constructed in nature (Finlay 2004), varying depending on the situation, the listener and the manner in which they are told. I explored in 8.1.2 above how Esther constructed prospective stories about each individual living in the house that the wider staff team might also share and how she co-constructed these stories with those, including myself, to whom she told those stories. As well as from discussions with colleagues, her narrative reasoning therefore developed through the process of participating in this research and through reflecting at length in interviews with me about that work. Whilst, naturally, the intervention remained hers, it arose out of this research. Along with other protagonists, I had a role in the co-construction of it: in the process of her becoming part of this research; in the ways that I interviewed her and analysed the data; and in how I shared my findings with her. Both my story of the case (my findings) and the occupational therapy within it can be seen as socially constructed through the interactions between Esther and myself.

A different researcher and/ or a different occupational therapist would have co-constructed a different story. As an occupational therapist in this field with a

research question focused on an aspect of occupational therapy, I am conscious of being a professional insider. I was aware that in many ways I identified with Esther, who I knew and whose role was very familiar to me, being similar to work I had previously carried out myself. Certainly I interviewed and observed her more than any of the other protagonists and her perspective is most visible in my story of the case. This was perhaps inevitable due to having a research question focused on her occupational therapy intervention, but was also due to her being my most accessible participant. I was aware the possibility of a “halo effect” (Standing 2004, p.451) whereby feelings can overcome cognitions when appraising others and how my positive feelings towards aspects of Esther’s personality and work might create biased judgements. I have referred to this in my subjectivity statement (see Appendix 2) and tried to guard against this by deliberately looking for and considering aspects of her work about which I felt less positive (for example, her focus on occupational balance, as discussed in 8.3.1.1).

Having worked in settings not dissimilar to Cavendish House, both as an occupational therapist and prior to that as a support worker and assistant manager, I also became fascinated with the organisational culture there, which led me additionally to identify with many of the support staff and with manager Sue in particular and I have taken steps to represent their perspectives as best I can (for example in the vignettes). My biography and my pre-existing conceptual framework inevitably influenced the choices I made regarding which data to collect and resulted in me focusing on particular aspects of the case more than others, but rather than seeing these as sources of bias, I would argue that they gave me the particular insight, the cultural knowledge, that allowed me to construct this story of the case.

Mindful of Stake’s previously cited description of “the [case study] researcher’s central role as interpreter and gatherer of interpretations” (2008, p.135), I set out to represent multiple perspectives about the case. Aware of how surprisingly open participants had been in interviews with me and acknowledging the potentially contentious nature of aspects of my case, I wanted to give them opportunity to respond to their portrayal. My intention was to discuss my findings with key participants and to include their responses, noting any variations from my own

perspective. In the event, during the period of well over a year that elapsed between the end of data collection and the completed initial draft of my findings, Norma, Sue and a number of support workers left Cavendish House and Esther, my gatekeeper, ended her work there. It only therefore in the end proved possible to discuss my findings with Esther herself.

Sharing an initial version of my story of the case with Esther did, however, prove extremely useful. She was able to confirm that my rendering of the case felt authentic to her, whilst also making a small number of suggestions of areas on which she felt I could expand or clarify. Most notably, whilst largely agreeing with my initial characterisation of her intervention as flexible and adaptable, she made a point of emphasising that she never wavered about the needs of those living in the house and the overall goal of her intervention and that her flexibility was therefore limited to the means of achieving that goal. Further analysis of the data supported this point. Realising this was instrumental in me beginning to see how she had been using narrative reasoning to create an unfolding story leading towards her imagined ending of sensory activity embedded into the way of working in the house. Changes of plan that I had initially thought of as examples of being adaptable and flexible, now could be seen as a series of decisions all designed to further the plot and bring about the hoped for story.

8.6.5 The challenge of using ethnographic methods

Effective as my methodology was in producing understanding, I found participant observation, whilst in many ways exciting and fascinating, overall a challenging method of data collection. I was generally welcomed into Cavendish House, but felt that, despite the explanations Esther and I gave for my presence, not all the staff team fully understood my reasons for being there. Some (Sue and Jean, for example) seemed to accept and even welcome my presence, whereas others (Dave and Olly, for example) seemed more cautious and somewhat suspicious. For some protagonists, particularly those who were cautious about Esther's presence and who I think associated me with her, I think I remained an outsider with an unconvincing reason for being present.

Participant observation is a time consuming method of collecting data. The distance between my home and workplace and Cavendish House meant that I made a total of 17 visits to the house. Whilst this produced a lot of data and was within the range that I had estimated I might carry out, I did feel that there was more that I would like to have seen, in particular observing support workers supporting engagement in occupation. Often when I did visit, however, planned observations or interviews did not prove possible, though responding to the ever-changing environment flexibly meant that something was always gained each time.

As someone who thinks of himself as a competent writer, I was surprised to find that I worried quite a lot about the process of writing field notes and whether or not they were of sufficient quality. Although I spent more time writing field notes than I spent in the field on each visit to the house, I was concerned for some time that what I was writing was not good enough. When I made both immediate jottings on site and subsequent more in depth field notes, my priority was to capture my thoughts as quickly as possible and the resultant notes therefore seemed rougher, messier and more partial than I had expected. In my research journal, I observed that over time, I began writing less extensive field notes than I had done at the outset of the case and despaired about whether I was ever going to be able to depict the case evocatively in writing.

Later, and particularly once I began writing Chapter 6 and started to see the case forming in words, I was more reassured. From this point I started to see my field notes differently. When I look at them now, despite their partial nature, they do immediately and evocatively remind me of the circumstances described and I can picture these in great detail. They are thus very effective at jogging my memory of events. I now see this as their main purpose, rather than being a more literal rendering of what happened, which in hindsight I conclude they were never likely to be. Reaching this conclusion, I was reassured by Jackson (1995) who interviewed ethnographic researchers about the meaning of their field notes to them. Some of her interviewees similarly reported disappointment with their own field notes and that, as their setting became more familiar and their understanding increased, the amount of field notes they produced reduced dramatically. In particular, one respondent's words ring true for me:

“... field notes fix in my memory the incident I’m describing so that when I later read them a flood of detail comes back into conscious memory and the subsequent analysis I do is not of the field notes, but of my memory” (1995, p.49).

8.7 Contribution to knowledge – a theory of the case

In the remainder of this chapter, I draw conclusions about the ways in which understanding has been developed about my research topic, about the extent to which my research question has been answered and the unique contributions to knowledge made by this thesis. I discuss some limitations of the study and suggest some implications and recommendations for practice in both the occupational therapy and wider intellectual disabilities fields. I also propose further research, including some that I might myself undertake and outline my strategy for dissemination of the findings.

I previously explained the ways in which my findings might have relevance beyond the case itself. The particularised knowledge from this single case are transferable in the way previously described: my detailed analysis and thick descriptions provide vicarious experience, allowing the reader to engage with the case, to imagine its details and compare these with their own experiences. Readers can thus make their own naturalistic generalisations (Stake 2008) impacting on their existing understandings of the world (Simons 2009). The case can therefore assist them in the construction of knowledge.

Further to this, the case provides exemplary knowledge, allowing generalisation by abduction (Thomas 2011) in the way previously explained. It can be used to develop theory and explanations that may help understand other cases and situations (Willig 2008) and my theory of the case is what connects ideas, explains patterns and holds the whole case together (Thomas 2011). I have drawn on a theoretical framework from diverse fields of occupational therapy, occupational science, intellectual disabilities, human development and social and organisational psychology. This theory seems not to have been previously combined together in this way.

8.7.1 Addressing gaps in knowledge and methodology within the literature

A particular contribution of this study is to address some aspects that I concluded in 3.5 to be missing from the literature reviewed in Chapters 2 and 3. In focusing specifically on people with *profound* intellectual disabilities, it begins to reduce their marginalisation within research, as observed in 3.5.1. It partially addresses the identified needs to know more about how people with profound intellectual disabilities can engage in occupation (especially at home); how we can develop skills amongst those providing day to day support; and the nature of occupational therapists' roles facilitating each of these two goals.

A further unique contribution is the way that it addresses some of the *methodological* gaps identified in the literature in 3.5.2, with a design that is very different to the majority of studies in the intellectual disabilities field. In building on the research of others (including my own), in using a qualitative methodology, with a social constructionist epistemology and ethnographic methods, in exploring the *process* by which change occurs and in gaining (albeit in a small way) something of the perspectives of people with profound intellectual disabilities, this research has achieved a depiction of practice at a high level of detail and is, I argue, distinctive.

8.7.2 Supporting the findings of others

One contribution of the case is to lend support to a number of the conclusions reached in Chapters 2 and 3 from reviewing the existing literature in the field. I have described in this chapter how it provides additional evidence for my previously reached conclusions that:

- There may be observable indicators when people with profound intellectual disabilities are engaged authentically in occupation.
- Such engagement is likely to require and emerge out of a social context, in other words a supportive relationship.
- The quality of this support is likely to impact on the extent to which people engage in occupation.

- Support workers and service managers may not always have a good understanding of the ways that severe and profound intellectual disabilities can engage in occupation.
- Occupational therapists' key focus with those with severe and profound intellectual disabilities is on *meaningful* engagement in occupation.
- This includes a consultative role facilitating enhanced quality of support, which may best be delivered by means of extensive, or lengthy input and which seems to require complex clinical reasoning.

8.7.3 Exemplary knowledge from this case

In addition to supporting the findings of others in this useful way, the case makes some important *unique* contributions to knowledge:

- It provides a very detailed exemplar of practice of potential insight to occupational therapists and others supporting people with intellectual disabilities.
- It illustrates a way in which it is ethically possible to recruit people with profound intellectual disabilities to a research study involving participant observation in their own homes, even though they may not have capacity to make the decision about participation themselves.
- It illustrates some ways in which occupation may be meaningful for people with profound intellectual disabilities and how they may therefore engage in occupation in ways that are authentic rather than tokenistic.
- It makes explicit something which is implicit in occupational therapy definitions of engagement: that this does not necessarily involve physically doing anything.
- It suggests that occupational therapists may have a particular interest in how people with profound intellectual disabilities spend their time and engage in occupation *at home*, something not generally prominent in intellectual disability policy and research other than the active support literature.
- It demonstrates how occupational justice theory can be a useful framework for considering the occupational lives of people with

intellectual disabilities and the risks they may face of occupational deprivation, alienation and marginalisation.

- It demonstrates how this theory can additionally highlight occupational risks, such as burnout, potentially faced by those *supporting* people with profound intellectual disabilities and how an intervention aimed at promoting occupational justice for people with intellectual disabilities may also (and perhaps needs also to) seek to achieve this for their supporters.
- It is a detailed example of a health professional carrying out consultative work seeking to effect a sustained change in practice through collaboration with a staff team.
- It suggests some ways professionals can promote their recommendations being implemented faithfully by support workers, as well as some reasons for low implementation fidelity.
- It demonstrates how an occupational therapist's intervention may progress through reasoning narratively and how this can propel an intervention towards a hoped for ending.

8.7.3.1 Petite, or fuzzy, generalisations

This exemplary knowledge can be presented in the form of the following five "*petite generalisations*" (Stake 1995, p.7), or "*fuzzy generalisations*" (Bassey 1999, p.51), each accompanied by supporting explanation. These statements make no absolute claim to knowledge and I recognise that there will be exceptions to them. Their credibility rests in their contextualisation, i.e. when they are read in conjunction with the more detailed descriptions in chapters 6 – 8 of the case from which they are derived.

The construction of these fuzzy or petite generalisations in this way represents a tentative theory of the case – a thinking tool, exemplary knowledge, or phronesis – from which generalisation by abduction may be possible. This theory relates directly to how an occupational therapist might embed a change in the way engagement in occupation is supported in a setting like Cavendish House, but I suggest that it may be of equal relevance to occupational therapists and other professionals seeking to embed different sorts of changes into similar settings.

Petite Generalisation 1.

Aspects of the organisational culture in the settings where people with profound intellectual disabilities live may impact on whether they are supported effectively to engage in occupation there.

Such aspects include the extent to which:

- The values of those providing support are aligned with those of the organisation.
- Those supported are constructed as 'like us' rather than 'other'.
- The culture is supportive of innovation.
- Planning and leadership is encouraged.

Opportunities to support engagement in occupation may be missed, which is likely to result in low levels of engagement, risking occupational deprivation, alienation and marginalisation.

Where the organisational culture is in the process of changing (for example, following a major transition in service philosophy such as adoption of supported living) there may be a particular need for those seeking to effect change to remain aware of any cultural conflict and/ or misalignment of values with the new culture.

Those working with people with profound intellectual disabilities may need training and support (provided either within their organisations, or by occupational therapists or others from outside) to understand how people can be capable of engaging in occupation *despite* having profound intellectual disabilities and complex health needs and how they can be supported to engage in occupations in authentic ways.

Petite Generalisation 2.

Recognising the level at which it is possible for people with profound intellectual disabilities to engage in activity and occupation seems to be important if they are to be supported to engage authentically (as opposed to in a merely tokenistic way).

Support workers and managers may find explanation of the developmental theory that underpins support for authentic engagement, for example the Pool Activity Levels (Pool 2012), insightful in helping them to understand how to achieve this:

- As people may only be able to engage in occupation at a sensory level, support may be best focused on adapting everyday personal care, domestic and leisure activity so that the sensory aspects of those activities are prominent, paying maximal attention to the process rather than the end result.
- As authentic engagement seems mostly to emerge from close relationships, support may best be focused on promoting shared physicality, intentionality and emotionality within co-occupations.

Signs that someone is engaged in occupation are observable, but these signs may be subtle, as being engaged in occupation seems not necessarily to require physical activity. Recognising these signs and understanding what might indicate engagement appears to require getting to know the person being supported very well.

Not feeling able to judge whether the person one is supporting is engaged in an activity may reduce motivation to persist with support and/ or to supporting engagement without enthusiasm or in a half-hearted way, less likely to be meaningful or successful.

Supporting engagement at a sensory level using ordinary daily activity, as opposed to using specialist equipment in a multi-sensory room, may provide helpful structure and be intrinsically motivating for support workers. It may then potentially be something that they might be inclined to persist with for longer and to try more frequently.

Petite Generalisation 3.

Support workers and managers of services may use words such “independence”, “choice” and “personalisation” as part of everyday language, but the way these concepts are meaningfully relevant to people with profound intellectual disabilities may nonetheless not be fully understood by them.

To prevent paying only lip-service to these concepts (and to support authentic engagement in occupation) support may be required to develop a more nuanced and meaningful understanding.

Not fully understanding these terms may lead to role ambiguity. As well as limiting opportunity to carry out work in meaningful ways, this may place support workers at risk of occupational alienation and burnout.

Recognising that these terms may not be fully understood (and the potential implications of this) may be helpful to organisations seeking to improve the practice of their support workers, for example when introducing active support into services.

Petite Generalisation 4.

An important focus for occupational therapists working with people with profound intellectual disabilities seems to be to facilitate a sustained cultural change in the way that engagement in occupation is supported at home.

Occupational therapists seem to have a particular interest in how people with profound intellectual disabilities spend their time and engage in occupation *at home*. This interest matches the emphasis on activity at home in active support, but could otherwise be more prominent in intellectual disability policy and research.

The case provides evidence to support occupational therapists having a focus on the quality of people’s engagement in occupation and to support them investing their time in extensive work to enable this. Effectively embedding a sustained new

way of working so that recommendations are implemented faithfully seems to require investment of a substantial amount of time, energy and creativity. More priority may need to be given to implementing recommendations made.

A clear and optimistic vision seems necessary, with creativity, flexibility and compromise, where necessary, about the means of achieving it. That vision and the reasoning behind it need to be clearly communicated to support workers and service managers.

Sustained change seems more likely to be achieved from working with support workers and managers in a collaborative and empowering way, possibly reflective of the way occupational therapists work with people with intellectual disabilities. Ensuring that support workers feel valued and have a sense of autonomy potentially reduces lethargy and increases support for innovation, initiative taking and leadership.

Resources and training specific to the individuals being supported and reflective of the actual context in which support is to be delivered seem to be more valued by support workers and managers than more general training:

- Possessing local knowledge seems to be a key factor in enabling change and support workers and service managers need convincing that recommendations from outsiders are based on a good understanding of those they are supporting.
- Providing filmed examples (for example on a DVD) of the way support is recommended to be carried seems a useful way of promoting implementation fidelity of recommendations regarding supporting engagement.

Focusing, directly or indirectly, on reducing any occupational risks (such as burnout) that support workers might face, may improve their working lives and enhance their levels of resilience, promoting occupational justice for them at the same time as improving the quality of support provided to people with intellectual disabilities.

Petite Generalisation 5.

Narrative reasoning seems to help occupational therapists to propel their interventions towards hoped for endings. Opportunities for reflection may be important facilitators of such reasoning.

Opportunities, provided in this case within research interviews, may similarly be provided by clinical supervision, potentially highlighting the importance of this.

8.8 Limitations

To reiterate points already made in Chapter 4, the findings I have presented and the conclusions I have drawn consist of my interpretations as a professional insider from just one single case of occupational therapy. I make no assumption that this case and the findings are necessarily generally representative of occupational therapy practice. Esther's intervention, for example, did not involve family members in any way, which could be seen as unusual. It cannot be assumed that her qualities visible in the case, her dynamism, enthusiasm and persistence, for example, are shared across all occupational therapists (though she herself considered her approach to be based on more than just her personality, describing it as resulting from her experience and training as an occupational therapist and as something she felt able to develop in others).

In particular, it cannot be assumed that this case represents typical or even common practice: the reason for not being successful in recruiting from NHS Trust A seems, for example, to have been because potential occupational therapists from that Trust no longer felt able to do the kind of work explored in this study. It could be argued that transferability of the findings is limited where insufficient funding in the current climate means that interventions of this type are often not possible. I would, however, counter this argument, by saying that the findings can be seen as aspirational and used to argue the case for carrying out occupational therapy differently, including by extensive intervention of a kind perhaps more likely to sustain cultural change and improve support practices.

A further limitation concerns the nature and extent of participant observation that was ultimately achieved. A setting closer to my home would have made more

frequent observation possible and could have allowed more flexible and more spontaneous visits. Perhaps inevitably, with a research question about how an occupational therapist supports engagement and with that occupational therapist a gatekeeper for access to the setting, most of my observations at Cavendish House were with Esther present. Aspects of the organisational culture (including Matt, Steve, Jane, Becky and Harold's individual diaries being locked in their rooms and unavailable at times when they were not present and arrangements made by telephone not consistently transferred subsequently to those diaries) meant that on a number of visits who or what I actually observed was different to that which had been planned. I would like to have observed more of the staff team supporting engagement and on more occasions, especially at times when Esther was not present. In particular, I would like to have gained the perspective of some of the support workers and of Norma and Sue on the findings (or my story of the case) rather than only in the end succeeding in gaining Esther's views.

Furthermore, there is uncertainty about what happened after the case, once Esther's work at Cavendish House had ceased. We do not know the extent to which a change of way of working was embedded and sustained in the long term (Norma and Sue's departures from Cavendish House may have had a negative impact on this, though new manager Maureen's interest in Esther's work (see Vignette 1, scene 10) might be seen as a more positive sign).

These gaps in the data do mean that my conclusions regarding the extent of the staff team's adoption of Esther's recommendations need to be read cautiously, which is why I have expressed them tentatively. The uncertainty limits any conclusions that can be drawn regarding the effectiveness of Esther's strategies, but I would point out that I did not set out to evaluate her practice, but merely to explore it. It is hoped that the description of the case along with my reflexivity (including in this section) is sufficiently detailed and rich to construct vicarious experience for the reader, to provide an audit trail of how I have reached my conclusions and to allow judgement as to the plausibility of the case and findings.

8.9 Implications and recommendations for practice

The transferability, or naturalistic generalisation in which it is possible for the reader to engage from reading the detailed description of this case study and the exemplary knowledge that it provides, are suggested to be particularly useful for professional practice (Thomas 2011). The findings have direct implications for occupational therapists working with people with severe and profound intellectual disabilities, but additionally, some aspects of the findings are relevant to a wide range of professionals interested in the quality of services provided to people with severe and profound intellectual disabilities. This includes those working in and managing such services and professional colleagues of occupational therapists in community intellectual disability teams like the one in which Esther worked. Wider still, there are potential implications for those providing services to other people with high support needs, such as people with dementia.

The following recommendations can tentatively be made.

8.9.1 Recommendations for occupational therapists (and others) seeking to embed change in intellectual disabilities (and other) services

The findings suggest that, when working with people with profound intellectual disabilities, occupational therapists should:

1. Remain aware that support workers and service managers may realise that occupational therapy has a potential role in supporting engagement in occupation and that therefore there may be a need to explain and promote this role.
2. Promote occupational justice (in particular, at home) by enabling people to engage in occupation in ways which are authentic rather than tokenistic.
3. Facilitate a sustained cultural change in the way that engagement in occupation is supported in people's homes. This requires working collaboratively with those providing direct support to empower them to enhance the quality of that support and to develop their understanding of how to support authentic engagement in occupations. Enabling support

workers to adopt recommendations faithfully and sustainably may require extensive, or long-term input.

4. Encourage constructions of people as individuals who, despite profound intellectual disabilities and complex health needs, are nonetheless capable of engaging in occupation.
5. Use developmental theory, such as the Pool Activity Levels (Pool 2012), to help support workers and managers to understand the levels at which people are likely to be able to engage in occupation and the fact that people may only be able to do so at a sensory level. They should:
 - Encourage support workers to adapt everyday personal care, domestic and leisure activity so that the sensory aspects of those activities are prominent, paying maximal attention to the process rather than the end result.
 - Promote shared physicality, intentionality and emotionality within co-occupations.
 - Recognise that engagement in occupation does not necessarily involve physically doing anything.
6. Facilitate an understanding of the terms “independence”, “choice”, “empowerment” and “personalisation” that is meaningful for people with profound intellectual disabilities and that goes beyond paying only lip service to such goals. This requires acknowledging that:
 - Support workers and service managers may not recognise how these terms may be understood in this context.
 - Not fully understanding these terms and not feeling able to recognise engagement in occupation may reduce motivation to persist with support, lead to supporting engagement in a half-hearted way and be less likely to be meaningful or successful. By limiting support workers’ opportunities to carry out work in meaningful ways, it may lead to role ambiguity and possibly place them at risk of occupational alienation and burnout.
7. Provide resources and training specific to individuals being supported and reflecting the real context in which support is to be delivered, as

these seem to be more valued by support workers and managers than general training:

- They should make it clear how they have gained a good understanding of the individuals about whom they are making recommendations, so that it is apparent to support workers and service managers that, despite being outsiders, they have the requisite “local knowledge”.
 - Filming examples of support being carried out in a recommended way, may be helpful in sustaining this practice.
8. Recognise the way in which organisational culture may impact on implementation fidelity of occupational therapy recommendations, for example:
- Where an organisation is going through or has been through a cultural transition, any cultural conflict and/ or misalignment of values with the new culture.
 - The way that role conflict, role ambiguity and perceived lack of equity in working relationships can be occupational risks for support workers which may contribute to burnout and high staff turnover and interfere with implementation fidelity.
9. Seek out opportunities to reflect verbally about their work (including in clinical or peer supervision) as these seem to facilitate narrative reasoning through telling and creating stories about work.

8.9.2 Recommendations for service providers

The findings suggest that providers of residential and other services for people with profound intellectual disabilities should recognise that:

1. Support workers may have training needs regarding:
 - Supporting engagement in occupation.
 - Recognising indicators of engagement in occupation.
 - The meaning of “independence”, “choice”, “empowerment” and “personalisation” in relation to people with profound intellectual disabilities.

2. Training (including from outside professionals, such as occupational therapists) and internal systems such as regular staff appraisals, team meetings and supervision, may all be important in meeting such needs.
3. If these needs are not met, resultant role ambiguity may contribute to burnout and high staff turnover, as well as low levels of engagement in occupation amongst those supported.
4. Planning and strong leadership is needed within services in order for engagement in occupation to be supported effectively.
5. Even some time after a change in the organisational culture (such as a transition to a supported living model) cultural conflict and/ or misalignment of values with the new culture may remain and impact on the quality of support provided.

8.9.3 Recommendations for education of occupational therapists and other health professionals

There may be a need to enhance content of curricula on pre-registration occupational therapy (and other health professions) courses regarding the skills of collaboration with service managers and support workers to embed sustained changes in support practices.

8.9.4 Recommendations for intellectual disabilities policy

Greater prominence should be given in policy to how people with profound intellectual disabilities spend their time and engage in occupation at home.

8.10 Further research

The case demonstrates the potential of case study methodology and ethnographic methods to gain a deep understanding of an aspect of occupational therapy and the organisational culture within the setting where it takes place. In this section, I outline some ideas for further research building on the story I have told, including possible post-doctoral research I may carry out myself.

I remain particularly interested in the efforts of occupational therapists and others to embed different ways of working into intellectual disability (and other residential) services. As Esther was only partially successful in this, there is more

that we need to know about how occupational therapists and others can achieve implementation fidelity:

- The case highlights for me how complex it is to understand and effect change in an organisation when one is an outsider. I suggest that future research, whether or not using case study methodology and ethnographic methods, would need to be more participatory in nature. A participatory action research project involving support workers and managers from a setting like Cavendish House might help further an understanding of the process of collaborating to effect change in such a setting and might overcome some of the tension of implementing recommendations made by an outsider.
- Further research could investigate the impact of providing filmed examples (along the lines of Esther's DVD) demonstrating support recommendations on their faithful implementation by support workers.
- Anecdotally, it seems that inclusive arts practitioners seek similarly to promote authentic engagement by people with severe and profound intellectual disabilities, in their case in art and craft activities, though the research evidence base for this work appears slim. Further research, using a similar methodology and methods to mine, could potentially look at an inter-disciplinary collaborative intervention between an occupational therapist and an inclusive arts practitioner both seeking to promote authentic engagement in occupation by people with profound intellectual disabilities.
- I am particularly interested in my finding that widely referred to and superficially straightforward concepts such as independence, choice, personalisation and empowerment seem poorly understood by support workers and managers in services supporting people with profound intellectual disabilities. There is a need to establish the extent and nature of their understanding in more detail by exploring further how they understand these concepts in the context of those they are supporting and what examples they give of promoting them in their work. This could

highlight training needs as well as informing future collaborative work by occupational therapists and others.

- Esther's intervention was based on an assumption that engagement in occupation would improve the wellbeing of the people with profound intellectual disabilities living in the house. Further research could evaluate the extent to which engaging in the ways she recommended is successful in achieving this.
- Further research could explore the impact that enabling support workers to successfully support authentic engagement in occupation (and recognise when there are beneficial outcomes) may have on support workers' prosocial motivation, judgement of the equity of their working relationships and risk of burnout.
- Further research could explore the extent to which clinical supervision facilitates occupational therapists to reason narratively in the way in which the research interviews encouraged Esther to in this case.

8.11 Strategy for dissemination

My evolving plan for dissemination of the findings of this study includes the following.

8.11.1 Internal conference and other presentations and teaching

- Incorporation of findings from this research into my pre-registration occupational therapy teaching - I gave an initial presentation to pre-registration MSc Occupational Therapy students on 28.5.15 and will develop my teaching further by including content on authentic engagement by people with profound intellectual disabilities and collaboration with support workers to ensure implementation fidelity.
- Presentation of findings at University of Brighton Doctoral Conference (21-22.7.15).
- Centre for Health Research Seminar Programme (session for colleagues to be arranged in 2015-16 academic year).

8.11.2 External conference and other presentations

- Paper presentation (topic: authentic engagement in occupation and/ or implementation fidelity) at International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Special Interest Research Group - Profound Intellectual and Multiple Disabilities (SIRG-PIMD) Roundtable (23-25.9.15), Mälardalen, Sweden (abstract submitted).
- Presentation at College of Occupational Therapists Specialist Section – People with Learning Disabilities Annual Conference and Study Day (London, 23rd October 2015) (abstract submitted).
- Paper presentation at College of Occupational Therapists Annual Conference, Brighton, June/ July 2016 (abstract due September 2015).

8.11.3 Academic publications

I plan to publish a number of articles focusing on different aspects of my findings and methodology, most likely in the occupational therapy, intellectual disability and qualitative research peer-reviewed journals indicated below.

- The nature of authentic engagement in occupation for people with profound intellectual disabilities (*British Journal of Learning Disabilities* and/ or *Journal of Applied Research in Intellectual Disabilities* and/ or *Research in Developmental Disabilities* and/ or *British Journal of Occupational Therapy*).
- Addressing occupational injustices (*British Journal of Occupational Therapy* and/ or *Journal of Occupational Science* and/ or *British Journal of Learning Disabilities*).
- Empowering support workers to sustain a different way of working (*Journal of Applied Research in Intellectual Disabilities* and/ or *British Journal of Learning Disabilities* and/ or *British Journal of Occupational Therapy*).
- My use of case study methodology (in *Qualitative Health Research* and/ or *Research in Developmental Disabilities* and/ or *British Journal of Occupational Therapy*).

- The ethical aspects of involving people in research who lack the capacity to make the decision about participating themselves (*Journal of Policy and Practice in Intellectual Disabilities*).

I have been invited to write a chapter about this social constructionist case study by the editors of a proposed book, which seeks to give examples of qualitative research from differing ontological and epistemological stances. A publisher is currently being sought for this book.

8.11.4 Wider dissemination

As well as presenting and publishing the findings for an academic and health professional audience, I am keen to explore ways that I can make them accessible more widely, including to support workers, service managers and people with intellectual disabilities themselves. Although I need, in due course, to think this through more fully, my initial ideas include:

- Writing up key findings in an accessible format and/ or presenting them to people with intellectual disabilities, perhaps at self-advocacy groups and local Partnership Boards. This will include a presentation to the people with intellectual disabilities who formed my consultation group.
- A report, or book aimed at providers of services for people with severe and profound intellectual disabilities.
- Building on the vignettes (e.g. Esther's monologue in Vignette 1) and ideas from ethnodrama, to explore creative ways of dramatising or filming the findings.

Chapter 9. CONCLUSION

This research has explored a case of occupational therapist Esther's work with Steve, Harold, Becky, Jane and Matt, five people with severe and profound intellectual disabilities and those that support them in their home, in Cavendish House.

A story of the case has been told with two overarching themes: the impact of shifting support and leadership cultures within Cavendish House on engagement in occupation by those living there; and characteristics of the occupational therapy intervention that aimed to create and sustain cultural change in the way that such engagement was supported there. That intervention had a particular understanding of authentic engagement in occupation; was underpinned by theory; involved getting to know those living in the house well; was creative and flexible; provided resources and ideas; and sought to work with the staff team and managers in a collaborative and empowering way. Three vignettes, constructed from field notes and interview transcripts, have brought the case and participants to life for the reader, illustrating in detail how occupational therapy sought to embed a different way of supporting those living at the house to engage in occupation.

In producing a very detailed exemplar of practice, using a methodology unusual in the intellectual disabilities field, this research is distinctive and the findings potentially have implications beyond the fields of both occupational therapy and intellectual disabilities. Critically considering the findings using theory and research from the fields of occupational therapy and intellectual disabilities has allowed unique contributions to understanding of four concepts:

1. How narrative reasoning, used by Esther as she told and created stories about the lives of those living at Cavendish House, can propel an intervention towards a hoped for ending.
2. That authentic engagement in occupation is possible for those with profound intellectual disabilities and essentially takes the form of engaging with them

in co-occupations at a sensory level, not necessarily involving them physically doing anything.

3. How occupational therapy sought to address occupational injustices not only for those with profound intellectual disabilities (who faced low levels of authentic engagement in occupation and, arguably, occupational deprivation, alienation and marginalisation), but also for those supporting them (who could be seen to be at risk of burnout, due to role ambiguity).
4. How occupational therapy sought to sustain a different way of working and facilitate faithful implementation of recommendations for supporting engagement by collaborating with and empowering support workers and service managers.

Exemplary knowledge from the case has been presented as a tentative theory of the case in the form of five “*petite generalisations*”. These are transferable beyond the case, but their credibility rests in their contextualisation, i.e. when they are read in conjunction with the more detailed descriptions of the case:

1. Aspects of the organisational culture in the settings where people with profound intellectual disabilities live may impact on whether they are supported effectively to engage in occupation there.
2. Recognising the level at which it is possible for people with profound intellectual disabilities to engage in activity and occupation seems to be important if they are to be supported to engage authentically (as opposed to in a merely tokenistic way).
3. Support workers and managers of services may use words such “independence”, “choice” and “personalisation” as part of everyday language, but the way these concepts are meaningfully relevant to people with profound intellectual disabilities may nonetheless not be fully understood by them.
4. An important focus for occupational therapists working with people with profound intellectual disabilities seems to be to facilitate a sustained cultural change in the way that engagement in occupation is supported at home.

5. Narrative reasoning seems to help occupational therapists to propel their interventions towards hoped for endings and opportunities for reflection may be important facilitators of such reasoning.

Implications of this new knowledge are suggested for occupational therapists working with people with severe and profound intellectual disabilities (and for occupational therapy education), as well as also for a wide range of people interested in the quality of services provided. This includes those working in and managing such services and other professionals working alongside occupational therapists in community intellectual disability teams. There are also potential wider implications for other groups of people with high support needs, such as people with dementia.

Overall, it is hoped that these findings can contribute to Mansell's call (2010), referred to at the very beginning of this thesis, for new models of providing services in a person-centred way to enable us to raise our sights for people with profound intellectual and multiple disabilities.

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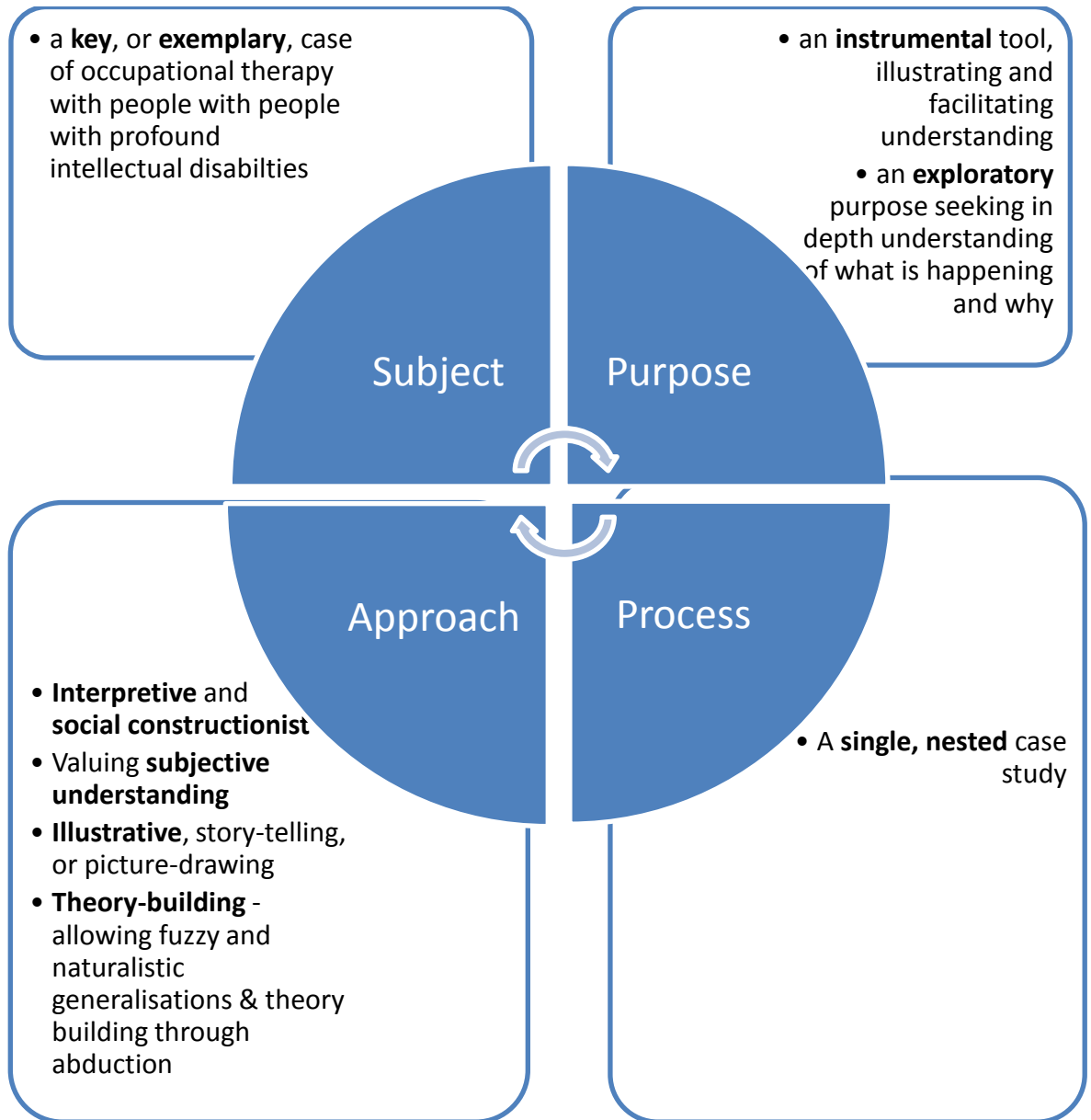
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APPENDICES

Appendix 1: Summary of nature of case study carried out



Appendix 2: Subjectivity Statement

*As well as through reflection in my research journal, one way in which I contributed to maintaining a reflexive stance within this research and made my knowledge, understanding and values, predispositions and feelings explicit was, to pull together my thoughts into (and add to from time to time) a **subjectivity statement**. I used this document to keep track of my own subjectivity and to highlight when I might need to take particular care try to be more objective when, for example, gathering or analysing data.*

The following extracts from this document, are presented to make aspects of my subjectivity more transparent.

I have worked with adults with intellectual disabilities in varying ways for over 20 years. I have, for example been a support worker and assistant home manager in settings not dissimilar to Cavendish House and have had jobs like those carried out by Norma, Jean, Doug and others.

I am myself an occupational therapist and have carried out that role in community teams similar to the one in which Esther works. I have inputted as an occupational therapist into settings like Cavendish House, working to increase the engagement of people with profound intellectual disabilities to engage in occupation.

I am passionate about people with intellectual disabilities, and in particular those with more complex needs (such as profound intellectual disabilities) being supported well and recognise that I can be critical of the quality of support that is sometimes provided. I loved working as a support worker and feel I did this well and that the teams I worked in and the organisation we worked for provided good support. I like to think that this has provided me with some credibility when I have made recommendations as an occupational therapist for support workers to follow and that it has given me confidence in judging that what I am asking is realistic.

I enjoy working with people in an empowering, enabling way and have gained great joy and satisfaction from seeing people (including those with severe and profound intellectual disabilities) develop their skills and engage in occupation even in very small ways. I carry with me assumptions that it *is* possible for people to engage in meaningful ways and about what those meaningful ways might be (and other ways that I consider to be tokenistic). I need to be open to other perspectives on this.

Thinking both of people I have worked alongside as a support worker and that I have asked to follow my recommendations as an occupational therapist, some stand out in my mind either very positively, or because I feel very critical about aspects of e.g. their work, attitude or values. I need to be mindful to try and avoid transferring my thoughts about those people onto participants in the research (e.g. that Doug is just like person x, Jean is like person Y).

Although I have not directly worked with Esther, we have known each other for a number of years, our paths crossing at conferences, meetings and so on over a number of years. I was aware of and respected the quality of her work prior to her becoming a participant in my research. I need to observe her practice with an open mind and not be blind to negative aspects, or aspects about which I might be critical.

I have strong feelings associated with my choice of topic and a high degree of emotional investment in it (e.g. my criticism of residential services that do not meet the occupational needs of the people they purport to support and my feeling that occupational therapists have something to offer in addressing this).

I do want to increase the evidence for occupational therapy in this area, though my overarching motivation is that this research might contribute to improving people's quality of life. I need to be mindful, though, of the risk of this research being (or even just appearing to be) merely self-serving for the benefit of the occupational therapy profession.

In my role as an occupational therapist, I am used to going into a residential settings, explaining my purpose, building rapport, carrying out assessments and

making recommendations etc. I am wary about the reaction I might get as a researcher however – will I be received with suspicion or hostility? How comfortable will I feel observing practice? Might I avoid certain situations that feel uncomfortable?

Appendix 3: Participant information sheet – occupational therapist

PART 1

1.1. STUDY TITLE

Engaging people with learning disabilities and complex needs in occupations at home: exploring the occupational therapy approach

1.2. INVITATION PARAGRAPH

My name is David Haines and I am an occupational therapist, currently working as a Senior Lecturer at University of Brighton. I am carrying out some research for a professional doctorate in occupational therapy and I would like to invite you to take part in my study. Before you decide I would like you to understand why the research is being done and what it would involve for you. This information sheet is particularly detailed due to the nature of the study and the importance of you fully understanding what will be expected of you before volunteering.

Part 1 of this Information Sheet tells you the purpose of this study and what will happen to you if you take part. Please read Part 1 and then, if you are considering participation, please go on to read Part 2 which will give you more detailed information about the conduct of the study.

I will go through this information sheet with you. Ask me if there is anything that is not clear and I will answer any questions you may have. Talk to others about the study if you wish.

1.3. WHAT IS THE PURPOSE OF THE STUDY?

This study concerns people with learning disabilities and complex needs, that is to say those with profound and multiple learning disabilities, or those with moderate or severe learning disabilities who have additional needs (for example, physical, sensory or mental health needs, autism, or behaviour that challenges those that support them). Such people often have too little to do. Opportunities may be missed by those supporting them to enable meaningful engagement in daily occupations, including their own self-care and domestic activities at home. This has an impact on their health and quality of life.

Occupational therapists are often involved in addressing these needs. Previous research suggests they feel their role in doing this is important, though the exact nature of this role and whether and how it may differ from the input of others is not clear from this research. The purpose of this study is therefore to explore the ways occupational therapists support, encourage and enable people to do more at home. I will explore in depth, from multiple perspectives and in a 'real life' context, a "case" which will consist of the occupational therapy of a small number of people with learning disabilities and complex needs. As a researcher, I will actively participate in this occupational therapy, observing and interviewing all those involved – the occupational therapists, individuals with learning disabilities and others such as support workers, or family members – in order to gain understanding.

The study aims to answer the research question "In what ways do occupational therapists support people with learning disabilities and complex needs to engage in occupations at home?"

1.4. WHY HAVE I BEEN INVITED?

You have been invited because:

- you are an occupational therapist, registered with the Health Professions Council; and
- you consider yourself to be experienced in supporting people with learning disabilities and complex needs to engage in their occupations at home; and
- you regularly undertake this kind of work; and
- you are likely to have people with learning disabilities and complex needs who need this kind of input from you on your waiting list or caseload in the next few months.

I am looking for a small number of occupational therapists such as yourself (probably up to four) together with a small number of their clients with learning disabilities and complex needs to participate in this study. I will begin by recruiting a single occupational therapist, but will likely seek to bring new participants into the study as it proceeds until I judge that I have sufficient data.

Solent NHS Trust has agreed that I can seek to recruit its occupational therapists and learning disabled service users as participants. It has received full ethical approval as described in 2.6 below.

1.5. DO I HAVE TO TAKE PART?

It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form, though you will be free to withdraw at any time, without needing to give a reason.

1.6. WHAT WILL HAPPEN TO ME IF I TAKE PART? WHAT WILL I HAVE TO DO?

If you agree to participate, the following will happen/ be asked of you:

INVOLVEMENT IN RECRUITMENT OF PARTICIPANTS WITH LEARNING DISABILITIES

I will first seek your support in recruiting either one or more participants with learning disabilities and complex needs:

- You and I will work closely together to agree criteria that can be used to determine whether someone with learning disabilities and complex needs is relevant to this study.
- I will then ask you to use these criteria to consider people on your caseload or waiting list who could be invited to participate.
- You and I will then (in general terms and without you at this stage divulging any identifiable personal information) discuss and agree who of these people it might be best to approach.
- I will then ask you to make the first contact with this person/ these people and their family or carers to see if they have any initial interest in finding out more about the study and are happy for me to contact them.
- If any people or their carers show such interest, I will then give them a full explanation of what participating in this study will involve (using a different version of this information sheet) and will answer any questions they may have.
- If they remain interested in considering participation, you and I will then work together to recruit them to the study, ensuring in particular that the provisions of the Mental Capacity Act 2005 are complied with. This will involve assessing their capacity to consent to participate in the study (taking into account information from others who know them well) and then ensuring that they are either enabled to give informed consent, or that a suitable consultee is involved and a decision to participate or not is made in their best interests. Note that research does not necessarily need to confer *direct* benefit to be in someone's best interests as there may be wider benefits to people like them, for example increasing our understanding of how to support people well.

EXPLORATION OF YOUR OCCUPATIONAL THERAPY WITH THESE PARTICIPANTS

To gain in depth understanding in context, I will spend time with you on successive occasions as you carry out your occupational therapy assessment and treatment with the person or people with learning disabilities and complex needs. I will explore what is going on as it takes place and will work and participate closely with you to understand what you do. My main ways of gathering information will, on several occasions, be:

- Observation of you together with the person/ people with learning disabilities;
- Video recording of particular aspects of this occupational therapy (both when I am present and, by yourself or others, at times when I cannot be present);
- Informal/ ad hoc interviews with you during/ immediately after observations;
- A small number of more formal interviews with you about the case, sometimes using the above video recordings to elicit reflection on your practice;
- analysis of the occupational therapy clinical notes of those recruited to the study and / or of artefacts created as part of their occupational therapy.

INVOLVEMENT IN RECRUITMENT OF OTHER PARTICIPANTS

At any point during your occupational therapy it may become apparent that someone else (e.g. a support worker or family member of a participant with learning disabilities) is relevant to the case and therefore potentially a useful participant in this research. Should this happen:

- I will ask you to make the first contact with them to see if they have any initial interest in finding out more;
- If they show such interest, I will then give a full explanation of what participating in this study will involve for them and will answer any questions they may have.

1.7. HOW LONG WILL I BE INVOLVED IN THE STUDY?

Before volunteering to participate in this study, please consider the amount of time that this may involve. This is largely dependent on the nature of the occupational therapy needs of the participants with learning disabilities and complex needs that you are working with and your clinical decision regarding the amount of time you remain involved with them.

Ideally, I would like you to remain involved in the study until you have finished working with a particular participant and have discharged them from your caseload. You are in the best position to judge the length of time you would normally expect to be working with such a person, but you should recognise that this could mean me gathering data from you for several months after your initial involvement with recruitment. During those months, I would hope to accompany you to as many of your sessions with them as possible in order to gather data as described in 1.6.2 above.

Much of your participation in this study would involve me observing what you normally do in the course of your occupational therapy practice and therefore would not take up extra time. The total number of hours of such observations will depend on the nature of your involvement, but the absolute maximum is anticipated to be no more than 20 hours.

You should be aware however that some aspects (in particular recruiting the participant with learning disabilities and discussion in interviews with me) could entail you devoting extra time over and above what you would normally do. The absolute maximum number of such hours is estimated to be no more than 20.

Please note, as explained more fully in 2.1 below, that you can decide to end your involvement in the study at any point and if you do I will not ask you to give an explanation for this.

1.8. WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

The main disadvantage of taking part is the possible inconvenience to you of having me present while you are working and the amount of time that you will be asked to devote to this study. Much of the time you will be doing things that are normally part of occupational therapy and thus not devoting extra time. Some of the tasks envisaged in 1.6 will however involve extra time, in particular:

- Involvement in the initial stages of recruitment of other participants; and
- Several informal and a smaller number of more formal interviews with me about your practice.

1.9. WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

I cannot promise that you will directly benefit from participating in this study, though you may value the opportunity it could provide to reflect on your practice. I hope that the findings may:

- develop general understanding of how to support people with learning disabilities and complex needs' to engage in occupations at home and therefore begin to address some of the occupational injustices they often face;
- inform occupational therapy practice and our ability to explain and justify this;
- contribute to the evidence base for important aspects of occupational therapy practice that can otherwise be difficult to justify in the current economic climate;
- inform the occupational therapy consultancy role with those who support people on a day to day basis (for example advising support workers and family carers regarding the best way to support someone).

1.10. EXPENSES AND PAYMENTS

No expenses will be incurred by you over and above those that you would normally incur in your work.

1.11. WHAT IF THERE IS A PROBLEM?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

1.12. WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1. If the information so far has interested you and you are considering participation, please go on to read the additional information in Part 2 before making any decision.

PART 2

WHAT WILL HAPPEN IF I DON'T WANT TO CARRY ON WITH THE STUDY?

You may withdraw from the study at any point and do not need to give any explanation if you wish to do this. As I am asking you to participate over an extended period, I will regularly check that you continue to wish to be part of the study and will genuinely endeavour to make you feel that you can withdraw at any point.

Due to the nature of the study, it will not be possible to extract data collected up to the point you choose to withdraw and the intention would therefore be to retain data already collected in the study.

WHAT IF THERE IS A PROBLEM?

If you have a concern about any aspect of this study, please ask to speak to me and I will do my best to answer your questions. Alternatively or additionally, you could speak to one of my research supervisors, whose contact details are at the end of this document. If you remain unhappy and wish to complain formally, they will be able to give you details of the University of Brighton procedures for doing this.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

During the study, I will gather data about you, some of which is personal data that could lead to risk of potential identification. This could for example consist of any or all of: your name and workplace; my notes from observations of you; my notes made during interviews, or from reading clinical notes written by you; audio recordings of interviews with you; video recordings of aspects of your practice; transcripts of these audio and video recordings; photographs of artefacts made as part of the occupational therapy observed. Please note that I will not see any confidential information regarding any service users unless or until they have either given informed consent to participate in this study, or an appropriate best interests decision has been made regarding their participation (see 1.6.1 above).

All such data will be kept strictly confidential and the procedures for handling, processing, storage and destruction of this data meet guidelines for good research practice and all appropriate legislation:

- I will only gather personal data where this is really necessary and relevant to the research question
- I will take precautions at the earliest opportunity to anonymise this data so that it cannot be linked to you – for example, a coding system (pseudonym) will be used and you will not be referred to by your actual name on notes or transcripts. Where your exact words spoken in an interview could lead to you becoming identifiable, these will be omitted or altered in the transcript.
- Data will only be stored on portable devices (for example my laptop computer, memory stick, or audio/ video recorders) for as long as is necessary to transport it to a more secure location and it will be password protected and/ or encrypted on such device.
- Data will then be stored on a computer at my home or workplace protected by a password known only to me.
- Data on paper will be stored in sealed envelopes in a locked drawer at my home or workplace.
- Particular care will be taken regarding the security arrangements for audio and video recordings
- Only my two supervisors and I will have any access to data in which you are identifiable (e.g. original video or audio recordings).
- All such data in which you are identifiable will be securely destroyed once the research is complete and I have graduated. Non-identifiable data will be stored at the University of Brighton for a further 10 years, in accordance with accepted research practice.

Please note that:

- I may wish to use direct quotation of your words in my thesis or in future publications regarding this research (see 2.4 below), though you will not be identified or identifiable. Care will be taken that the combination of incidental details e.g. details about your occupation, location, age, gender and ethnicity, do not lead to you becoming identifiable. If necessary some of these details may be changed in order to ensure that this does not happen.

- Although all steps will be taken to preserve your anonymity, the nature of the study (for example the length of time you are asked to participate) means that others may realise you have participated and therefore this cannot completely be guaranteed.
- Data will be collected only for use in this research and will not be retained for use in future studies.
- A small group of people with learning disabilities have been very supportive of my research by acting as consultants about its design. As they have found it difficult to imagine what the research methods will look like, they have asked if they can see some of the video recordings made, to support them with on-going consultation. I may therefore ask you if I can show them particular video clips, though I will seek consent for those specific clips from yourself and anyone else filmed and will disguise faces (e.g. with pixelisation) to preserve anonymity. You can choose to withhold your consent for this at that time and will not be asked to give a reason for doing so.
- You have the right to check the accuracy of data held about you and to correct any errors.
- During your participation in this research, you may inadvertently reveal things that you do not intend to and I would like to offer you some control over your data. I will remain alert to signs that you wish to keep something private (e.g. visible discomfort) and will negotiate and check with you throughout the research (including at write-up) any data that you wish to be kept confidential. For example, at the end of an interview or observation, I will ask you for permission to use the content or whether anything needs excluding.
- There may be certain circumstances where an exception needs to be made to maintaining confidentiality in order to avoid future harm to someone else. For example, it may become clear that there have been instances of criminal activity, violence, abuse, neglect or poor practice and I would then be obliged to respond to this. I would discuss appropriate courses of action with my supervisors before acting, though it may prove necessary to report to a relevant authority, for example in accordance with policies to safeguard vulnerable adults.

WHAT WILL HAPPEN TO THE FINDINGS OF THE RESEARCH STUDY?

I will write up the findings of the study for my thesis. I also hope to present these findings at relevant conferences and to publish articles in peer-reviewed journals (and therefore you may be able to read the findings in such publications or hear them at such conferences). I will give you the option of receiving a summary of the findings at the end of the study. I also intend to produce an accessible version of the findings for people with learning disabilities.

Note that you will not be identified or identifiable in any such publications.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

This research is organised by me for a Professional Doctorate in Occupational Therapy at University of Brighton. It is funded by myself.

WHO HAS REVIEWED THE STUDY?

The scientific quality of the research has been reviewed and approved by my supervisors and also by the University of Brighton Faculty of Health and Social Sciences Research, Ethics and Governance Committee and the NHS National Research Ethics Service (Ref: 12/LO/0319).

FURTHER INFORMATION AND CONTACT DETAILS

If you have any questions, or would like further information about this study, please contact me as follows (I would be happy to hear from you at any point during the data collection period of my study, which is likely to continue until the end of 2013):

David Haines
School of Health Professions
University of Brighton
Robert Dodd Building
49 Darley Road
Eastbourne
East Sussex BN20 7UR
01273 643661
d.haines@brighton.ac.uk

If you are unhappy about any aspect of the study, you can contact one of my academic supervisors, or my Programme Leader as follows:

Dr Jon Wright
School of Health Professions
University of Brighton
Robert Dodd Building
49 Darley Road
Eastbourne
East Sussex BN20 7UR
01273 643877
j.wright@brighton.ac.uk

Dr Huguette Comerasamy
School of Nursing and Midwifery
University of Brighton
Westlain House
Village Way
Brighton BN1 9PH
01273 644512
h.comerasamy@brighton.ac.uk

Dr Nikki Petty
Programme Leader Professional Doctorate in Health and Social Care
Clinical Research Centre for Health Professions
University of Brighton
Aldro Building
Darley Road
Eastbourne BN20 7UR
01273 641806
n.petty@brighton.ac.uk

Appendix 4: Consent form – occupational therapist

TITLE OF PROJECT:

Engaging People with learning disabilities and complex needs in occupations at home: the occupational therapy approach

NAME OF RESEARCHER:

David Haines

PLEASE INITIAL ALL BOXES AND SIGN BELOW

- I confirm that I have read and understand *Participant Information Sheet 1 (Occupational therapist participants)* dated [] (version []) for the above study. I have had the opportunity to consider the information and to ask questions. These questions have been answered satisfactorily.
Initials_____
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
Initials_____
- I agree to take part in the above study, as described in that participant information sheet and in particular:
 - to being audio and video-recorded
 - to anonymised direct quotation of my words in the report of the study and other future publicationsInitials_____

Name of Participant

Signature

Date

Name of Person taking consent

Signature

Date

Appendix 5: Participant information sheet – other participant

PART 1

1.1. STUDY TITLE

Engaging people with learning disabilities and complex needs in occupations at home: exploring the occupational therapy approach

1.2. INVITATION PARAGRAPH

I would like to invite you to take part in my research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. This information sheet is particularly detailed due to the nature of the study and the importance of you fully understanding what will be expected of you before volunteering.

Part 1 of this Information Sheet tells you the purpose of this study and what will happen to you if you take part. Please read Part 1 and then, if you are considering participation, please go on to read Part 2 which will give you more detailed information.

I will go through this information sheet with you. Ask me if there is anything that is not clear and I will answer any questions you may have. Talk to others about the study if you wish.

1.3. WHAT IS THE PURPOSE OF THE STUDY?

This study concerns people with learning disabilities and complex needs. By this, I mean those with profound and multiple learning disabilities, or those with moderate or severe learning disabilities who have additional needs (for example, physical, sensory or mental health needs, autism, or behaviour that challenges those that support them). Such people often have too little to do. Opportunities are easily missed to support and enable meaningful involvement in daily activities, including their own self-care and domestic activities at home. This has an impact on people's health and quality of life.

Occupational therapists are often involved in addressing these needs. The purpose of this study is therefore to explore the ways they support, encourage and enable people to do more at home. I am exploring in depth a case of the occupational therapy of a small number of people with learning disabilities and complex needs. All those involved in this occupational therapy are being invited to be observed and interviewed. Potential participants therefore include a small number of occupational therapists, individuals with learning disabilities and others (perhaps support workers, or family members) who become part of that occupational therapy.

The study aims to answer the research question "In what ways do occupational therapists support people with learning disabilities and complex needs to engage in occupations at home?"

1.4. WHY ARE ESTHER AND HAROLD, BECKY, JANE, STEVE AND MATT TAKING PART IN THIS STUDY?

Esther is one of the occupational therapists taking part in this study. As you know, she is currently working with Harold, Becky, Jane, Steve and Matt who live at Cavendish House.

We have established that Harold, Becky, Jane, Steve and Matt cannot (fully) understand the purpose of this study and the reason for being invited to take part. Their consultees have however agreed that it is nonetheless in their best interests to do so. This is because:

- We need to understand and gain insight into the experiences of people like Harold, Becky, Jane, Steve and Matt in order to understand how we can best support them. It is a missed opportunity for them to be excluded from research that could be used to gain a fuller understanding of their needs.
- Involving them (and particularly observing them) enables me to find out something about what *they* think about their occupational therapy, rather than relying solely on others' views, such as family members or support staff.
- Only recruiting people who *do* have the capacity to consent would not answer my research question.
- There are additional indirect benefits to him similar to those described in 1.10 below.

1.5. WHY HAVE I BEEN INVITED?

You have been invited because:

- you work for Futures and with Harold, Becky, Jane, Steve and Matt at Cavendish House; and
- you have become involved in some way in Esther's occupational therapy with them; and
- you are an adult (aged 18 or over).

1.6. DO I HAVE TO TAKE PART?

It is up to you to decide whether to join the study. I will describe it and go through this information sheet with you. If you agree to take part, I will then ask you to sign a consent form. You will be free to withdraw at any time, without needing to give a reason.

1.7. WHAT WILL HAPPEN TO ME IF I TAKE PART? WHAT WILL I HAVE TO DO?

If you agree to take part, the following will happen/ be asked of you:

To gain in depth understanding of Harold, Becky, Jane, Steve and Matt 's occupational therapy, I have been spending time with them and Esther on several occasions as she carries out her occupational therapy assessment and treatment. As you have become involved in their occupational therapy I would therefore like also to include you. I will explore what is going on as it takes place and will work closely with everyone involved to understand what Esther does.

My main ways of gathering information from you will be (as appropriate):

- Observation of you and Esther with Harold, Becky, Jane, Steve and Matt when involved in occupational therapy;
- Video recording of particular aspects of this occupational therapy (both when I am present and at times when I cannot be);
- Informal interviews (conversations) with yourself during/ immediately after observations;
- One or a small number of more formal interviews with you about their occupational therapy.

1.8. HOW LONG WILL I BE INVOLVED IN THE STUDY?

Before volunteering to participate in this study, please consider the amount of time that this may involve. This is largely dependent on the nature of Harold, Becky, Jane, Steve and Matt's occupational

therapy needs and Esther's clinical decisions regarding the amount of time she remains involved with them.

Ideally, I would like you to remain involved in the study for as long as you have any involvement in Harold, Becky, Jane, Steve and Matt's occupational therapy. This could mean me gathering data from you on just one occasion, though it is possible that it could be longer than this, even over several months. During this time, I would hope to be present during some of the occasions when you become involved in Harold, Becky, Jane, Steve and Matt's occupational therapy as practicable in order to gather data as described in 1.7 above.

Much of your participation would involve me observing things that you would in any case be doing when you are involved with Harold, Becky, Jane, Steve and Matt's occupational therapy and therefore would not take up extra time. The total number of hours of such observations will depend on the nature of their occupational therapy, but the absolute maximum is anticipated to be no more than 5 hours.

You should be aware however that some aspects (in particular discussion in interviews with me) could entail you devoting some time over and above what you would normally do. Although it is difficult to be precise, the absolute maximum number of such hours is estimated to be no more than 4.

Please note, as explained more fully in 2.1 below, that you can decide to end your involvement in the study at any point and if you do I will not ask you to give an explanation for this.

1.9. WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

The main disadvantage of taking part is the possible inconvenience to you of having me present while you are working and the amount of time that you will be asked to devote to this study. Much of the time you will be doing things that are normally part of [your work/ the time you spend] with Harold, Becky, Jane, Steve and Matt and it will not therefore take extra time. Some of the tasks envisaged in 1.7 will however involve extra time, in particular informal and a smaller number of more formal interviews with me about your practice.

1.10. WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

I cannot promise that you will directly benefit from participating in this study, though you may value the opportunity it could provide to reflect on your work with Harold, Becky, Jane, Steve and Matt. I hope that the findings from this study may:

- develop general understanding of how to support people like them to participate in activities at home and therefore to improve the quality of support services and of individuals' lives. This may begin to address some of the injustices people like Harold, Becky, Jane, Steve and Matt often face;
- inform the practice of occupational therapists like Esther;
- contribute to the evidence base of this practice;
- inform the occupational therapy role with people like yourself who support people like Harold, Becky, Jane, Steve and Matt on a day to day basis.

1.11. EXPENSES AND PAYMENTS

No expenses will be incurred by you over and above those that you would normally incur in your work.

1.12. WHAT IF THERE IS A PROBLEM?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

1.13. WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1. If the information so far has interested you and you are considering participation, please go on to read the additional information in Part 2 before making any decision.

PART 2

WHAT WILL HAPPEN IF I DON'T WANT TO CARRY ON WITH THE STUDY?

You may withdraw from the study at any point and do not need to give any explanation if you wish to do this. As I am asking you to participate over an extended period, I will regularly check that you continue to wish to be part of the study and will genuinely try to make you feel that you can withdraw at any point.

Due to the nature of the study, it will not be possible to take out data collected up to the point you choose to withdraw and the intention would therefore be to retain data already collected in the study.

WHAT IF THERE IS A PROBLEM?

If you have a concern about any aspect of this study, please ask to speak to me and I will do my best to answer your questions. Alternatively or additionally, you could speak to one of my research supervisors, whose contact details are at the end of this document. If you remain unhappy and wish to complain formally, they will be able to give you details of the University of Brighton procedures for doing this.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

During the study, I will gather data about you, some of which is personal data that could lead to risk of potential identification. This could for example consist of any or all of: your name and workplace; my notes from observations of you; my notes made during interviews; audio recordings of interviews with you; video recordings of you with Harold, Becky, Jane, Steve and Matt and/ or Esther; transcripts of these audio and video recordings.

This data will be kept strictly confidential and the procedures for handling, processing, storage and destruction of this data meet guidelines for good research practice and all appropriate legislation:

- I will only gather personal data where this is really necessary and relevant to the research question
- I will take precautions at the earliest opportunity to anonymise this data so that it cannot be linked to you – for example, I will use a coding system (pseudonym) and will not refer to you by your actual name on notes or transcripts. Where your exact words spoken in an interview could lead to you becoming identifiable, I will leave these out or alter them in the transcript.
- Data will only be stored on portable devices (for example my laptop computer, memory stick, or audio/ video recorders) for as long as is necessary to transport it to a more secure location and it will be password protected and/ or encrypted on such device.

- Data will then be stored on a computer at my home or workplace protected by a password known only to me.
- Data on paper will be stored in sealed envelopes in a locked drawer at my home or workplace.
- Particular care will be taken regarding the security arrangements for audio and video recordings
- Only my two supervisors and I will have any access to data in which you are identifiable (e.g. original video or audio recordings).
- All such data in which you are identifiable will be securely destroyed once the research is complete and I have graduated. Non-identifiable data will be stored at the University of Brighton for a further 10 years, in accordance with accepted research practice.

Please note that:

- I may wish to directly quote your words in my thesis or in future publications regarding this research (see 2.5 below), though you will not be identified or identifiable. I will take care that the combination of details e.g. details about your occupation, location, age, gender and ethnicity, do not lead to you becoming identifiable. If necessary, I may change some of these details in order to ensure that this does not happen.
- Although all steps will be taken to keep you anonymous, the nature of the study (for example the length of time you are asked to participate) means that others may realise you have participated and therefore this cannot completely be guaranteed.
- Data will be collected only for use in this research and will not be retained for use in future studies.
- A small group of people with learning disabilities have been very supportive of my research by acting as consultants about its design. As they have found it difficult to imagine what the research methods will look like, they have asked if they can see some of the video recordings made, to support them with on-going consultation. I may therefore wish to show them particular video clips, though I will seek consent for those specific clips from yourself (if you are in them) and anyone else filmed and will disguise faces (e.g. with pixelisation) to preserve anonymity. You can choose to withhold your consent for this at that time and will not be asked to give a reason for doing so.
- You have the right to check the accuracy of data held about you and to correct any errors.
- During your participation in this research, you may inadvertently reveal things that you do not intend to and I would like to offer you some control over this. I will look for signs that you wish to keep something private (e.g. visible discomfort). I will negotiate and check with you throughout the research (including at write-up) any data that you wish to be kept confidential. For example, at the end of an interview or observation, I will ask you for permission to use the content or whether anything needs excluding.
- There may be certain circumstances where an exception needs to be made to maintaining confidentiality in order to avoid future harm to someone else. For example, it may become clear that there have been instances of criminal activity, violence, abuse, neglect or poor practice and I would then be obliged to respond to this. I would discuss appropriate courses of action with my supervisors before acting, though it may prove necessary to report to a relevant authority, for example in accordance with policies to safeguard vulnerable adults.

WHAT WILL HAPPEN TO THE FINDINGS OF THE RESEARCH STUDY?

I will write up the finding of the study for my thesis. I also hope to present these findings at relevant conferences and to publish articles in journals. I will give you the option of receiving a summary of the findings at the end of the study. I also intend to produce an accessible version of the findings for people with learning disabilities.

Note that you will not be identified or identifiable in any such publications.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

This research is organised by me for a Professional Doctorate in Occupational Therapy at University of Brighton. It has been funded by myself.

WHO HAS REVIEWED THE STUDY?

The scientific quality of the research has been reviewed and approved by my supervisors and also by the University of Brighton Faculty of Health and Social Sciences Research, Ethics and Governance Committee and the NHS National Research Ethics Service (ref: 12/LO/0319).

FURTHER INFORMATION AND CONTACT DETAILS

If you have any questions, or would like further information about this study, please contact me as follows:

David Haines
School of Health Professions
University of Brighton
Robert Dodd Building
49 Darley Road
Eastbourne
East Sussex BN20 7UR
01273 643661
d.haines@brighton.ac.uk

If you are unhappy about any aspect of the study, you can contact one of my academic supervisors, or my Programme Lead, as follows:

Dr Jon Wright
School of Health Professions
University of Brighton
Robert Dodd Building
49 Darley Road
Eastbourne
East Sussex BN20 7UR
01273 643877
j.wright@brighton.ac.uk

Dr Huguette Comerasamy
School of Nursing and Midwifery
University of Brighton
Westlain House
Village Way
Brighton BN1 9PH
01273 644512
h.comerasamy@brighton.ac.uk

Dr Nikki Petty
Programme Leader Professional Doctorate in Health and Social Care

Clinical Research Centre for Health Professions
University of Brighton
Aldro Building
Darley Road
Eastbourne BN20 7UR
01273 641806
n.petty@brighton.ac.uk

Appendix 6: Consent form – other participant

TITLE OF PROJECT:

Engaging People with learning disabilities and complex needs in occupations at home: the occupational therapy approach

NAME OF RESEARCHER:

David Haines

PLEASE INITIAL ALL BOXES AND SIGN BELOW

- I confirm that I have read and understand *Participant Information Sheet 3 (other participants)* dated [] (version []) for the above study. I have had the opportunity to consider the information and to ask questions. These questions have been answered satisfactorily.

Initials_____

- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

Initials_____

- I agree to take part in the above study, as described in that participant information sheet and in particular:

- to being audio and video-recorded
- to anonymised direct quotation of my words in the report of the study and other future publications.

Initials_____

Name of Participant

Signature

Date

Name of Person taking consent

Signature

Date

Appendix 7: Ethics Approval Statements



Health Research Authority

NRES Committee London - Camberwell St Giles
(Formerly known as The Joint South London and Maudsley and Institute of Psychiatry
Research Ethics Committee)
Administrative address: Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597509
Facsimile: 01223 597645

26 April 2012 (via e-mail to d.haines@brighton.ac.uk)

Mr David J Haines
Senior Lecturer
University of Brighton
School of Health Professions
Robert Dodd Building, 49 Darley Road
Eastbourne, East Sussex
BN20 7UR

Dear Mr Haines

Study title: Engaging people with learning disabilities and complex needs in occupations at home: exploring the occupational therapy approach
REC reference: 12/LO/0319

Thank you for your letter of 02 April 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter: from David Haines		06 February 2012
Evidence of insurance or indemnity: Zurich Municipal		06 July 2011
Interview Schedules/Topic Guides	1	16 January 2012
Investigator CV: David Haines		
Letter from Sponsor: from Julie Scholes, University of Brighton		09 February 2012
Letter of invitation to participant	4	06 February 2012
Other: CV for academic supervisor: Huguette Comerasamy		
Other: CV for academic supervisor: Jon Wright		
Participant Consent Form: Consent Form 1: Occupational therapist participants	2	06 February 2012
Participant Consent Form: Consent Form 2: Other participants	3	06 February 2012
Participant Consent Form: Best Interests Decision Form: Consultee of participant lacking capacity	3	06 February 2012
Participant Consent Form: Consent Form 4: Participants with learning difficulties who have capacity	2	06 February 2012
Participant Information Sheet: Sheet 4: Participants with learning difficulties who have capacity	2	06 February 2012
Participant Information Sheet: Sheet 1: Occupational therapist participants	6	02 April 2012
Participant Information Sheet: Sheet 2: Consultee of participant lacking capacity	5	02 April 2012

Participant Information Sheet: Sheet 3: Other participants	5	02 April 2012
Protocol	3	06 February 2012
REC application: 88496/290321/1/610		06 February 2012
Referees or other scientific critique report : e-mail from J. Scholes		06 February 2012
Response to Request for Further Information: from David Haines		02 April 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

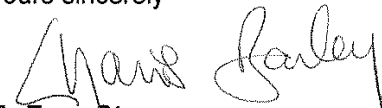
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/LO/0319	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely


Mr Evan Stone
Vice Chair

Email: charis.bailey@eoe.nhs.uk

Decision Letter (FREGC-11-062.R1)

From: J.Scholes@brighton.ac.uk

To: d.haines@brighton.ac.uk

CC:

Subject: Faculty of Health and Social Science Research Ethics and Governance Committee - Decision on Manuscript ID FREGC-11-062.R1

Body: @@date to be populated upon sending@@

Dear Mr. Haines:

It is a pleasure to accept your manuscript entitled "Engaging people with learning disabilities and complex needs in occupations at home: exploring the occupational therapy approach" in its current form for publication in the Faculty of Health and Social Science Research Ethics and Governance Committee. The comments of the reviewer(s) who reviewed your manuscript are included at the foot of this letter.

Thank you for your fine contribution. On behalf of the Editors of the Faculty of Health and Social Science Research Ethics and Governance Committee, we look forward to your continued contributions to the Journal.

Sincerely,

Prof. Julie Scholes

Editor-in-Chief, Faculty of Health and Social Science Research Ethics and Governance Committee

J.Scholes@brighton.ac.uk

Reviewer(s)' Comments to Author:

Reviewer: 2

Comments to the Applicant

I would like to thank the author for a very comprehensive and thoughtful response to my comments. I recommend that the application be approved.

The IRAS system allows for a protocol to be attached and so you may wish to include some of the rationale provided in your responses to support areas that may need further clarification I am thinking particularly about the number of data collection episodes and the use of the video material.

Date Sent: 06-Feb-2012

Appendix 8: Participant information sheet –consultee of participant with intellectual disabilities without capacity

PART 1

1.1. STUDY TITLE

Engaging people with learning disabilities and complex needs in occupations at home: exploring the occupational therapy approach

1.2. INVITATION PARAGRAPH

I would like to invite Matt to take part in my research study. I have established that he does not have capacity under Mental Capacity Act 2005 to consent to taking part himself. I would therefore like to invite you as his consultee to consider whether or not taking part would be in his best interests.

Before you decide I would like you to understand why the research is being done and what it would involve for Matt. This information sheet is particularly detailed due to the nature of the study and the importance of you fully understanding what will be expected of him before you make your decision.

Part 1 of this Information Sheet tells you the purpose of this study and what will happen to Matt if he takes part. Please read Part 1 and then, if you are considering recommending participation, please go on to read Part 2 which will give you more detailed information about the conduct of the study.

I will go through this information sheet with you. Ask me if there is anything that is not clear and I will answer any questions you may have. Talk to others about the study if you wish.

1.3. WHAT IS THE PURPOSE OF THE STUDY?

This study concerns people with learning disabilities and complex needs. By this, I mean those with profound and multiple learning disabilities, or those with moderate or severe learning disabilities who have additional needs (for example, physical, sensory or mental health needs, autism, or behaviour that challenges those that support them). Such people often have too little to do. Opportunities may be missed by those supporting them to enable meaningful involvement in daily activities, including their own self-care and domestic activities at home. This has an impact on their health and quality of life.

Occupational therapists are often involved in addressing these needs. The purpose of this study is therefore to explore the ways they support, encourage and enable people to do more at home. I will explore in depth a case of the occupational therapy of a small number of people with learning disabilities and complex needs. All those involved in this occupational therapy will be observed and interviewed. Potential participants therefore include a small number of occupational therapists, individuals with learning disabilities and others (perhaps support workers, or family members) who become part of that occupational therapy.

The study aims to answer the research question “In what ways do occupational therapists support people with learning disabilities and complex needs to engage in occupations at home?”

1.4. WHY HAS MATT BEEN INVITED?

Matt has been invited because he is an adult (aged 18 or over) who has learning disabilities and complex needs as described above and because he has been referred to the [xxx] team for occupational therapy.

I am looking for a small number of people like Matt (probably up to four) to participate in this study. I will begin by recruiting a single person, but will likely seek to bring new participants into the study as it proceeds until I judge that I have sufficient data.

1.5. WHY AM I INVITING MATT WHEN HE CANNOT CONSENT TO TAKE PART HIMSELF?

Matt's is unlikely (fully) to understand the purpose of this study and the reason for being invited to take part. I would argue that it is nonetheless important to invite him because:

- We need to understand and gain insight into the experiences of people like Matt in order to understand how we can best support them. It is a missed opportunity for him to be excluded from research that could be used to gain a fuller understanding of his needs (and the needs of people like him).
- Involving him (and particularly observing him) would enable me to find out something about *his* perspective on his occupational therapy, rather than relying solely on others' views, such as family members or support staff.
- Only recruiting people who *do* have the capacity to consent would not answer my research question.

1.6. DOES MATT HAVE TO TAKE PART?

It is up to you to decide whether it is in Matt's best interests to join the study. I will describe what will be involved by going through this information sheet. I will give you plenty of opportunity to ask questions and clarify what will happen and why. Please consider the broad aims of the research, the risks, benefits and practicalities of being involved and whether you think Matt would be content to take part or whether doing so might upset him.

I will not include Matt in the study if you advise against this. If you agree that taking part is in his best interests, I will then ask you to sign a form to this effect.

1.7. WHAT WILL HAPPEN TO MATT IF HE TAKES PART? WHAT WILL HE HAVE TO DO?

To gain in depth understanding of Matt's occupational therapy, I will spend time with him and his occupational therapist Esther on several occasions as she carries out her occupational therapy assessment and treatment with him. I will explore what is going on as it takes place and will work closely with Esther to understand what she does. My main ways of gathering information will, on several occasions, be:

- Observation of Matt in occupational therapy with Esther;
- Video recording of particular aspects of this occupational therapy (both when I am present and at times when I cannot be);
- Informal interviews (conversations) with Esther during/ immediately after observations;
- A small number of more formal interviews with Esther about Matt's occupational therapy;
- Analysis of Matt's occupational therapy clinical notes and / or of artefacts created or used as part of the occupational therapy.

If Matt takes part, you are welcome to be present during some or all of my observations of him (provided that he does not show signs of objecting to you being there and that Esther does not think this will affect his occupational therapy).

Throughout the period that Matt takes part in the study, I will keep in touch with you regularly. This will be particularly important to ensure that Matt can participate in decisions and that I notice and respond to signs of objection (see also 2.1 below).

1.8. HOW LONG WILL MATT BE INVOLVED IN THE STUDY?

Whilst deciding whether it is in Matt's best interests to take part, please consider the amount of time that this may involve. This is largely dependent on the nature of his occupational therapy needs and Esther's clinical decision regarding the amount of time she remains involved with him.

Ideally, I would like Matt to remain involved in the study until Esther has finished working with him and has discharged him from her caseload. You should recognise that this could mean me gathering data from Matt for several months, during which I would hope to accompany her to as many of her sessions with Matt as possible.

Much of Matt's participation in this study would involve me observing what would happen anyway in the course of his occupational therapy and therefore would not take up extra time. The total number of hours of such observations will depend on the nature of Esther's involvement with him, but the absolute maximum is estimated to be no more than 20 hours.

You should be aware however that participation would entail him devoting some additional time (for example familiarisation with each other). Although it is difficult to be precise, the absolute maximum number of such hours is estimated to be no more than 10.

Please note, as explained more fully in 2.1 below, that if at any point it becomes clear or you decide that it is no longer in Matt's best interests to continue to take part, he will be withdrawn from the study and his involvement will then cease.

1.9. WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

The main disadvantage of taking part is the possible inconvenience to Matt of me being present during his occupational therapy and the amount of time that he could be asked to devote to this study. I do not anticipate however that my presence is likely to have any impact on the quality of his occupational therapy and I will remove myself/ withdraw him from the study if this appears to be happening. Also, the types of experiences that he could have from being part of this study are not different to or riskier than the things he routinely experiences in his daily life.

1.10. WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

Although I cannot promise that Matt will *directly* benefit from participating in this study, I do hope that there may be *indirect* benefit to him. The study may:

- develop general understanding of how to support people like him to participate in activities at home and therefore to improve the quality of support services and of individuals' lives. This may begin to address some of the injustices people like Matt often face;
- inform the practice of occupational therapists like Esther;
- contribute to the evidence base for this practice;
- inform the occupational therapy role with those who support people on a day to day basis.

1.11. EXPENSES AND PAYMENTS

No expenses will be incurred by Matt as a result of taking part in this study.

1.12. WHAT IF THERE IS A PROBLEM?

Any complaint you may have about the way Matt has been dealt with during the study or any possible harm he might suffer will be addressed. The detailed information on this is given in Part 2.

1.13. WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1. If the information so far has interested you and you are considering recommending that it would be in Matt's best interests to take part, please go on to read the additional information in Part 2 before making any decision.

PART 2

WHAT WILL HAPPEN IF MATT DOESN'T WANT TO CARRY ON WITH THE STUDY?

Matt may withdraw or be withdrawn from the study at any point, for example if it becomes apparent that it is no longer in his best interests to take part. You can decide this at any point and will not need to give any explanation if you wish to do so. As I am asking Matt to participate over an extended period, I will regularly check with you that you still consider it to be in his best interests to take part.

I will do as much as I can to enable Matt to participate in all decisions about his involvement, including for example whether or not the research methods are acceptable to him and whether he is happy on each occasion for me to be present. Nothing will be done to him to which he appears to object and, I will pay constant attention to his willingness to engage.

Taking into account Matt's individual ways of communicating, I will ask you to agree in advance examples of changes in his behaviour that might indicate distress or unwillingness. I will respond to such behaviour by either removing myself that day or withdrawing Matt from the study (as appropriate). My experience working this field will assist my judgement, but I will make a decision in close collaboration with others, including you.

Due to the nature of the study, it will not be possible to take out data collected up to the point Matt withdraws and the intention would therefore be to retain it in the study.

WHAT IF THERE IS A PROBLEM?

If you have a concern about any aspect of this study, please ask to speak to me and I will do my best to answer your questions. Alternatively or additionally, you could speak to one of my research supervisors, whose contact details are at the end of this document. If you remain unhappy and wish to complain formally, they will be able to give you details of the University of Brighton procedures for doing this.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

Some of the data I gather about Matt will be personal data that could lead to risk of potential identification. This could for example consist of any or all of: his name and address; my notes from observations of him and made during interviews, or from reading his clinical notes; audio and video recordings and transcripts of these recordings; photographs of artefacts made as part of his occupational therapy.

This data will be kept strictly confidential and the procedures for handling, processing, storing and destroying this data meet guidelines for good research practice and all appropriate legislation:

- I will only gather personal data where this is really necessary and relevant to the research question
- I will take precautions at the earliest opportunity to anonymise this data so that it cannot be linked to him – for example, I will use a coding system (pseudonym) and will not refer to him by his actual name on notes or transcripts. Where the exact words spoken in an interview could lead to him becoming identifiable, I will leave these out, or alter them in the transcript.
- Data will only be stored on portable devices (for example my laptop computer, memory stick, or audio/ video recorders) for as long as is necessary to transport it to a more secure location and it will be password protected and/ or encrypted on such device.
- Data will then be stored on a computer at my home or workplace protected by a password known only to me.
- Data on paper will be stored in sealed envelopes in a locked drawer at my home or workplace.
- Particular care will be taken regarding the security arrangements for audio and video recordings
- Only my two supervisors and I will have any access to data in which he is identifiable (e.g. original video or audio recordings).
- All data in which Matt is identifiable will be securely destroyed once the research is complete and I have graduated. Non-identifiable data will be stored at the University of Brighton for a further 10 years, in accordance with accepted research practice.

Please note that:

- In future publications regarding this research (see 2.5 below), Matt will not be identified or identifiable. I will take care that the combination of details e.g. location, age, gender and ethnicity, do not lead to him becoming identifiable. If necessary I may change some of these details in order to ensure that this does not happen.
- Although all steps will be taken to keep Matt anonymous, the nature of the study (for example the length of time he is asked to participate) means that others may realise he has participated and therefore this cannot completely be guaranteed.
- Data will be collected only for use in this research and will not be retained for use in future studies.
- A small group of people with learning disabilities have been very supportive of my research by acting as consultants about its design. As they have found it difficult to imagine what the research methods will look like, they have asked if they can see some of the video recordings made, to support them with on-going consultation. I may therefore ask at some point whether it is in Matt's best interests for some specific clips to be shown to them. The faces of Matt and anyone else filmed will be disguised (e.g. with pixelisation) to preserve anonymity. You can decide at that point that it is not in Matt's best interests for this to happen and will not be asked to give a reason if you decide that it is not.
- There may be certain circumstances where an exception needs to be made to maintaining confidentiality in order to avoid future harm to Matt or someone else. For example, it may become clear that there have been instances of criminal activity, violence, abuse, neglect or poor practice and I would then be obliged to respond to this. I would discuss appropriate courses of action with my supervisors before acting, though it may prove necessary to report to a relevant authority, for example in accordance with policies to safeguard vulnerable adults.

WHAT WILL HAPPEN TO THE FINDINGS OF THE RESEARCH STUDY?

I will write up the finding of the study for my thesis. I also hope to present these findings at relevant conferences and to publish articles in journals. I will give you the option of receiving a summary of the findings at the end of the study. I also intend to produce an accessible version of the findings for people with learning disabilities.

Note that Matt will not be identified or identifiable in any such publications.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

This research is organised by me for a Professional Doctorate in Occupational Therapy at University of Brighton. It has been funded by myself.

WHO HAS REVIEWED THE STUDY?

The scientific quality of the research has been reviewed and approved by my supervisors and also by the University of Brighton Faculty of Health and Social Sciences Research, Ethics and Governance Committee and the NHS National Research Ethics Service (ref: 12/LO/0319)

FURTHER INFORMATION AND CONTACT DETAILS

If you have any questions, or would like further information about this study, please contact me as follows:

David Haines
School of Health Professions
University of Brighton
Robert Dodd Building
49 Darley Road
Eastbourne
East Sussex BN20 7UR
01273 643661
d.haines@brighton.ac.uk

If you are unhappy about any aspect of the study, you can contact one of my academic supervisors, or my programme lead, as follows:

Dr Jon Wright
School of Health Professions
University of Brighton
Robert Dodd Building
49 Darley Road
Eastbourne
East Sussex BN20 7UR
01273 643877
j.wright@brighton.ac.uk

Dr Huguette Comerasamy
School of Nursing and Midwifery
University of Brighton
Westlain House

Village Way
Brighton BN1 9PH
01273 644512
h.comerasamy@brighton.ac.uk

Dr Nikki Petty
Programme Leader Professional Doctorate in Health and Social Care
Clinical Research Centre for Health Professions
University of Brighton
Aldro Building
Darley Road
Eastbourne BN20 7UR
01273 641806
n.petty@brighton.ac.uk




Appendix 9: Participant information sheet – participant with intellectual disabilities with capacity

1. STUDY TITLE


Engaging people with learning disabilities and complex needs in occupations at home: exploring the occupational therapy approach

2. INVITATION PARAGRAPH

	<p>My name is David</p>
	<p>I am doing some research. Research is what we do when we want to find the answer to a question. Research gives us information that we can use to:</p> <ul style="list-style-type: none"> • Understand why things are the way they are. • Challenge something we believe is wrong. • Make suggestions for making things better. • Plan for the future
	<p>Some people do not have much to do at home They might be bored</p>









	
	<p>I am trying to find out</p> <ul style="list-style-type: none"> • what people do at home • how OTs support them to do more things
	<p>I am inviting a few people with learning disabilities and complex needs to take part</p>
	<p>I would like to invite you Would you like to take part?</p>

3. DO I HAVE TO TAKE PART?



	<p>You do not have to take part. It is your choice</p>
---	--

4. WHAT WILL HAPPEN TO ME IF I TAKES PART? WHAT WILL I HAVE TO DO?



<p>[Photo of Esther] [photo of Michael] [photo of house/ person's actual home]</p>	<p>I will visit you when Esther, your OT, comes to see you I will spend time with you and Esther at home</p>
--	--


	<p>I will watch what you do together</p>
	<p>I may record some things on video</p>
	<p>I will talk to you about what you are doing</p>
<p>[photo of Esther]</p> 	<p>I will talk to Esther about what she is doing</p>
 	<p>I will look at Esther's notes about what you do together</p>
 <p>[photo of support worker/ family member]</p>	<p>I may talk to some other people, like [name of support worker], [name of family member] about what you and Esther are doing</p>
	<p>I will write lots of notes about what I see and hear</p>

5. HOW LONG WILL I BE INVOLVED IN THE STUDY?


	<p>I will stop coming to see you when Esther stops working with you</p>
	<p>If you want me to stop coming before then, you can</p> <ul style="list-style-type: none"> • Tell me • Tell someone else (e.g. [support worker/ family member]) <p>That will be fine and you do not have to say why</p>

6. WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?


<p>Help You no</p>	<p>Taking part might not help you directly</p>
	<p>It might help people like Esther do their jobs well</p>
	<p>It might help people like [support worker] do their jobs well</p>

	<p>It might mean people like you get better support</p>
---	---


7. WHAT IF I HAVE SOME QUESTIONS?

	<p>You can ask questions before you decide to take part Here are some examples of things you can ask about</p>
	<p>You can ask what will happen</p>
	<p>You can ask how it will help you or people like you</p>
	<p>You can ask what might go wrong</p>
	<p>You can ask for more time to think about it</p>
	<p>You can ask to speak to someone else about whether to take part (perhaps a friend or a family member)</p>
	<p>Any other question you want to ask</p>




8. WHAT IF THERE IS A PROBLEM?

	<p>If there is a problem, or you want to complain, you or someone else can:</p> <ul style="list-style-type: none"> • Speak to me • contact any of the people listed at the end
---	--


9. WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

	<ul style="list-style-type: none"> • I will look after all the information I find out about you carefully • I will not use your real name • I will lock papers away • I will use a password on my computer
---	--







10. WHAT WILL HAPPEN TO THE FINDINGS OF THE RESEARCH STUDY?


	<ul style="list-style-type: none"> • I will write a big report about the research
<p>Talk/ conference</p>	<ul style="list-style-type: none"> • I will tell people about it at a conference
<p>Magazine/ read</p>	<ul style="list-style-type: none"> • I will write an article for a journal
	<ul style="list-style-type: none"> • I will write an “Easy Read” version for people with learning disabilities
	<ul style="list-style-type: none"> • I will not use your real name so no one will know it is about you

11. WHO HAS REVIEWED THE STUDY?


	<p>People from:</p> <ul style="list-style-type: none"> • University of Brighton • the NHS <p>have looked at my research to make sure it is good and have approved it</p>
---	--

12. FURTHER INFORMATION AND CONTACT DETAILS

<p>?</p>	<p>If you have any questions, or would like further information about this study, please contact me as follows:</p>
	<p>David Haines</p>
 <p>Office</p>	<p>School of Health Professions University of Brighton Robert Dodd Building 49 Darley Road Eastbourne East Sussex BN20 7UR</p>
	<p>01273 643661</p>
 <p>E</p>	<p>d.haines@brighton.ac.uk</p>
<p>?</p>	<p>You could also speak to</p>
<p>Solent  NHS Trust</p>	<p>Patient Advice and Liaison Service</p>
 <p>Office</p>	<p>Adelaide Health Centre Western Community Hospital William Macleod Way Southampton Hampshire</p>


	SO16 4XE
	02380608900

13. COMPLAINTS

	If you want to complain, please contact one of the following people
---	---

Name	Dr Jon Wright
	School of Health Professions University of Brighton Robert Dodd Building 49 Darley Road Eastbourne East Sussex BN20 7UR
	01273 643877
	j.wright@brighton.ac.uk

Name	Dr Huguette Comerasamy
	School of Nursing and Midwifery University of Brighton Westlain House Village Way Brighton BN1 9PH
	01273 644512

	h.comerasamy@brighton.ac.uk
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<p>Name</p>	<p>Dr Nikki Petty</p>
	<p>Programme Leader Professional Doctorate in Health and Social Care Clinical Research Centre for Health Professions University of Brighton Aldro Building Darley Road Eastbourne BN20 7UR</p>
	<p>01273 641806</p>
	<p>n.petty@brighton.ac.uk</p>

Good things and bad things about saying yes to David



It may help Esther's work

(Photo of Esther appeared here)

It might not help Mo herself



It may help people like Doug to do their jobs well



It might take some time



It may help other people who need support



It might feel strange being watched or videoed



Appendix 10: Best interests form – participant with intellectual disabilities without capacity

TITLE OF PROJECT:

Engaging People with learning disabilities and complex needs in occupations at home: the occupational therapy approach

NAME OF RESEARCHER:

David Haines

NAME OF PARTICIPANT LACKING CAPACITY

[]

PLEASE INITIAL EACH POINT AND SIGN BELOW

- I confirm that I have read and understand *Participant Information Sheet 2 (for Consultee of participant lacking capacity)* dated [] (version []) for the above study. I have had the opportunity to consider the information and to ask questions. These questions have been answered satisfactorily.
Initials _____
- I understand that []'s participation is voluntary and that he/ she is free to withdraw at any time without giving any reason.
Initials _____
- I agree that it is in Matt's best interests to take part in the above study, as described in that participant information sheet, including for him to be video-recorded.
Initials _____

Name of Consultee

Signature

Date

Name of Person taking best interests decision

Signature


Date

**Appendix 11: Consent form – participant with intellectual disabilities
with capacity**

Title of Project:

Engaging People with learning disabilities and complex needs in occupations at home: the occupational therapy approach


Name of Researcher:




	David Haines
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Name of Participant


[photo]	[name]
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Please initial all boxes and sign below

	I have read the information sheet about David's research
---	---

?	David has answered my questions
	I understand what taking part means
	I am happy to be observed by David
	I am happy to be videoed by David
	I am happy to be interviewed by David

	<p>I would like to take part in the research</p>
---	--

	<p>Signature _____</p>
---	------------------------

	<p>Date _____</p>
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Appendix 12: Example Category (Set of codes: Issue Leadership, autonomy, initiative (including how valued staff feel))

_ISSUES_ISSUES CH\Issues with a large staff team
_ISSUES_ISSUES CH\Staff not feeling valued
_ISSUES_ISSUES re leadership, manager and autonomy and leadership\Conflict between staff team and manager or values of organisation
_ISSUES_ISSUES re leadership, manager and autonomy and leadership\It doesn't always filter down very well from the manager'
_ISSUES_ISSUES re leadership, manager and autonomy and leadership\the leadership went', lack of leadership (change in leadership style)
_CULTURE\Shift to staff being allowed, encouraged to take initiative
_ISSUES_ISSUES re activity levels and ways of supporting engagement\People make more of an effort when you (OT) go in
_STRATEGIES_STRATEGIES with staff team and other professionals\working with the staff in the same way as we work with our service users'
_ISSUES_ISSUES Intervention of OT and wider community team\ 'telling the staff what needs to happen' approach
_ISSUES_ISSUES CH\Previous culture - initiative not valued, knocked back
28.9.13 Ideas re Central Issue 'Leadership including how valued people feel' set
_BELIEFS, ideological position, frameworks\Knowledge sought by organisation when recruiting support workers
_ATTITUDES_ATT sought by organisation when recruiting support workers
_ISSUES_ISSUES CH\Not everyone can take on or wants to take on leadership role
_ISSUES_ISSUES re activity levels and ways of supporting engagement\Staff confidence carrying out session plans (e.g. introverted staff member v banter)
'28.9.13 and 29.8.14 Memo on SET 'Leadership including how valued people feel' set'

28.9.13 Ideas re Central Issue 'Leadership including how valued people feel' set

There is a moiety around **leadership style**.

Primary stakeholders are: the nurses, the staff team, the managers, Esther, (the residents)

The staff team at CH is a large one and one of the nurses said that life is (should be) easier for staff now as staffing levels are much higher than before.

In such a large staff team, leadership seems of particular importance. It seems that under the previous **NHS culture, there was a very top down 'telling the staff what needs to happen' directive style of management/ leadership from the nurses**. Through the hierarchy, they basically seem to have told the staff what to do. Initiative was apparently not encouraged or valued and it has been described that people had their ideas 'knocked back'. I interpret this that staff had an idea and tried something/ made the effort, but that then they were (as Adam said) 'bollocked' when a mistake was made. My hypothesis is that this links (causes/ contributes to?) what I have identified as inability to show creativity. Is there also some link with bullying?

Since the transfer to **Futures** when the nurses withdrew with the restructuring, there has been a **change in leadership style with a shift to staff being allowed, or in fact encouraged to take initiative**. Adam described it as a lack of leadership however, there being difficulties associated with what he described it as a 'powerful staff team's and **shift leaders leading from within a 'team of equals'**. There is a manager and an assistant manager, but no seniors. The assistant manager (and also to an extent the manager) are very 'matey' with the staff team.

Within this large staff team there seem to be a number of issues, notably

- around communication, which seems to be particularly difficult
- Conflict between (some of the) staff team and the manager and/ or the values of the organisation.
- the degree to which information filters down from the manager to the rest of the staff team, e.g. about the detail of Esther's intervention. Communication of ideas and of practical arrangements does not seem always to be effective. This may be to do with politics as much as to do with the largeness of the team
- Shortnesses of staff mean that there seem to rarely be team meetings, even link worker meetings. Esther has attended a few handover meetings, but otherwise it is difficult to speak to groups of staff.
- There is a sense in the house that staff do not feel valued (certainly loss of enhancements, rebanding and loss of pay must have contributed to this).

Esther seems to be trying to work in a different way to both the current manager and to the directive nursing style. She talks about 'working with the staff the same way we work with our service users', which I interpret as an empowering style, trying to help them be in control, not imposing things on them. Helping them to feel they own the intervention.

One point made by Adam was that he felt that people do things differently when Esther is there and that she may not see what is going on at other times (which the nurses might due to their presence there).

29.8.14 additional Memo re set Leadership, autonomy and how valued staff feel

Sue talked about the attitudes and the knowledge that she and the organisation are expecting when she recruits new members of staff to the team. As well as everything around supporting rather than caring for people, they seem to be looking for people with initiative and who can be creative.

There is a shift now (since the move from the NHS to Futures/ health to social care/supported living) to staff being allowed/encouraged/ expected to take initiative and to take on a leadership role in the house and on shift. This contrasts with the very hierarchical model of leadership that existed in the past, when essentially the staff were told what needs to happen. This I think stifled initiative and creativity and initiative was described as not valued and people 'knocked back' if they came up with ideas. Sue's description of allowing the team to follow through on ideas within their shift contrasts greatly with this.

Tied in with leadership is I think how valued the staff team feel. I sense that in the past many people did not feel valued, perhaps came up with ideas, had them knocked back and therefore stopped taking the initiative. On the one hand the new culture values individual staff members' contributions more, but at the same time some staff – particularly those who have been in the house since before the change – do not feel valued because their salaries and terms and conditions have been cut (pay cuts, senior roles removed, split shifts etc). Not feeling valued does I think impact on how much effort, initiative and creativity people will make in their work.

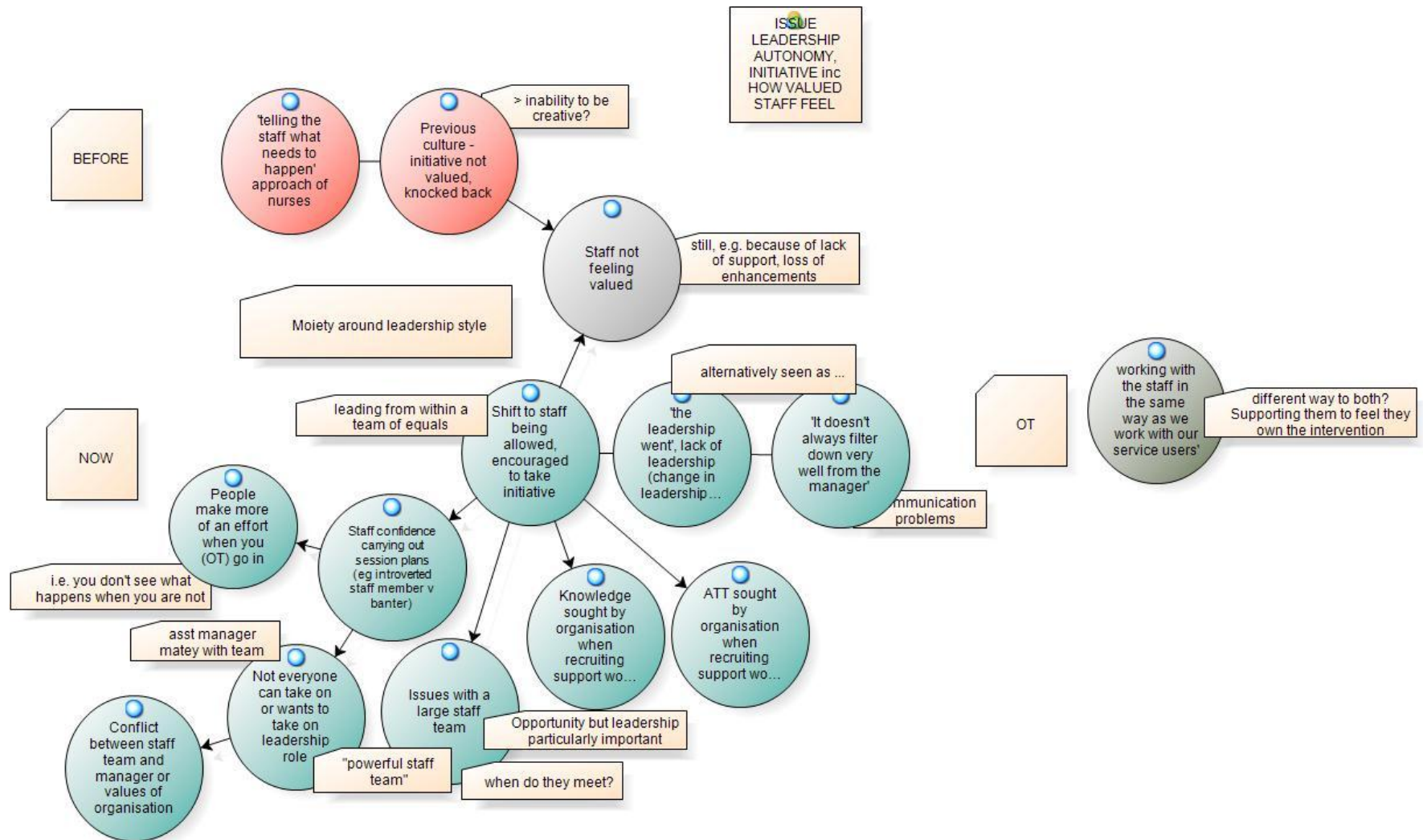
Esther then talks about “working with the staff team in the same way as we work with our service users” meaning an empowering, person-centred way of working. She says she wants them to know that “I value what you do with these people”

One thing said by Doug and I think implicit in the way that a numbers of interviewees differentiate themselves from “the rest” of the staff team is that not everyone can take on or wants to take on the leadership role. He talked about himself doing that, but compared himself to the support worker who interrupted our interview, who seemed to need to check her planned actions with him (needing validation for him). Some clearly perceive there to be a lack of leadership in the house (“it doesn't always filter down from the manager” in the current set up and “the leadership went” when the nurses went). S the change in leadership style can be perceived as a lack of leadership, a vacuum. With manager Sue present in the house less and an assistant manager who is at odds with her and with the organisation's way of thinking this seems to reduce the likelihood of team following organisational processes, or of them following new ways of working that have been agreed by the manager will be adopted (I.e. Esther's recommendations).

There are clearly different levels of knowledge, skills and (self) confidence within the staff team, which contribute to readiness to take on that leadership (note not management) role. The different levels of confidence in carrying out Esther's session plans might also be to do with personality or self-confidence e.g. Whether a quieter or more introverted staff member feels able to engage in banter.

Whether people will take the initiative and lead from the shifts does seems also to depend on whether they believe in the new philosophy of the organisation, or in what Esther is trying to achieve. Lots of examples of participants explicitly saying they are, implying that they are, or being said to be at odds with the views of the organisation (and to a lesser extent Esther).

Issues with a large staff team – communication is a big issue, as is achieving some consistency across everyone. I think the size of the staff team might make leadership more necessary.



Appendix 13: Code Book from NVivo

ATTITUDES
ATT Being open to new ideas
ATT Cynicism toward the intervention, resistance, uncertainty
ATT seeing her as someone who can help me
ATT sought by organisation when recruiting support workers
ATT 'To the nurses they will always be patients'
ATT wariness towards Esther, Sarah
BELIEFS, ideological position, frameworks
Knowledge sought by organisation when recruiting support workers
'recognising that OT might seem like common sense to us, but we are trained to think like that'
Theory - Pool Activity Levels
Theory - cognitive and developmental
Theory - occupational balance and occupational science
Theory - person centred active support
Theory - SEEEC
Theory - Sensory integration
CULTURE
ATT doing things FOR people rather than with them
'Culture of not thinking sensory and needing things to be functional and normal life'
Difficulties, time it takes to make changes in culture
Previous culture under NHS - focus on health
Shift to staff being allowed, encouraged to take initiative
supported living culture of CH, 'now we are social care', change in culture
Value in 'getting the ideas from someone else' outside the culture
EMOTIONAL RESPONSES
ATT Seeing the positives when hit obstacle, optimism
'Brilliant' in response to Esther's intervention
'Feeling a bit defeated', disappointed with progress
Feeling overwhelmed
Felt really positive afterwards, 'brilliant'
Frustration - 'he is still not doing anything
'I don't want to deal with her again'
Interviewee discomfort in interview
OT, OTA discomfort working in the house due to dynamics there
Researcher discomfort during interview
Researcher discomfort with content of interview
EVENTS

Change in dynamics in house
change in rota structure
Feedback from Esther re progress not filtering down to staff
Finding it easier with more able residents
CH 'personalisation journey and away day
Restructure at CH to supported living - shifting culture
Sue keeping job as manager
Sue seeing, getting the link between personalisation journey, active support, PCP and Esther's work
staff not getting opportunity to comment on session plans
Staff response to L
Suggestion that staff seem to love recording forms
_IMPACT, OUTCOMES
'Break through moment', indicators of progress
'Aaahh I see where you are coming from now' i.e. lightbulb moments
Doing more (sensory) activity than they were doing before
indication of a 'step outside the norm' eg with Steve
'She had CLEARLY read the session plans'
Staff and manager talking to others about the project
staff recording 'sensory gardening' rather than 'gardening'
Staff requesting input, giving extensive feedback
Staff stating that intervention was a 'kick up the arse' to do more
OT identified things we wouldn't have thought of, helped us understand them
OT input has confirmed some things we had already worked out
Partial success
Positive impact of occupation on health, mental health, distress etc
ISSUES
_ISSUES CAVENDISH HOUSE
Adjusting to change in culture from focus on health, still partially stuck in the old culture
ATT Differences between new staff and old staff, eg in motivation, freshness, different camps
ATT 'How are we going to fit this in'
ATT lethargy, lack of passion towards the work
ATT 'we have tried all this before'
ATT we know what we are doing, are already doing that (or we were)
Cancelled sessions, miscommunications about timing, perhaps ATT not valuing intervention
Chaotic nature of CH - plans constantly changing
Conflict between staff, dynamics in team
Difficulties liaising with ALL staff, meetings never happen
Driven by the paperwork
How can people have good lives DESPITE all the inevitable difficulties with residential settings
Issues with a large staff team

Lack of understanding leading to defensiveness, rigidity with policies etc
Lack of, more limited induction
Misunderstandings of resident's history passed on
Not everyone can take on or wants to take on leadership role
not taking intervention seriously, undermining the intervention
Perception of staff as to reason Esther has become involved
Philosophy of independence, choice, individuality, age appropriateness misinterpreted for those with PIMD
Previous culture - initiative not valued, knocked back
reduction in funding for service, care packages, staffing levels
Relationship between manager and or organisation and staff team
Rota not allowing forward planning
Staff not feeling valued
staff resistance to shift changes
staff shortages
staff turnover
ISSUES Intervention of OT and wider community team
ATT 'a good support worker could do what you do'
ATT Community team perceived 'interfering' or imposing
ATT that is too rigid, prescriptive, inflexible
ATT we know the residents and you haven't taken that into account
Conflict with family of participant
Confusion caused by HAP leading to defensiveness
Expense, extent of the intervention
Highlighting lack of knowledge and saying 'well then listen'
'I might have fooled people all these years'
'I never knew OTs did this'
intervention perceived as aiming to have people meaningfully occupied all the time
Lack of understanding of LD nurse role
Need for full guidelines - session plans, not just flash cards
Not recognising that some things come from Esther's previous intervention
Question model of community team working i.e. issues working through others
Risk of coming across as defensive, battle
Risk of disengagement if overly critical
Risk of losing them with too many ideas
Should be withdrawing but not sure it is embedded enough
Some interventions can be prescriptive, one size fits all
sustaining staff behaviour change, proposed way of working
'telling the staff what needs to happen' approach of nurses
Tension between ownership and fidelity
'they didn't engage very well with the previous intervention

'they lump me in with the IONT'
'They might think I can solve all the problems'
<u>ISSUES re activity levels and ways of supporting engagement</u>
ATT tokenistic or superficial engagement, just 'jumping through hoops'
'Cognitively, developmentally that is not where they are functioning'. level of knowledge about what they do
Dehumanising effect of working with people for too long
Getting stuck in a routine - 'you just get on with it', inability to be creative
Individuals' low levels of engagement in activity, occupation
it's his choice to be asleep in the afternoon
Limiting people, holding them back
Medication, health needs perceived as a priority over engagement (incl in new staff induction)
Misunderstanding what sensory activities are, how to do them
Not following recommendations, the OT session plans, carrying the cards, using switches, completing recording sheets
Not having (or obtaining) the resources, the right environment to support (sensory) activity
Not realising when they ARE actually doing sensory activities
Occupational imbalance
'off their perception of what they should be doing'
People make more of an effort when you (OT) go in
Staff confidence carrying out session plans (eg introverted staff member v banter)
Staff 'don't feel confident with indoor stuff', out and about
staff missing resident cues, misunderstanding likes and dislikes
Staff struggling with sensory activities for men
staff worried going out with residents
'They lose the peer thing, the banter'
they think of leisure as relaxation, but really bad at meaningful engagement in leisure
Varying, interpreting, putting own stamp on recommendations of OT and others
'You can't have a standard accessible format!'
<u>ISSUES re leadership, manager and autonomy and leadership</u>
Conflict between staff team and manager or values of organisation
'It doesn't always filter down very well from the manager'
Manager sickness, managers leaving or under threat
'the leadership went', lack of leadership (change in leadership style)
<u>ISSUES research process</u>
Experience of being research participant
having to stop myself defending Esther's intervention
Identifying the researcher with the community team
Impact of being research participant on the intervention
Researcher missing something, getting it wrong
<u>ISSUES Residents</u>
agitation, behaviour, self-injurious behaviour

Capacity and consent
Differences between (sensory) preferences of different residents
Difficult to find occupations for PMLD
Need sensory engagement brought to them
Not having peers she can interact with, more able than the others
One resident with a lot of visitors impacting on outcomes
PMLD have ++ health needs
Residents who are particularly difficult to read, narrow sphere of communication
sensory self-regulating behaviour, self injury
supporting with personal care
NARRATIVE
_Judging, evaluating, criticising, generalising about colleagues
Contradictions in things interviewee says
Differentiating self from colleagues (support worker)
'I completely under-estimated that'
Imagining the voice of the participant
interviewee changes subject
Interviewee proudly showing understanding
interviewer discomfort
Narrative reasoning - desire, imagined endings
Narrative reasoning - motive
Narrative reasoning - plot
Narrative reasoning - suspense, riskiness
Narrative reasoning - telling stories
Narrative reasoning - trouble, enemies
Narrative reasoning transformation
Praising colleagues
Revealing surprising or controversial material
Speaking for self not whole team
Vagueness, evasiveness in interviewee
'what the nursing team are doing might be sensible and appropriate'
STRATEGIES
STRATEGIES Assessment of participants with PLD by Esther
assessing skills, strengths and needs, interests, (sensory) preferences - knowing them really well
Getting staff to complete forms
Observing staff engaging residents
sensory processing, sensory preferences general
Sensory processing - Auditory
Sensory processing - olfactory
Sensory processing - proprioceptive

Sensory processing - tactile
Sensory processing - vestibular
Sensory processing - visual
Trial and error, educated guesses
Using standardised assessments
STRATEGIES directly with service users promoting engagement
adapting the environment and activity
allowing time, reducing pressure
ATT genuineness, passion
ATT seeing the potential - 'wouldn't want to assume she couldn't do that yet', provisional conclusions
attitude of engagement despite reaching problems
Communication
Demonstrating that service users DO give feedback if you know what to look for
Facilitating communication with others about the person's life
intensive interaction, bring them out of their world
Interpreting behaviour as communication e.g. as indicating mood, interest
Language
'Levels of intentional communication'
objects of reference, symbols, pictures (level of understanding)
talking to the person assuming that they understand
Doing activity alongside people
'doing regular things in a really really sensory way'
Focusing on individual strengths, the positives
'Getting people out into local community'
grading, getting the challenge right
'he doesn't have to physically participate'
'I do tend to climb over things'
leaving by self to calm him down
'letting her feel comfortable to come to me and the activity'
'making the environment more sensory'
'making the resources with the guys' 'an activity in itself'
'making things individual for each of them'
'natural ability to engage the residents'
Openness to being surprised by the service users
Orientation, cues, sensory signatures
Recognising that they are 'Functioning at that very sensory level'
sensory diet, eg deep pressure, vibration
Sensory signatures
Sensory stories
short periods of activity

'stuff going on' so there is 'opportunity to try things' - making things available
supporting 'hand over hand'
Supporting occupational engagement at home that is meaningful
Taking notes
Talking or not talking during activity, talking over person
'the atmosphere, the banter'
They need a variety of activities or they might get bored
Trying again later
Using interactive technology
Using switches to cause an effect on (control) environment
Valuing doing activities as a group
Visual timetable
'waiting for his bath and doing something'
'you don't (only) have to go out of the house to do stuff - focus on activities at home
STRATEGIES nature of the OT intervention and general actions taken
Advice re equipment
'an approach that I think I can support others to use'
Being ambitious, aiming high
Changing approach, allowing intervention to evolve
Colour-coding plans etc
Creativity
Drawing on experience and OT training
'having a deadline in my head', it has to be a time limited intervention
including everyone in the house
making it 'a projecty thing'
Preparing reports, recommendations, session plans, equipment lists, resources, care plans, files
Sharing what we have done well
'Some will cut corners' hence need for checking up
Using evidence base to justify actions
Using theory, models to explain, justify plans, to support recommendations
'You can't just work in isolation with the service users'
STRATEGIES setting goals, outcome measures, reviewing progress, having clear goals in mind
Goal - actually pass objects
Goal - communication
Goal - community activities important, but haven't set that as my remit
Goal - create resources I can use with others
Goal - 'good balance across the day of different sorts of activity'
Goal - increase choice, control, understanding of routines
Goal - increase tolerance to touch
Goal - increasing engagement in (sensory) activities

Goal - independence and (opportunities for) skill development
Goal - maintain friendships
Goal - promote OT profession
Goal - promote self-advocacy
Goal - promoting quality of life
Goal - reaching for objects or sharing objects using intensive interaction
Goal - reduce challenging behaviour
Goal - things to do with staff and things by self
Goal - use switch to control environment
Goal functional activity
setting bar low
Setting the goals at the right level
Tangible evidence of outcomes, not just paperwork
_STRATEGIES with staff team and other professionals
attending, using Team meetings and handovers at CH
Being accessible, Making self available to chat with new staff members
Building blocks - Esther's ideas as templates for staff to build on to move people on
Building relationships with staff, humour, comfortable not a threat
'Can I grab you'
Challenging gently, criticising cautiously, feeding back carefully
checking understanding, conclusions reached with staff team
Collaborating, 'let's work on this together', 'Journey together to try and improve it'
Compromising
Educating gently, training with a small T
Embedding sensory activity, engagement into the culture
encouraging leadership by doing it, modelling
Getting manager to embrace it so can lead from the top, practice leadership
Guiding - giving feedback and gradually letting them take the lead
'Helping them to see how this fits alongside their philosophy'
'I do just sort of bound in',
'I don't want to dishearten them' (by setting the bar too high)
'I have worked in residential, I know the pressures'
'I value what you do with these people'
'keep chipping away at it'
Key people pass it on
making suggestions rather than telling what to do
Modelling
'Motivating staff', get them excited, momentum
'OT rescuing situations, pulling people together'
'Providing them with resources' and ideas (of activities)

'Revitalising the work I did before'
Seeing individual staff strengths and playing to them, nurturing them
Shift planning, support planning, modifying routines (staff and residents)
showing the staff you can let yourself go, have a laugh
Standing back and letting them run with it
starting off slowly to adjust
Taking time to explain things in detail
'team embracing it and getting on board'
Team working with family members and outside agency
Team working with community team nurses
Team working with manager, 'opening a dialogue'
Team working with MDT
Team working with OTA
Team working with reps
Team working with student
Varying the levels of detail of information
working with the staff in the same way as we work with our service users'
METAPHORS
Metaphor - a shift in culture
Metaphor - moving it or pushing it forward
Metaphor - nagging, chivvying people along
Metaphor - playing to people's strengths
Metaphor - (giving or taking) ownership
Metaphor - a battle
Metaphor - a bit of a win
Metaphor - a framework
Metaphor - a journey together, a process
Metaphor - balance
Metaphor - barrier
Metaphor - be on the inside
Metaphor - being full on
Metaphor - brain jumping all over the place
Metaphor - brainstorm
Metaphor - breakthrough moment
Metaphor - build a relationship with them
Metaphor - build on as we go
Metaphor - came back round
Metaphor - capture their interest, motivation
Metaphor - champions, allies
Metaphor - deadline in my head

Metaphor - defeated
Metaphor - different strengths
Metaphor - dipping in and out
Metaphor - doing alongside
Metaphor - drilled into people
Metaphor - drip feed, constant drip, drip
Metaphor - driving it
Metaphor - embed it in the culture, latching onto it
Metaphor - flying
Metaphor - framing it differently, putting it into a language that fits, dispelling myth
Metaphor - gentle nudge
Metaphor - get off the ground
Metaphor - getting everyone to sign up, on board, on side with you, a joint venture
Metaphor - getting it into their psyche, in their minds the whole time
Metaphor - getting them to embrace it
Metaphor - give them momentum
Metaphor - giving it a go
Metaphor - giving them a bit more direction
Metaphor - go down the route of
Metaphor - going out of their way
Metaphor - having a presence there
Metaphor - having something they can work with
Metaphor - i do climb over things
Metaphor - I do feel torn about it
Metaphor - I have planted a seed
Metaphor - I pinned too much on
Metaphor - I'll lose them, a bridge too far
Metaphor - information filtering or not filtering down
Metaphor - invested time
Metaphor - it does or does not pay off
Metaphor - it might have triggered something
Metaphor - keep chipping away at it
Metaphor - keeping it fresh, keeping it alive
Metaphor - keeping it on people's radars
Metaphor - lead from the top
Metaphor - living through the transition
Metaphor - making it more concrete
Metaphor - meet people half way
Metaphor - my piece of the puzzle
Metaphor - opening a dialogue

Metaphor - parents and grandparents
Metaphor - parting shot
Metaphor - pat on the back
Metaphor - paying lip service to me
Metaphor - pick your brains
Metaphor - place them on the bridge, levels
Metaphor - project
Metaphor - pulling people together
Metaphor - revitalise it, tap into the old energy
Metaphor - rubbishing of staff
Metaphor - running with it
Metaphor - sell it to them
Metaphor - setting the bar low or high
Metaphor - she was a bit spiky
Metaphor - shift my expectation a bit
Metaphor - sitting back
Metaphor - start stepping back from it, backing off
Metaphor - swooping in
Metaphor - teething problems
Metaphor - the banter
Metaphor - the more we show our faces
Metaphor - they feel they are jumping through hoops
Metaphor - they lump me in with
Metaphor - they turned their nose up at it
Metaphor - they were pulling back again
Metaphor - they will feel checked up on
Metaphor - things need to be normal life
Metaphor - training with a small t
Metaphor - turning point
Metaphor - tweak it
Metaphor - walking through treacle
Metaphor - what makes them tick
Metaphor - when the cat's away
Metaphor - whole big barrage
Metaphor - win the staff over
Metaphor -not to put too much energy into it

Appendix 14: Supported living

The following is an excerpt from Wood and Grieg (2010, pp. 7-9).

How is Supported Living different from residential care?

Supported living is a concept that was developed as an alternative to institutional care for people with learning disabilities and brought into the UK by the NDTi in the 1990's. The main principles of supported living are that people with learning disabilities own or rent their home and have control over the support they get, who they live with (if anyone) and how they live their lives. Supported living assumes that all people with learning disabilities, regardless of the level or type of disability, are able to make choices about how to live their lives even if the person does not make choices in conventional ways.

Supported living has no legal definition but has a commonly accepted set of principles:

- I choose who I live with.
- I choose where I live.
- I have my own home.
- I choose how I am supported.
- I choose who supports me.
- I get good support
- I choose my friends and relationships.
- I choose how to be healthy and safe.
- I choose how to take part in my community.
- I have the same rights and responsibilities as other citizens.
- I get help to make changes in my life.

The residential care model is legally defined in the Care Standards Act 2000 as an establishment that provides accommodation and personal care which is defined as *assistance with bodily functions such as feeding, bathing, toileting* when required. Within the residential care model there is an assumption that an older or disabled person needs care and therefore it provides a full package of housing, care and everyday needs for living on the person's behalf.

The Care Quality Commission has issued guidance³ to its inspectors to determine whether a home should be registered as a care home. These criteria fit closely with the definition of supported living in the Reach Standards and state that if the following criteria are met, it is unlikely to be registerable as a care home:

- The separate providers of accommodation and care do not need to co-ordinate their work and are not accountable to each other.
- People who use the service have real choice, e.g. they can change their care provider without jeopardising their accommodation rights.
- People using the service have exclusive occupation and can deny entry to others, even carers.
- The tenancy can be assigned to someone else.
- Occupants can remain even if they no longer need a care service.
- There are separate contracts for the care and the accommodation.

Supported living is not a prescriptive model of service design and can look very different for different people. For one person it may be a few hours support a week to live alone in a rented flat, for another it may be round the clock support to live in a home they own, and for others it may be a shared house with friends and support to meet individual needs. The key to whether it is supported living or not is how much choice and control the person has over their home and life rather than what the service looks like.

Different models for supported living include:

- Living in a rented or owned property and getting an individual support package.
- Sharing with others in a rented property and each person getting an individual support package.
- Extra care or sheltered housing.
- Lodging in someone else's home and getting an individual support package
- Living in an extension to a family home and getting an individual support package.

- Living in a network of houses or flats and supporting others as well as getting support.

Appendix 15: Participants' Levels of Engagement (Pool 2012) and Intentional/ pre-intentional communication (Coupe O'Kane and Goldbart 1998)

Excerpts from occupational therapy reports by Esther dated 28.6.13

	Level of engagement in activity	Level of Communication	Symbolic development
Harold	<p>"Functioning between the sensory and exploratory level of engagement. This means that he has some understanding of tasks that we traditionally see as functional. He may understand that tasks have stages but the purpose of participating in stages of tasks may be limited and not particularly motivating to him. He was found to be particularly motivated by interaction with others, more than the sensory elements of tasks. Any sensory activities should involve interaction and turn taking. He will enjoy simple cause and effect games. He will enjoy watching others participate and enjoy the activity as much as participating himself"</p>	<p>"Level of communication is intentional, pre-verbal which means he has some understanding that his actions influence other people and therefore some of his vocalisations are communicative in nature. As Harold's vocalisations are used to indicate a range of needs he remains reliant on staff to interpret and respond to his needs."</p>	<p>"Functioning at the object level. This means that he is unlikely to take meaning from photographs, symbols or pictures. Harold will be able to make associations between objects and activities, for example, he may associate a towel with a bath."</p>
Matt	<p>"Functioning between the reflex and the sensory level of engagement. This means that he is unlikely to take meaning from tasks that we traditionally see as functional. He will not understand the purpose of participating in stages of tasks such as putting laundry in the washing machine or doing the shopping. He will therefore not experience enhancements in self-esteem as a result of these types of activities in the way that people who have more advanced cognitive skills might. He will however enjoy engaging in the sensory elements of day to day tasks if they are brought straight to him and he is given hand over hand prompts and bodily contact to help him engage. By actively participating in</p>	<p>"Level of communication is pre-intentional, reactive which means he will react to stimulus and to his own body but that he has little understanding of the impact of his own behaviours on others. The noises he makes are reactions to his mood but they are not intentionally communicative. He is reliant on staff to recognise these reactive behaviours and respond to them."</p>	<p>"Functioning at the object level. This means that he is unlikely to take meaning from photographs, symbols or pictures. Matt will be able to make associations between objects and activities, for example, he may associate a towel with a bath. Because of his visual impairment he will need objects with distinct textures. He may also benefit from some environmental cueing</p>

	Level of engagement in activity	Level of Communication	Symbolic development
	sensory activities he is likely to develop a better sense of self and skills which will enhance quality of life. Matt does not notice sensory stimulus in the environment without support and will therefore not indicate when he wants to engage in something. It is important to facilitate regular sensory activities with Matt.”		such as particular smells in each room and sensory signatures for different staff members.”
Steve	“Functioning at the sensory level of engagement. This means that he is unlikely to take meaning from tasks that we traditionally see as functional. He will not understand the purpose of participating in stages of tasks such as putting laundry in the washing machine or doing the shopping. He will therefore not experience enhancements in self-esteem as a result of these types of activities in the way that people who have more advanced cognitive skills might. He will however enjoy engaging in the sensory elements of day to day tasks. By actively participating in sensory activities he is likely to develop a better sense of self and skills which will enhance quality of life. He does notice motivating sensory experiences in the environment and will reach for them, it is therefore important that opportunities to engage and objects to engage with are available to him.”	“Level of communication is pre-intentional, reactive which means he will react to stimulus and to his own body but that he has little understanding of the impact of his own behaviours on others. The noises he makes are reactions to his mood but they are not intentionally communicative. He is reliant on staff to recognise these reactive behaviours and respond to them.”	“Functioning at the object level. This means that he is unlikely to take meaning from photographs, symbols or pictures. Steve will be able to make associations between objects and activities, for example, he may associate a towel with a bath.”
Jane	“Functioning between the sensory and exploratory level of engagement. This means that she has limited understanding of tasks that we traditionally see as functional. She may understand that tasks have stages but the purpose of participating in stages of tasks will not be clear to her. We should not assume she will experience enhancements in self-esteem as a result of these types of activities in the way that people who have more advanced cognitive skills might. She is more likely to experience pleasure and build skills if she is provided with repetitive and consistent	“Level of communication is Intentional, pre-verbal which means she has some understanding that her actions influence other people and therefore some of her vocalisations and actions are communicative in nature. Although she has some clear communications for things such as requesting food, her repertoire is still	“Functioning at the object level. This means that she is unlikely to take meaning from photographs, symbols or pictures. This is evident from her lack of understanding of the photo prompts on the cupboard doors in the kitchen. Jane will be able to make associations between objects and

	Level of engagement in activity	Level of Communication	Symbolic development
	<p>sensory activities. She will however enjoy engaging in the sensory elements of day to day tasks. By actively participating in sensory activities she is likely to develop a better sense of self and skills which will enhance quality of life.”</p>	<p>limited and she remains reliant on staff to work out what she wants when she is unable to physically lead staff.”</p>	<p>activities, for example, she may associate a towel with a bath.”</p>
Becky	<p>“Functioning at the sensory level of engagement. This means that she is unlikely to take meaning for tasks that we traditionally see as functional. She will not understand the purpose of participating in stages of tasks such as putting laundry in the washing machine or doing the shopping. She will therefore not experience enhancements in self-esteem as a result of these types of activities in the way that people who have more advanced cognitive skills might. She will however enjoy engaging in the sensory elements of day to day tasks. By actively participating in sensory activities she is likely to develop a better sense of self and skills which will enhance quality of life.”</p>	<p>“Level of communication is intentional, pre-verbal which means she has some understanding that her actions influence other people and therefore some of her vocalisations are communicative in nature. Because she does not have a clear system for communicating a range of needs she remains reliant on staff to work out which need she is indicating she needs met.”</p>	<p>“Functioning at the object level. This means that she is unlikely to take meaning from photographs, symbols or pictures. Becky will be able to make associations between objects and activities, for example, she may associate a towel with a bath. Because of her visual impairment she will need objects with distinct textures. She may also benefit from some environmental cueing such as particular smells in each room and sensory signatures for different staff members.</p>

Appendix 16: Reasoning through telling and creating stories (excerpts from interviews)

Esther: "Historically before the structure changed I had worked with them quite a lot and they had got to a place where they were a bit more there. But then the nurses withdrew and the support workers that are there lost that a bit.... The leadership went, you know they would have a named nurse, a shift leader who was a nurse on every shift and that nurse would go in and dictate what happened. Then when the nurses left, I think they lost that direction and leadership a bit - as well as they lost all the ... some of the background understanding of why we were doing what we were doing. The support workers did it but whether they truly understood why they were doing it." (4.1.13).

Esther: "you really get the sense that people that have been there a long time and sort of understandably cos when they worked there before they were on a higher band, got paid enhancements, they had people to lead, they had nurses on the unit that told them what to do and when, whereas now they have to kind of organise themselves, they don't have the same level of leadership, I think they feel really aggrieved they have lost their enhancements. I think they have been rebanded ... effectively they have had a pay cut by losing their enhancements.... So I think there is lots of feeling not motivated because of those things. And they have noticed a shift, so before there was a real value in doing sensory activities and now I don't think there is and they have lived through that transition, they I don't know whether they feel disappointed by, but it feels like there is a lethargy, they have lost their drive around it. So it could be that new people come in and they are fresh and they want to do activities and they are not ground down by the you know and they haven't noticed having a pay cut cos they came in on that level. Lots of things that affect it isn't there?" (22.2.13).

Esther: So what I am thinking I would do is assessment work with each of the people there but then trying to engage the staff in a bit of a project. I was thinking of ... really practical things like having a board, which is the sensory board, which gets changed every week. So you know this week it is sensory story week, so on the board we have got some stuff about sensory stories and we set up some goals around

writing sensory stories.... They just start thinking more about sensory activity every day and it becomes more part of their everyday work.... I think I know already that all the guys that live there are functioning at that very sensory level so I am thinking of sensory activities and trying to get them to think about how they adapt everyday stuff into sensory, rather than these separate little sensory sessions. (4.1.13)

Esther: *I think we just need to embed it in the culture, so Norma needs to be on board absolutely needs to understand it and be promoting it as does Sue..... I think everybody needs to know what it is about and what I am doing and things like having the board on the wall is the constant daily reminder about we are supposed to be doing that. (22.2.13)*

Esther: *But actually what I really do want to do is to get things into people's psyches, to get them thinking sensory all the time. Because that is where the guys are functioning all the time. So those [prompt] cards I think will start to get people thinking about well I have got to do this today, which one am I going to do, so that might be happening. (10.4.13)*

Esther: *Once you've got one person on board and they are talking about it in the unit when you're not there, then it starts to spill over and other people start to hear it and it is not just coming from us (30.4.13).*

Esther: *I guess the long term aim is that it will be Sue and the service that keep this alive and that when they get new staff in the future that they show them the DVD and they talk about it and they keep it alive in the unit. (1.11.13)*