The multi-faceted experience of empathy in intellectual disability settings:

An IPA Study

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In my work and life, I have discovered one absolute truth – empathy is the light that shines through the darkness of our pain and our fear to reveal what we have in common as human beings

– Ciaramicoli and Ketcham –

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ABSTRACT

This research thesis explored the concept of empathy. The specific purpose was to further understand the idea of empathy in relation to the experience of male support workers who provide residential care to adults with intellectual disabilities (ID) and challenging behaviour. The thesis aimed to provide some insights into how support workers develop and extract meaning from their experiences of relationships with clients and the impact of this on their own self-care, namely, self-compassion. Since personal accounts of experience were required, a qualitative methodology was employed, Interpretative Phenomenological Analysis (IPA) (Smith, 2004). This methodology was selected as it allows for the exploration and interpretation of idiographic lived experience and meaning making. 8 experienced support workers were interviewed using a semi structured interview. Four superordinate themes emerged from the data. These included: 1. Making sense of the others inner world; 2. Processes that enhance empathic practice; 3. Tensions and conflicts, and 4. Management of distressing feelings. Differing accounts of interpreting the needs of clients were identified which helped participants understand, make sense of their interpersonal experience and participate in their role. These included utilising academic knowledge and senses, particularly sight and hearing, which were seemingly complemented by a level of reflective practice. Additionally, to make sense of the experience of a client, they appeared to put themselves in their position, suggesting a form of empathy. Participants appeared to engage in a process of reflection on their relationships with clients, which helped them think about what they had learned about the person's needs, moreover, this process enabled them to identify some of their own responses and feelings. However, participants seemed to struggle to recognise the occurrence or impact of distressing emotional experience and to express their feelings, possibly in response to a deep sense of responsibility and fear of transferring emotional distress to others. This dilemma of holding two potentially conflicting views of experience seemed to inhibit self-compassion. Although not specifically testing theories of empathy, from the overall findings, it could be suggested that empathy may be a dynamic, transient process that is influenced by reflexivity, values and context. The context in which participants

discussed their practice, and situated within their accounts, suggested a sense of confusion and uncertainty. Consequently, it is suggested this impacted on how participants understood and related to clients, and to themselves.

There were some specific implications for Counselling Psychology practice, mostly concerning training and supervision. These included recommendations for staff training and supervision, systemic organisational intervention, policy development, recommendations for revisions to models of specialist care frameworks and clinical training.

Keywords: Empathy, self-compassion, intellectual disability, challenging behaviour, support worker, qualitative research.

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CHAPTER 1

INTRODUCTION

The following research study is an exploration of the experiences of empathy and self-compassion as described by male care staff (support workers)[1] working within residential intellectual disability (ID)[2] and challenging behaviour services[3]. Although exploring notions of empathy, this study did not seek to test out theories or to make assumptions about empathic ideas and how these are applied in clinical practice. Moreover, it aimed to understand how theories of empathy might help us to understand how support workers make sense of their experiences and the impact of this on their self-care. This in turn may provide some insight into fostering improved client/support worker relationships and capacity for self-compassion. Male support workers were chosen for this research as it has been argued within psychological literature that men exhibit less traits of empathy and struggle with communication of emotional experience (Kingerlee, 2011), furthermore it has been suggested that deeper levels of empathy are useful in interpreting and understanding the complex behaviours and relationships presented by clients with ID who challenge services (Bollas, 1987; Lovett, 1996; Hodges, 2003). Grounded in participants' reported experiences the aim of this research was to explore how processes of relating are understood and whether they enhance or inhibit self-compassion. This chapter will provide a rationale for my interest in the area, including my epistemological and reflexive position.

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[1] Support worker is the common vocational title given to staff who provide support to vulnerable people in care settings. Although context dependent this role usually includes fostering independence and engaging in health and social care tasks (Manthorpe & Martineau, 2008). I have used the terms support worker and staff interchangeably for ease of reading.

[2] Intellectual disability (ID) refers to impairment in cognitive functioning, diagnosed before the age of 18, with related limitations in two or more skill areas (Luckasson et al, 1992). I have used the term person with ID and client interchangeably for ease of reading.

[3] Challenging behaviour is a socially constructed term (Emerson, 2008) used to convey behaviour(s) which place a person at risk to themselves or others and limits or restricts access to the community and its amenities (Emerson, 1995).

1.1 Experiences that shaped my interest in empathy

I have always held an interest in the nature of human connection and the experience of relating to the experience of the other. Growing up there was often a sense of struggle in understanding my position in relation to others and navigating the terrain of childhood and adolescence. At times it seemed the more I was open, strove for meaningful connection and demonstrated interest, the more distanced and isolated I became. Essentially I felt misunderstood. In part these experiences led to an analytical approach in interpreting my relationships and identifying ways that would help me understand what it means to share a congruent authentic human connection. On reflection, part of my sense of distance may have stemmed from events which led to me occupying a responsible role within my family from an early age. Consequently, the lens in which I viewed the world seemed different to that of my peers.

My working life has been within the company of people with ID and challenging behaviours. I have often experienced this population and their relationships and social networks (including staff) to be marginalised, misunderstood and poorly supported by governing bodies and professional agencies. When I began employment as a support worker I experienced a wealth of experiences which were rewarding and enjoyable yet also confusing and stressful. Although peer and managerial support was available, often there was a sense of isolation and necessity to learn from my own experiences of being with somebody and the unique transactions that transpired.

As I have progressed within clinical roles, I now wonder what insight support workers might have into processes of interpreting the world of people with ID, or how they relate and respond to their own feelings. My experience of therapy, support work and staff training has led to the view that construction of knowledge is fluid, idiographic and subjectively experienced and developed. As a clinician I integrate therapeutic theories and modalities to meet the unique needs of the client. This bespoke approach facilitates a process of intersubjective construction of experience which can be utilised to inform assessment, formulation and treatment. Post training, I have begun to realise how knowledge of myself, relationships and psychological

functioning has changed. I consider in more depth how I think about others and myself in relation to them. I feel more confident in validating and accepting my vulnerabilities and weaknesses. This has proved helpful to bridge how I strive to understand, relate to and connect with clients. Holding in mind the richness, fragility and uncertainty of the human condition. This process of knowledge elucidation and elaboration I view as an ongoing and fluid ontological journey in which what we know of ourselves and others is never truly fixed and static, but nonetheless meaningful.

My experience as a support worker shaped an understanding that my perspective of reality can be very different to a person with ID. Being open to how information, the environment and relationships are experienced enabled me to gain a sense of congruence and understanding with clients through leaps of imagination, clarification and learning from interpersonal experience. Drawing on uncertain subjective experiences of affect helped to form relational connections. As a trainer I have realised that to facilitate learning it is important to consider language and individual differences. These approaches seem to be underpinned by attempts to empathise with the experience of others.

Derived from the Greek language, "empatheia", (empathy) can be interpreted as meaning "within" (em) "feeling" (pathos) (Oxford Dictionary, 2015). The notion that empathy involves being within a feeling, including the feelings of others is believed to be fundamental to counselling psychology practice. It fosters a sense of safeness (Gilbert, 1989), and underpins the therapeutic alliance (Strawbridge & Woolfe, 2010). Therapeutic descriptions of empathy are often associated with early work by Carl Rogers. He seemed to view empathy as entering the world of another, sensing changing meanings and communicating these back (Rogers, 1980). Interestingly his conceptualisation of empathy evolved over time (Howe, 2013), perhaps illustrating a dynamic quality and elusiveness.

Role play is believed to be a helpful exercise in gaining a sense of understanding others and empathising with their experience (Gilbert, 2013). It requires a capacity to reflect on feelings, and parts of ourselves that are reflected in others which may be painful, scary or uncomfortable (Gilbert, 2013). As a result of this, empathic practice

may enable clients to recognise internal judgements that are hidden by distressing feelings (Gilbert & Leahy, 2010), a critical aspect of the therapeutic process.

The word empathy is frequently used to convey conditions for therapy (Rogers, 1987), explain social motivations (Gilbert, 2010) and inform diagnostic tests (Baron – Cohen & Wheelwright, 2004). It is here, in the differing definitions and constructions of empathy that perhaps complexity arises in how it can be understood. Despite substantive studies and references within practitioner handbooks the phenomenon of empathy continues to seduce and evade me. There is something attractive and alluring in the idea that, within the context of vulnerability, people can share a moment or experience, and be connected in a meaningful way. It is this sense of relating or understanding, above all material things that moves me. Particularly in relation to the values of our current society, in which it appears a business model permeates much of our lives, solely concerned with efficiencies, targets and competition. Arguably this detaches us from our humanity and relationships with others.

However, I experience challenges in understanding which model of empathy to draw upon, and how in practice it informs my relationship and work with clients. I am curious about empathy as a process, yet often it is couched within conditions (Rogers, 1987) or as an experience, for example being in the shoes of another **(**Gilbert & Leahy, 2010). If indeed I have had experience of empathising with clients, my understanding is further complicated by the pain that can be felt in relation to connecting with the feelings of others, and how I care for, empathise and make sense of my own experience and its meanings. This perhaps suggests that engaging in empathy may require effort, resilience and direction. In contrast, other accounts suggest that empathy occurs in relation to the experience and internalisation of patterns of attachment between care giver and care provider (Shaver, 2015). Moreover, these experiences are reported to influence our capacity to be compassionate towards ourselves, and can have an impact on our esteem, and consequently inform how we empathise with others (Neff 2011)**.** These differing definitions of empathy and its relationship to self-compassion fuel my interest in researching these phenomena.

In sum, upon reviewing the literature and in discovering its rich heritage what becomes apparent is that its clarity appears to have alluded many, not least due to its multiple constructions and perceived functions. The associated concept of self-compassion (empathy directed towards self) appears equally elusive.

1.2 My epistemological stance

Each experience, interpretation or internalisation of a relationship is unique. Positivist understandings inhibit ability to make sense of the nuanced experiences of life and our feelings towards others. I have learnt people can interpret how I feel in very different ways and in different contexts. Fortunately, paradigms within psychological research are broad and also include focus on discovery orientated approaches and qualitative methodologies.

Qualitative methods are underpinned by particular ways of thinking about knowledge and how it is applied. Phenomenological approaches (Husserl, 1970) aim to develop knowledge about people's lived experience, whilst attempting to bracket the researchers' values. It is grounded in the view that language reflects the experiences and meanings of events and social situations. The hermeneutic position considers beliefs, context, practice and culture in exploration of how people acquire meaning, including the researcher (Schwandt, 1999). Since it aims to clarify the conditions in which understanding takes place (Gadamer, 1975), it differs from phenomenological research as context and researcher values are embedded within the process of knowledge construction. In relation to this, the perception of our reality and the language used to construct and make sense of our emotional, interpersonal and intrapersonal experience is informed by our culture and values; thus integration of hermeneutic and phenomenological approaches permits access to descriptions of the essence of emotional life (Heidegger, 1962).

My experience has been one of elusion and confusion in the qualification of emotional experience in people with ID, through a critical phenomenological lens, perhaps explication of meanings and cultural influence may assist in the clarification of what it means to be empathic and self-compassionate. Subsequent chapters

delve into what is understood about these phenomena and provide a rationale for my methodology and research questions, leading into my consequent analysis within the context of residential care settings for people with ID and challenging behaviour.

1.3 Reflections on beginning the research study

From the onset I found the process of research challenging, perhaps reflecting my novice status, fluctuating academic confidence and resistance to the idea of producing knowledge that potentially could be used in powerful ways. There is a great sense of responsibility in the acknowledgement that applied research has significantly directed therapeutic practice leading to government initiatives such as improving accessing to psychological therapies (IAPT) (DOH, 2008) and clinical work with people with ID (DSM, 2000), which perhaps has not always resulted in improvements in practice or care.

CHAPTER 2
LITERATURE REVIEW

This chapter will draw on psychological and philosophical literature with an aim to contextualise the research area and illustrate how this has informed the focus of inquiry. Couched within the extant literature, I will attempt to describe what is understood about people within ID, challenging behaviour and support workers. I then move onto the exploration of care settings and practice guidelines. Following this, current understandings of empathy and self-compassion are considered within the context of ID and care settings. A particular focus will be on the support worker's experience of interpreting people with ID and how this is understood within their relationships and the service setting. Emergent themes are identified to elucidate present gaps in knowledge. Finally identified themes are discussed in relation to counselling psychology practice, and lead into the rationale for the research focus.

2.1 Intellectual Disability (ID) and Challenging Behaviour

Historically the terms learning disability (LD) and intellectual disability (ID) have been used interchangeably. Emerson (2008) argues that the term intellectual disability (ID) is the current preferred terminology within the international scientific community. This term is thought to avoid derogatory labelling, but is used synonymously with the terms learning disability and mental retardation. The term ID evokes a sense of struggle in the domain of "intellect" in contrast to LD which may be construed as deficits in learning. My experience of clinical work suggests that learning new skills and ways to adapt behaviour is not impaired, thus I contend the term LD can be misleading. Moreover, over-reliance on perceived ability, to assess capacity to form a therapeutic relationship means that practitioners or support workers may not consider the potential for the sharing of minds that can be experienced within a relational space (Greenhill, 2011), and enhanced by principles of attachment theory (Bowlby, 1979). Attachment theory is used to describe a set of behavioural patterns that enable an individual to attain and maintain proximity to another individual,

usually perceived to be stronger and/or wiser (Bowlby, 1977). Attachment occurs across the lifespan although may be more clearly observed in infants. It is often affiliated with psychodynamic approaches in therapy (Lemma, 2011).

ID has been defined as "substantial limitations in present functioning (IQ<70), existing concurrently with related limitations in two or more adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work," occurring "before age 18", (Luckasson et al, 1992, p.5). It is socially constructed, influenced by mental health, culture, context and linguistic diversity (Hatton, 2001). Cultural beliefs are thought to influence the way people with ID are viewed to have capacity (MCA, 2005) and accountability (Wolfensberger, 1972). This may be attributed to the positivist grouping of symptomology pertinent to the diagnosis of ID, influencing the cultural perception of people with ID within society. Nonetheless, diagnosis may be important to access much needed services including psychiatry and psychology provision. Historically there have been difficulties classifying this population (Fryer, 1993) whom for long periods have been devalued and misunderstood. Hodges (2003) argues that this legacy can have a significant impact on each encounter a person with an ID may experience.

The term challenging behaviour refers to a broad class of behaviours. It has been defined as "culturally abnormal behaviour (s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities". (Emerson, 1995, p.3). There is evidence to suggest that for people with ID, challenging behaviours can become part of their behaviour repertoire as a result of the development of adaptive responses to aversive situations (Emerson, 2008). It therefore has a function and is meaningful. A specific challenging behaviour may serve a number of functions. Research has shown that people who challenge services are more likely to be physically abused, be prescribed unnecessary or excess medication, have physical restraints applied to them, be excluded from services or activities that are available to other people and be systematically neglected (Emerson, 2008).

Challenging behaviour is socially constructed, influenced by social rules and beliefs and the capacity to manage risk (Emerson, 2008). It can be understood as a process between the person and their social environment. Given the complex needs of people with ID, the social environment often largely consists of support workers. Ironically the mediation between people with ID and staff has been reported to elicit stress, (Jenkins et al, 1997), emotional reactions to behaviour which may lead to social avoidance, (Mitchell & Hastings, 1998) and distorted views of the person (Dagnan, Trower & Smith, 1998). There is limited research on the experience of working with people with ID, or of the relationship. In relation to this, exploration of the experience of the working relationship with people with ID, couched within notions of empathy, may assist our understanding of reported challenges. Moreover, how empathic thinking or practice might influence relational tensions and capacity for self-care.

Historically research in this field has focussed predominantly on service systems and practice guidelines (Allen et al, 2005; Devereux et al 2009; Horner, 2000; LaVigna & Willis, 1995) and staff burn out (Hastings 2002; Burns 2005) drawing heavily on positivist methodology. This is likely to have been underpinned by social agendas which drove to develop generic services that needed to be consistent, proactive, comprehensive and integrative (Hatton, 2001). Recent studies have adopted a qualitative approach exploring relational experience in elderly and forensic settings (Luff 2010; Sandhu et al, 2011). Shifts in research are thought to be linked with current views on the importance of mediation between staff and people with ID or other complex needs (Gore et al, 2013; NICE Guidelines on ASPD Treatment Management and Prevention, 2013). However, there seems to be continued importance ascribed to research designed to improve the broad framework of service provision, rather than understanding at a micro level the idiographic relational experience of people with ID and support workers.

2.2 The support worker and service setting

People with ID and challenging behaviour often exhibit a number of complex needs requiring a multi-disciplinary approach to care provision and drawing on a range of health and social care provisions. A large proportion of this population require 24

hours' supervision and support. In the 1980s services were developed to meet the complex needs of people with ID, often referred to as residential community based services. This occurred following increased interest in the civil rights of vulnerable people and emphasis on social policy such as The White Paper (1971; 2001b). In particular, focus was paid to the integration of wider systems that provided services to people with ID, including care management and funding authorities, and evaluation of the informed use of person focussed theory and models of care in delivering services (Cambridge & Carnaby, 2005). The importance of promoting the key areas of rights, independence, inclusion within the community and choice and control were and continue to be stressed (DOH, 2001). The framework proposed to guide practice would suggest that historically people with ID have been marginalised, neglected and given little autonomy.

The role of the support worker varies dependent on the context and nature of care provided. Following a scoping study Manthorpe and Martineau (2008) suggested three categories define the role: 1. fostering independence; 2. generally working without professional qualification and 3. frequently engaging in health care and social care tasks. They reported that role clarification may be vague and pay often low. Aggregated literature also identified problems with infrastructure, training and regulation. Hatton and Lobban (2007) found 30% or more of support workers working in ID, mental health or challenging behaviour settings reported experiences of clinically significant levels of psychological distress. The nature of distress is not specified so it is unclear from this review what processes elicited or maintained difficulties.

The area of staff stress and burn out appears to dominate research that can be construed as relational. Substantive studies have focused on the effect of stress in care settings on the nature of support that is provided (Burns, 2005; Johnson, 2006; Stebnicki, 2000) and impact on wellbeing (Howard et al, 2009). Studies generally attribute causal links between stress and being exposed to challenging people, however little attention has been paid to the experience of staff in their individual role, relationships or exploration of additional processes that may shape or maintain distressing feelings. For example, staff attribution towards people who challenge services has been understood to influence support (Dagnan & Hill, 2002; Hastings

2002; Howard et al, 2009). Lewis and Stenfert Kroese, (2010) investigated nursing staff attitudes and emotional reactions towards people with ID in hospitals. Attitudes and emotional reactions were informed by empirical findings and measured using self- report, vignette style questionnaires. The emotion scale rated five positive and five negative emotions but excluded empathy, which is arguably important to an understanding of attitudes and emotions which influence care. The emotion measures were framed as "I would feel….." This may have elicited cognitions about future hypothesised ways of feeling, perhaps leading to detachment from situational lived emotional experience, and additional social cues.

What the literature suggests is that there is some evidence for the idea that people who work with this client group experience difficulty with the relational aspect including, stress, burnout, and problems developing and maintaining empathic based relationships. A focus on relational issues has been proposed by Brown and Smith (1992) who briefly discuss relational dynamics in their description and critique of normalisation (Wolfensberger, 1987). In brief normalisation promotes ideology that people with ID should be supported in attaining socially valued roles. Wolfensberger argued the payment of staff created a chasm in the relationship as there was a lack of equality, however Brown and Smith question whether moral motivation alone to care is a healthy basis for a relationship between cared for and carer. Identification with people with ID is thought to influence self-worth (Lamb, 1979) and may be connected with projections of loss and reflecting on one's own vulnerabilities and conflicts (DeGroef & Heinemann, 1999). Perhaps unsurprisingly, compassion fatigue is likely to occur in work with people with limited prognosis who require long hours of support (Figley, 2002). There may also be pressure to inhibit negative affect for fear of being perceived as incompetent (Lloyd & Williams, 2003). Themes of power, control, distress and esteem appear prevalent amongst the experience of support workers.

Although there is some research in the area, positivist research appears to result in a lack of access to reported experiences of caring or relating and to the idiographic construction of emotions. Given the demands faced in this work, current research seems to lack insight into the phenomenological experience of support workers. Hence, it would appear despite recent interest, research into individual processes

that may enhance or inhibit relating to people with ID and challenging behaviour is limited. Furthermore, there seems to be little understanding of the experience of this work from the perspective of the support worker, and how this may influence wellbeing. This also seems to be the case in review of practitioner guides, client treatment plans, service design and provision, staff training and organisational policies.

2.3 ID Services and best practice guidance

A focus on developing better care for people with ID has been proposed. Legislation, regulation and government policies guide the provision of care for people with ID; The Mental Health Act (MHA, 1983) and Mental Capacity Act (MCA, 2005) have played key roles in the development of individual and systemic practices. Valuing people: A New Strategy for Learning Disability for the 21st Century (DOH, 2001b) and Valuing People Now (DOH, 2009) set out the governments manifesto to improve the lives of this client group. It advocates rights, independence, choice and inclusion as key initiatives. Locally based specialist community ID services are advocated to work alongside commissioners and care managers. The Report of the Mansell Committee (DOH, 1993) identified the importance of commissioning services on an individual basis, and application of modern behavioural approaches for people who challenge services.

Principles of Positive Behaviour Support (PBS) (Baker, 2005) became prevalent in the early 1990s and made a distinction between modern and past behavioural approaches. Past intervention placed emphasis on behaviour modification, limiting consideration of individual qualities, experiences and the person's autonomy. The aim of PBS is to provide sustainable management of challenging behaviour in conjunction with strategies in which to reduce its occurrence over time. Functional assessment is key to understanding factors that elicit and maintain behavioural contingencies (O'Neill et al, 1997). Challenging behaviours which are functional for the person remain an option in their repertoire whenever alternatives cease to be as effective, and emphasis may move to reducing intensity and risk. Pitonyak (2002) has formulated that all behaviour is a form of a communication, he argues that the

objective of intervention should be to encourage listening. Lovett (1996) has acknowledged that in contrast, the relational function for practitioners of behavioural assessment appears to be distancing; he argues that this can lead to denial of the mutuality of the common condition that is being human. Nonetheless, PBS does offer a multi-element approach in which specific interventions can be developed to produce a better fit with the environment, promote self-help, self-management and social skills and develop planned responses to dangerous behaviours. It avoids the use of aversive or punishment techniques and minimises use of restrictive practices.

The Positive Behaviour Support Competence Framework (PBS Coalition, 2015) is a comprehensive document outlining practice within three main domains: values, theory and evidence base and process. Analysis of the framework suggests scope for enhancing knowledge and guidance within the context of the relationship between support workers and clients. Current emphasis seems to be on actively supporting family and social relationships and enhancing social inclusion. There is no explicit mention of the relationship with the support worker except for in terms of identification of change enhancers and barriers that may influence support. The importance of personal resources for support workers is identified, but only in the context of how this may impair support. This construction of the role is argued to minimise a sense of individuality, the importance of the unique relationships that can transpire between people and the need for adaptability and emotional support. Interactions described as enhancers or barriers to treatment seem to depersonalise relational intimacy and meaning making that occur between support workers and clients. This appears to be counter to including people with ID in their choice and autonomy within relationships, values advocated by current government policy. There is no doubt that this is an important document to inform ethical and evidence based practice, moreover it is not uncommon for practitioners informed by principles of PBS to refer to the importance of social values and of working relationally. However, Lovett (1996) has noted that until people with ID are in a position to decline therapeutic approaches, even models that are innovative and well-meaning, elements of control and coercion remain implicit within the theory underpinning practice. Elaboration of mediating social processes and development of systems to explore relational experience and conflict, and to provide emotional support for staff may enhance effectiveness of care provision and staff wellbeing. This is

commensurate with the person centred value base that underpins the PBS framework.

Person centred planning (PCP) (DOH, 2001) is underpinned by ideas associated with person centred therapy (Rogers, 1958). PCP considers the person to be central to the provision of care. Focus is on increasing community access and inclusion, developing relationships, enhancing opportunities for choice, improving personal skills and advancement of valued and respected roles (Magito-Mclaughlin, 2002). Mansell & Beadle- Brown (2004) have indicated that challenging behaviour can elicit negative feelings in support workers and lead to problems empathising. They argue this may reduce incentive to provide person centred care. Matters are complicated further in review of critiques of PCP and in its implementation (Mansell & Beadle-Brown, 2003; Towell & Sanderson, 2003; Dowling et al, 2006). In the aggregation of literature authors identify a range of reported challenges in facilitating PCP: 1. difficulties communicating with non-verbal people with ID and assessing their abilities (Mansell & Beadle-Brown, 2005); 2. narrow vision within staff cultures (Todd, 2002); 3. negative social attitudes towards mental health problems (Stainton, 2002); 4. staff skill deficits (Mansell & Brown, 2004); 5. limited budgets (Towell & Sanderson, 2003) and 6. inadequate systems to facilitate PCP values (Mansell & Beadle-Brown, 2003). Consistent with PBS, much of the literature surrounding PCP places emphasis on people with ID, with support workers occupying the role of facilitator. However, there is greater acknowledgement of the relationship and struggles that might be encountered (Dowling et al, 2006). Authors ascribe a range of supportive interventions including mentoring, training, supervision and informal support groups (Dowling et al, 2006; Mansell & Beadle-Brown, 2003). It would seem that human and relational values are present in the way models of care and service provision are formed and developed. What appears to be problematic is the synthesis of theory and transferring these values into service delivery. Part of this dilemma seems to be underpinned by a focus on implementation of protocols rather than the values that underpin them, and how they can be complicated by individual differences. Empathising with the experience of support workers and exploration of theories that may assist in the development of an empathic culture, may go towards improving the fit between PBS and PCP theory and practice.

2.4 Current understandings of empathy

The phenomenon of empathy has its linguistic roots in ancient Greek however the recent intellectual heritage was borne out of nineteenth century philosophy within the context of aesthetics (Howe, 2013). The German term Einfuhlung translated as "feeling into" was used to convey a sense of understanding and reaction to powerful pieces of art (Freedberg & Gallese, 2007). This aesthetic stance elicited interest in the psychological community in relation to how we understand, interpret and find meaning in our interaction with others; concepts of empathy and understanding have historically been adopted interchangeably to delineate between the methodologies of natural and human sciences (Stueber, 2006). A range of disciplines have conceptualised empathy including neuroscience, (Lamm, 2014; Yiend & Mackintosh, 2005), psychology, (Churchland, 1991; Gallese & Goldman, 1998; Neff, 2007), sociology, (Luff, 2010) and philosophy, (Lipps, 1907). There is arguably no agreed universal definition, (Smajdor, 2011). The phenomenon has been conceptualised as a cognitive skill (Gilbert, 2000), a personality disposition (Davis, 1983), an emotion state (Duan & Hill, 1996) and in terms of relational responding following operant reinforcement (Roger, 2009). In the phenomenological tradition it is argued that emphasis should focus more directly on the experience of expressed states in human body, expressions, gesture and tone of voice (Scheler, 1973). Empathy is thought to be developmental increasing with age (Barr et al, 2009; Siegel, 2001) and influenced by cultural meanings and interpretations (Pugh, 2009). Counter to its epistemological underpinnings, limited research appears to have been conducted on how it feels like to be empathic or how we individually ascribe meaning to this phenomenon.

Given the significance of empathy in counselling psychology practice (Rogers, 1990) and rooted in phenomenological epistemology (du Plock, 2010) there appears to be a lack of rigor and investigation into the idiographic experience of empathy. In contrast, it appears that emphasis has been on researching its properties, functions and neuropsychological structures. For example, cognitive accounts of empathy suggest that self-other schemas develop to guide people to seek specific roles such as attachment or alliances, interpret social roles in others and instruct affective and behavioural responses (Gilbert et al, 2006). Role forming systems have been

referred to as social mentalities[4] (Gilbert 2000). Theorists have studied the function of cognitive components and how they may focus on different aspects of perspective taking (Eisenberg, 1990). These accounts suggest that social interpretation and perspective taking form part of the empathic process. Perspective taking or theory or mind (ToM) (Baron – Cohen, 2011) is couched within two competing theories; simulation theory (ST) and theory – theory (TT). ST is a broad framework which proposes that one's own mental apparatus is used to simulate the psychological and neuropsychological experience of others thus facilitating predictions and explanations of actions (Harris, 1995). In contrast TT borne from more of a nativist tradition claims that theories of mind emerge from common sense understanding and acquisition of rules (Churchland, 1991). Gallese & Goldman (1998) argue for an integrated theory in which when ST processes fail, TT approaches may compensate, as in the case of people with autism who can acquire ToM skills through learning (Currie, 1996). In sum, existing theories suggest the ability to imagine the position of another person might be important in our capacity to empathise.

Neuropsychological research (Lamm et al, 2014) has examined how people might respond to others when affective stimuli or experience is unfamiliar. It suggests that inferring the affective state of someone leads to the activation of the same neural structures as empathy for someone who has had similar experiences. These findings suggest that the fronto-cortical attention network is crucially involved in this process. This perhaps provides support for the formulation that empathy is a flexible phenomenon involving both automatic and controlled cognitive mechanisms. It could also imply that despite possible differences in understanding oneself and the world, it may be possible to experience a sense of empathic understanding.

Other neurological studies (Iacoboni, 2009) have conveyed the importance of imitation in empathic processes. Psychological models of imitation are assumed to have strong associative links between perception and action which are supported by neural mirroring. The core neural circuitry of imitation is composed of a higher-order

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[4] Social mentalities refer to information processing competencies that facilitate and orientate goal focussed behaviours (Gilbert, 1989). Goal focussed behaviours may include care seeking, care giving, co-operating, seeking power/status or sexual reproduction.

visual area (the posterior part of the superior temporal sulcus) and by the fronto-parietal mirror neuron system. In neuropsychology it is thought empathy is implemented by a simulation of the mental states of other people and may be elicited automatically following appraisal processes (de Vignemont & Singer, 2006). Mental simulation requires an ability to mentalize (Bateman & Fonagy, 2006), namely thinking about the thoughts and feelings of others and reflecting on one's own thoughts and feelings as separate. The impact of stress is thought to impair capacity to mentalize.

Empathising is also thought to be connected to context, such as nuanced situations and the quality of the relationship. Preston and de Waal (2002) view continuous contact and co-ordinated activity leads to a process of bonding that fosters accurate communication of affect and capacity to empathise. Soothing experiences are believed to activate neuro activity and release of oxytocin, dopamine and endorphins and influences brain development in babies (Howe, 2013). Functional magnetic resonance imaging studies have indicated that observing a person in distress activates the limbic system and areas of the brain that process affective information (Singer, 2004). This suggests subcortical primitive processes occur prior to social and cognitive processing in the prefrontal cortex (Eisenberg & Eggum, 2011), we feel before we think. This infers it is important for people in care giving roles to possess knowledge of how emotional experience may influence their cognitions and behaviour.

2.5 Empathy in men

Studies have suggested that on average men are less empathic than women (Baron-Cohen & Wheelwright, 2004; Kingerlee, 2011) and less responsive to affective scenes (Proverbio, 2009). Proverbio's electrophysiological investigation used a small sample (24) and brain activity was monitored whilst participants observed slides. This perhaps limited contextual cues and naturally occurring reactions. Findings may however have implications for the capacity of male support workers to identify early signs of observed distress.

It has been argued in the literature that in contrast to being interested in the minds and feelings of others, that perhaps men have evolved to pay closer attention to systems, analysing and problem solving. This may have been borne out of the need to plan for hunts, predict and control physical events (Howe, 2013). Extreme systemising abilities have been associated with neuropsychological structures and presentations in people with autism (Baron-Cohen & Wheelwright, 2004). This evolutionary understanding might account for why nurturing, care and relational skills are thought to be more prevalent in women, and why systemising skills are thought to be more prevalent in men.

However, context is thought to influence empathising in men, and empathy scores have been found to be higher in nursing settings than in male normative groups (Williams, 1989). This would suggest that despite possible predispositions, men adapt in response to particular social or caring environments. The author postulated that experiences of emotional empathy in care settings may increase the likelihood of burn out or fatigue, if it is not mediated by a sense of purpose or personal accomplishment. In light of this, role clarity and intrinsic values might be important concepts that inform empathising and emotional resilience.

More general ideas associated with what it means to be male, and capacity to acknowledge or show feelings, suggests that culture plays a key role in how men understand and express themselves. Research suggests that men who endorse traditional masculinity ideologies may experience a number of challenges including low self-esteem (Reilly, Rochlen & Awad, 2014), problems with intimacy (Edwards, 2014), depression, anger and anxiety (Genuchi & Valdez, 2014; Zimmerman, Morrison & Heimberg, 2014), and difficulties seeking help (Sullivan, Camic & Brown, 2014).

It has also been suggested that men endorse negative attitudes towards help seeking (Courtenay, 2003). This may in part be linked to a sense of pressure, when emotional expression conflicts with cultural expectations of male behaviour, for example when seen as feminine or unmanly (Pease, 2012). In response to feelings of vulnerability, it is argued in the literature that positional power is used to regain a sense of security (McLean, 1995). This has implications for empathising with others

when a sense of threat or emotional concern is experienced, as this may inhibit empathic practice.

2.6 Empathy as a form of self-compassion

Recent research has explored how empathy can be understood as a form of self-compassion (Neff et al, 2007; Kelly et al, 2008; Gilbert et al 2006; Kingerlee 2011). Self-compassion has been constructed as an adaptive form of self to self-relating (Gilbert & Irons, 2005) and involves being compassionate and caring towards oneself (Neff, 2007). It is thought to include elements of self-kindness, common humanity and mindfulness (Neff, 2003). The concept of self-compassion and self-care is grounded in both spiritual (Germer, 2009) and evolutionary (Gilbert, 2013) perspectives. Buddhist practice, in particular mindfulness (Kabat-Zinn, 2005) focusses on non-attached awareness. This process can reduce over-identification with negative experiences and promote acceptance and understanding (Gergen, 2009). This occurs as a result of increased self-awareness. Neuropsychological research has suggested that awareness of our own inner states can increase empathy in social situations (Singer et al, 2009). There appears to be a link between attending to the experience of ourselves and being able to attend to the experience of others.

Through the lens of evolutionary psychology, Gilbert (2013) offers physiological accounts of self-compassion. He describes how our affect regulation systems have become burdened as a result of the development of complex cognitive activity and changes in social behaviour. Interaction between the threat and self-protection system, incentive and resource seeking system and soothing and contentment system can become distorted by patterns of ruminating and over stimulating environments (Gilbert, 2013). The soothing and contentment system can be understood as a structure that facilitates self-compassion. However, in some contexts it appears to make sense that the soothing and contentment system would not be activated. Consideration has been paid to the impact of self-compassion being maladaptive, for example in the context of war in which attending to ones suffering could be problematic (Neff et al, 2003). The experience of stress is likely to occur following a sense of threat and subsequently lead to activation of the threat

and self-protection system. Inquiry into the tensions between accessing self-soothing experience and its relationship with the capacity to empathise is sparse in the extant literature.

It appears that inquiry into empathy and self-compassion has been largely influenced by ideas associated with cognitive structures and functions. In contrast, phenomenological focus on these phenomena seems limited. However, despite differences in focus, what appears to be conveyed in the literature is the understanding that empathy may be dynamic; influenced by developmental factors, capacity for perspective taking, and the quality of the relationship and the nature of communication. This dynamic conceptualisation appears to be underpinned by context. It has been suggested that context, cultural meanings and the context of interaction play a part in how we might empathise. Perhaps, context can have an impact on how we relate to ourselves or others for example, when experiencing conflict or feeling threatened. This could imply that notions of empathy and self-compassion are not fixed or static.

These ideas have implications for the way in which these phenomena are experienced in ID settings. For example, the use of perspective taking to empathise with people with ID may be problematic. Support workers could struggle to interpret what it is like to process information differently in relation to cognitive, affective or social impairments. Moreover, the challenging context of the work place may lead to stress, influencing both capacity for self-soothing and the quality of the relationship.

2.7 Empathy in care settings

As empathy is believed to provide a framework for understanding others and relating to oneself (Neff, 2007) it is perhaps not surprising that researchers have begun to explore empathy in care settings (Luff, 2010; Larson et al, 2005) and within the context of the therapeutic rapport (Gilbert 2010; Pugh, 2009; Strawbridge & Woolfe, 2010). Recent qualitative research in elderly care settings has provided a theoretical framework which suggests empathy consists of a number of inter-relating dichotomous constructs (Luff, 2010) including direct and indirect, group and

individual and general and situational. In relation to this, an IPA study of emotional challenges faced by staff working with ID sex offenders suggested that therapists who have empathy for their own experience are more likely to empathise with their clients (Sandhu et al, 2011). This provides support for the theory that self-awareness and compassion can foster empathic practice.

Case study accounts of therapeutic work with people with ID have been used to explore the relational aspect in care settings. These accounts have suggested that there can be challenges interpreting inner worlds when narrative content is absent (Bollas, 1987; Hodges, 2003). Psychoanalytical ideas and theories can be applied to the examination of relationships within care settings. Borne out of Psychoanalysis (Freud, 1914), approaches have evolved over the years and consist of three main schools which differ but may converge in epistemological underpinnings, training pathways, theory and practice. Contemporary therapies are often termed psychodynamic or relational. Central to these practices is acknowledgement of the role of the unconscious and intra-psychic tension that underpins the motivating or defensive nature of our actions.

In psychoanalytic literature non-verbal modes of empathy and nonreciprocal social transactions have been acknowledged, Kohut (1977) described empathy as mirroring or reflecting the experience of the baby leading to a process whereby responses would help the baby to internalise the experience. Schore (2003) discussed relating through facial expression, eye contact, tone of voice, tempo, and breathing. He argued the therapist creates a kind of wordless but dense and charged felt presence, which permeates the being of both therapist and client. He termed this process "relational unconscious". Paralysed facial muscles are reported to lead to lack of synchrony in relationships (Szalavitz & Perry, 2011). The theme of human commonality is prevalent in psychotherapeutic accounts of empathy in which the process is viewed as being able to view ourselves and others as the same (Neff, 2003) and begins from the position that we share the same needs, emotions and vulnerabilities (Gilbert, 2010). In conclusion, although present, there appears to be limited phenomenological research in this area with regard to the examination of the lived experiences of empathic practice.

2.8 Conclusion

The literature review suggests limited phenomenological research into the experiences of empathy and self-compassion as described by support workers. This appears to be changing with more recent use of phenomenological paradigms to explore the essence of empathy in medical settings (Tavakol et al, 2012) and explore experiences of empathy and self-compassion in forensic settings (Sandhu et al, 2011). There has also been some inquiry into experiences of empathy in care settings with elderly populations (Luff, 2010). The inclusion of more qualitative approaches to understanding empathy might be attributed to evolving interests in the impact of the carer relationship (Tavakol et al, 2012; Gore et al, 2013), and renewed interest in the role of empathy in relating to participants in research (Watts, 2008) and within the therapeutic rapport (Gilbert & Leahy, 2010). Qualitative exploration of empathy and self-compassion within the field of ID however, remains scarce.

Overall, the research literature appears to predominantly yield understandings relating to conceptualisation and function (Yield & Mackintosh, 2005; Gilbert, 2000; Davis, 1983; Duan & Hill, 1996; Roger, 2009), neurological activity (Iacoboni, 2009; de Vignemont & Singer, 2006; Eisenberg & Eggum, 20011; Proverbio (2009) and assessment (Baron-Cohen & Wheelright, 2004). Non-verbal modes of empathy have been identified amongst both neurological (Iacoboni, 2009; Proverbio, 2009) and psychoanalytic psychological perspectives (Schore, 2003; Kohut, 1977, Bollas, 1987) yet limited phenomenological research has been conducted in these areas.

It can be argued that the quality and nature of the relationship permeates the literature and all studies specify importance of time and contact to facilitate an understanding of people's needs (Preston & de Waal, 2002). These place a focus on interpersonal and intrapersonal processes such as, potential dilemmas in being able to tolerate identification with distress and provide care (Lamb, 1979; DeGroef & Heinemann, 1999) and role confusion (Manthorpe and Martineau, 2008). Relational tensions are reported to significantly influence psychological wellbeing (Hastings, 2002; Burns, 2005; Lobban, 2007; Howard et al, 2009; Jenkins, 1997); these tensions can influence ability to empathise with others (Dagnan & Hill, 2002; Sandhu et al, 2011; Mitchell & Hastings, 1998), and men have been identified as exhibiting

less empathic traits than women (Baron-Cohen & Wheelwright, 2004; Proverbio, 2009). Furthermore, cultural influences (Pease, 2012) and the context of work is thought to contribute to capacity to empathise (Williams, 1989), express emotions (Lloyd & Williams, 2003) and direct self-care (Neff, 2003). Additionally, it may lead to stressful experiences (Figley, 2002).

Government Policy (DOH, 2001; DOH, 2007) has instigated interest in the mediation between support workers and people with ID and challenging behaviour to improve service provision. This has led to interest in macro factors such as "staff burn out" (Allen et al, 2005; Devereux et al 2009; Horner, 2000) and systemic failures (Gore et al, 2015; Emerson, 2008) that may inhibit performance. This perhaps dehumanises the role and limits opportunities to understand the range and nature of difficulties that are experienced and what these mean. Elaboration of the concept of empathy to include self-compassion has led to research that indicates men may be less able to reflect on and express their feelings, which can have harmful consequences (Kingerlee, 2011).

However, it should be noted that a capacity for self-compassion has been reported to reduce depression, anxiety, self-criticism, shame, inferiority, and submissive behaviour (Gilbert, 2006; Neff, 2003) which are emotional experiences likely to occur in interaction with people with ID. However, in some contexts identification and expression of vulnerabilities can be maladaptive (Nett et al, 2007). What perhaps can be suggested is that there seems to be tensions between a need to communicate emotional problems and impact of context (Preston & de Waal, 2002), and importantly, the extent which this can exacerbate vulnerabilities and influence performance (Neff et al, 2007; Figley, 2002).

In sum the role of the support worker, political demand, work context and complexities of the relational dynamic are likely to influence capacity for self-compassion and empathic practice. However, this role is poorly defined and little understood. Given that counselling psychologists work within these fields some further understanding is needed.

2.9 Study significance

Fundamental to the practice of counselling psychology is the ability to establish a meaningful relationship. Warmth and empathy are key to facilitating a sense of being understood, and to foster conditions in which one can express internal experience. Development of a therapeutic alliance can lead to improved treatment outcomes (Safron & Segal, 1990; Neff, 2003; Ivey & Ivey, 2003; Feltham & Horton, 2006; Watson, 2002; Reynolds & Scott, 1999). Investigation into the idiographic experience of empathy, self-compassion and empathic practice may enable expansion of existing knowledge relevant to a range of disciplines and applied work.

This study was designed to provide a contribution to our understanding of the relationship between support workers and people with ID who challenge services; specifically, the way in which staff construct their understanding of client's needs and make sense of this experience to inform their practice. This includes the way in which they may reflect on processes of relating to make sense of their own experience and how distressing feelings might be managed. This is relevant given the substantive research that evidences staff distress in ID settings. Studies seem to omit understanding of how this occurs in relationships with people with ID and how this may influence capacity to empathise. There is a need to elaborate and clarify tensions that support workers experience in the establishment of intimate bonds and possible distancing from distressing emotional experience. Current emphasis on behavioural approaches appears to minimise the role of the relationship and possibly inner experience. Inquiry into experiences of empathy could potentially enhance existing best practice guidance. This is relevant not only for people with ID but with vulnerable people in general and across a range of contexts.

Elucidation of features of experiences of empathising with people with ID may identify potential helpful practices and staff/client strengths. Identification of challenges, contexts and systems that elicit or maintain distress could be used to inform support systems that are in place for support workers. For example, in the areas of personal resources and coping with complex interactions and confusing role expectations. An understanding of the way staff interpret and act on the needs of people with ID has implications for staff training and induction. Furthermore,

enhancing and supporting relationships between support workers and people with ID is likely to complement other therapeutic and policy driven approaches that emphasises the importance of autonomy and growth. Moreover, this may assist in the reduction of the use of restrictive practices as staff might subsequently have the freedom to be more adaptable and draw on their knowledge of the person and shared trust.

Changes in practice are currently being advocated by the Department of Health (Positive and Proactive Care: reducing the need for physical interventions, 2014) and within related fields where the confusing and distressing experience of being with people with complex presentations and behaviour is recognised to pose problems in service provision (ASPD guidelines on treatment, management and prevention, 2010). Increasing self-awareness may give rise to more meaningful engagement, assist staff to make sense of the challenges in the relationship and how they may influence problems (Wright, 2007).

2.9.1 The research focus

Given that this area is interested in understanding the personal and social experiences of people, qualitative studies (Smith, 2011) are relevant. Phenomenological research may help to bridge the gap between phenomenology and evidence based practice which is required to progress understanding of human experience in a systematic way (Owen, 1996).

A review of the literature suggests that phenomenological approaches to studying empathy is a recent development. Werz (2005) suggests that informal phenomenological inquiry is integrated within counselling and that the ontology and methodology is appropriate to counselling psychologists. It has been argued that there is a requirement to derive concepts from social research to formulate policies and practices to support adults with ID who challenge services rather than basing policies on data (Emerson, 2008). This study is in line with researching social phenomenon relevant to engaging with this population thus both socially and clinically relevant. There appear to be few studies that focus specifically on empathy in residential care settings and none known to the author that explore empathy and

self-compassion in male staff who work in challenging behaviour settings supporting people with ID; there is therefore a current research gap.

Empathic practice may occur through the individual meaning making process staff engage with and the subsequent application of this knowledge in practice. This is of interest due to the complex interactions that are experienced in relation to attempting to understand and respond to individual needs and coping with anti-social, deviant or self-harming behaviours. Therefore, the aims of this study were to: 1. explore how male support workers experience, interpret and respond to people with ID and 2. explore how processes of relating are understood and whether they enhance or inhibit self-compassion.

To guide inquiry research questions or dilemmas are developed to explore openly and in detail a central focus of interest. In qualitative research questions are not designed to test a predetermined hypothesis (Smith, 2008). Rather, it facilitates the ongoing process of questioning that is integral to the exploration of the experiences and perspectives of others (Agee, 2009). An overarching question or dilemma can capture the main aim of the research and give direction to the study design and other related areas of inquiry (Agee, 2009). Given the above discussion this thesis had an overall research question with 4 sub questions.

2.9.2 Research Question

What are the experiences of self-compassion and empathic practice in male staff supporting adults with ID and challenging behaviour?

Sub-questions

- How do support workers interpret the experience of working with people with ID?
- What meanings do experiences of interpretation or relating hold for staff?
- What aspects of the relational experience enhance or impair empathy and practice?

- How do support workers respond to their own experience of distress?

These research questions aim to generate phenomenological data and identify sense making processes specific to the inquiry of empathy and self-compassion. The questions are neutral and seek to study how the phenomena are constructed and understood, appropriate to the application of Interpretative Phenomenological Analysis (IPA) qualitative methodology (Smith, 2004). The following chapter outlines in greater detail IPA methodology and its application within the exploration of empathy and self-compassion.

CHAPTER 3

METHODOLOGY

Overview

This study aims to explore experiences of empathic practice and self- compassion in male support workers providing care to adults with ID. It seeks to explore how they interpret the experience of people with ID and what meanings these experiences of interpretation or relating might hold. It also considers how support workers respond to their own experience of distress. Interpretative Phenomenological Analysis (IPA), developed by Smith and Osborn (2008) was employed to meet these research aims. In adopting an idiographic approach with a focus on the participant as expert, IPA has been developed to explore phenomenon which is dynamic, contextual and subjective. (Smith, 2004). This chapter explains the rationale behind the employed methodology, detailing participant recruitment, data collection and analysis. It summarises the process I have taken to adhere to ethical and quality guidelines.

3.1 Qualitative approaches in the exploration of empathy

Empathy has at its roots aesthetics (Howe, 2013). Aesthetic process is concerned with relating to perception by the senses (Oxford Dictionary, 2015). It is argued that the unique way we relate to our perceptual and sensuous experience is an idiographic lived experience in which we are likely to perceive our world within the context and values in which we live. The study of empathy may benefit from focus on the experience of expressed states in human body, expressions, gesture and tone of voice (Scheler, 1973), however in relation to this, scarce phenomenological research exists. Exploration of relational dynamics suggests that empathy may not only occur in the intersubjective interaction we experience with others, but also within ourselves (Schore, 2003; Winnicott, 1965; Kohut, 1977). This may influence how we empathise with others (Neff, 2007). If there is convergence in these understandings, it is suited

to qualitative inquiry. Qualitative approaches focus on the conception of human action as meaningful and emphasise the contribution of human individuality and subjectivity (Schwandt, 1999).

Application of quantitative methodology has frequently been used to investigate aspects of the experience of support workers to isolate measurable variables such as the topography of peoples' behaviour, or the emotions, beliefs or actions of staff (Dilworth, Phillips & Rose, 2011; Ravoux et al, 2011; Dagnan & Hill, 2002; Hastings 2002; Howard et al 2009). Despite recent interest in the experiences of support workers and empathic practice (Luff, 2010; Neff, 2007), there remains limited phenomenological research into the subjective experience of support workers and their emotional experience with clients.

Epistemological Position

As the aim of this study was to capture and critique in detail empathic and self-compassionate experience, I adopted a qualitative methodology. This positioning enables a detailed study of phenomena that are not quantifiable by quantitative methods, but alternatively by explorative and discovery focussed research (Lyons, 2007). One of the distinguishing features of counselling psychology that separates it from other disciplines is the use of humanistic and phenomenological frameworks to capture and interpret human experience, whilst maintaining scientific rigour (Kasket, 2012). A key tenant of phenomenological thinking (Heideggar, 1962) is the understanding that reality is personal and subjective, and that how we interpret our realities and experience is variable, and not fixed. It is concerned with how we relate to the world and how we communicate this to others. One way to gain access to phenomenological experience is through a process of reflexive interpretation. The hermeneutic position (Palmer, 1969), examines the value and limitations of interpretation in the creation of knowledge (McLeod, 2005), researcher influence, reflexivity, cultural values, context and the meaning of language in text are considered (Radnitzky, 1970). The meaning of what is revealed is accounted for within the context in which knowledge was formed. As the phenomenological experience of another person can never truly be free of researcher presuppositions

within qualitative research, synthesis of epistemological values can facilitate exploration of linguistic material and elucidation of meaning and meaning making processes (McLeod, 2006).

Commensurate with my position in therapeutic practice, integration of phenomenological and hermeneutic epistemologies can allow for exploration of the way people individually perceive, experience and respond to their worlds. In adopting an openness to how reality is understood, these integrated epistemologies may facilitate the elicitation of nuanced accounts of experience, whilst minimising the constraints of predetermined quantitative definitions and categories.

3.2 Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) (Smith, 2004) was selected for this research. IPA is critical in nature and concerned with idiographic lived experience. In this section I will elaborate on these values to communicate their significance to the exploration of empathy and self-compassion.

IPA is broadly couched within phenomenological and hermeneutic epistemology. Phenomenological approaches seek to clarify situations lived through people in everyday life in contrast to reducing phenomenon to variables and controlling the context in which the phenomenon is studied (Giorgi & Giorgi, 2008). This was applicable to the unique and nuanced relational and emotional experiences of support workers. IPA acknowledges the central role of the researcher in making sense of participants' experiences, thus it is also connected with the hermeneutic tradition (Palmer, 1969). The researcher engages with the experience of the participant and reflects on the process of interpretation to make subjective inferences of data which may illuminate meaning, cognition, affect and action (Flowers et al, 2005). Interpretative activity therefore consists of a double or two stage hermeneutic (Smith & Osborn, 2010).

IPA places focus on participant individuality and adopts an idiographic approach. Emphasis is on the interplay of the experience and contexts specific to a participant,

in contrast to the identification of scientific laws used in positivist research, which govern the behaviour of people as a group (Allport, 1961). This was relevant for the following reasons: 1. little attention appears to have been paid to the experience of support workers in their individual role; 2. the nature of unique relationships and relational processes with people with ID is unclear and 3. limited exploration of social processes that may shape or maintain distressing feelings has been conducted.

Adopting semi structured interviews allows for open yet detailed exploration of accounts of how participants individually make sense of experiences of their personal and social world. It facilitates access to conceivable meanings that these experiences have for them (Smith & Osborn, 2010). Subsequent transcription analysis can assist in the explication of what may be unknown or hidden from the participants' awareness. This may add depth to data and sign post future research.

It has been argued that current psychological literature lacks interpersonal accounts of the experience of empathy (Luff, 2011). However, since the object of analysis is lived experience, IPA could provide a useful framework to explore the personal nuanced experiences of this phenomenon. Moreover, empathy occurs in relation to others (Schore, 2003), accounts of interpersonal experiences could readily be amenable to interpretation and critique. In sum IPA was appropriate for exploring self-compassion and empathy as verbal exploration may help to understand how emotional experience is articulated, perceived and understood. It is the participants' account of their experience, not the narrative that becomes the unit of analysis (Dickson et al, 2008).

3.2.1 Reflections on understanding and implementing qualitative research

My interest in empathy construction, motivations, experience and practice motivated me to explore qualitative methodologies that would enable me to explore human qualities and nuanced accounts of individual lives and their meanings. IPA (Smith, & Osborn, 2008) provided an epistemological position, theory and practice in which to explore and interpret empathy and related constructs as elements of human life. Acquisition of an understanding of the methodology was a long and arduous

process, not least in relation to the time in which I had to absorb and make sense of the approach in the context of my identity and role as a father, husband, son, sibling, friend, therapist and supervisor. These layers of life compounded my learning and perhaps led to a feeling of confusion and frustration. My sense of conflict can be situated within cognitive dissonance theory in which urges are experienced in attempts to avoid or minimise internal inconsistency when there is a dissonance with external experience (Shaver, 1987). At times I did not understand what was important, surely inquiry into empathy and self-compassion should not interfere with how I was able to understand and relate to those closest and most important to me. This was a recurrent struggle variable dependent on how I was feeling, or how others around me seemed to be feeling or were experiencing significant life events.

3.2.2 IPA QUALITY EVALUATION

Although my experience in support work with people with ID could assist in the direction of necessary elicitation of "real experience" and relevant analysis. Care was taken to ensure emphasis remained with the experience of the participant and not my subject position, to avoid disproportionately influencing the analysis. I am aware of my view that standards of care and practices are variable and influenced by values, and that I have historically been informed by positivist methodologies. This indicated a need to monitor the research process and evaluate the quality and validity of the study. Reflective practice was one approach used to manage these issues and is explicitly presented in reflective sections of various chapters throughout the thesis. Qualitative research accepts that the experience of the researcher shapes the construction of knowledge, however validity must be demonstrated (Smith, 2011). Yardley (2000) developed a framework in which key criterion can be evaluated to demonstrate validity. Evaluation criterion and features of my research are presented in this section.

Sensitivity to Context

A central tenet of qualitative research is to demonstrate that the research focus clearly reflects the vital characteristics of the phenomena in question. This can be achieved by demonstrating sensitivity to existing theory and research and to the perspective and position of participants. I have striven to provide a clear and coherent literature review in which to situate current knowledge and practice pertinent to understanding empathy and self-compassion, people with ID, support workers and clinical practice. I endeavoured to demonstrate these aspects by reviewing literature in the context of current policy agenda and ID services. I also explored relevant research on the experience of support workers in the context of their relationships with people with ID and response to emotional distress. I have reflected on my subject position and how this may both complement and impair the analysis and considered the importance of facilitating the emergence of independent participant data.

Commitment and Rigour

Fundamental to demonstrating commitment to the aims of the research is to ensure that a range of data is obtained. This permits in-depth engagement with material. I sourced multiple participants from different ID services. As part of my recruitment criteria I articulated a need for full time support workers rather than part time or agency staff, as this may have reduced access to and depth of the emotional experiences of being with people with ID and challenging behaviour. My long standing interest in the research phenomena and consideration of participant positions illustrate the level of commitment I have in producing meaningful data. I have striven to be reflexive throughout the research process both monitoring and clarifying various research phases and analytical steps. I have acknowledged my novice status in the application of IPA and sought training associated with the London IPA group to develop my competencies in use of the method and to inform my interpretations and reporting of data. Identified themes were compared to existing literature to ensure relevance to the phenomena either in extension of existing theory or findings, or acquisition of knowledge that enhances current understanding.

Coherence and Transparency

In consideration of transparency of the research process, data was discussed in detail with my research supervisor and in a research consultation group with peers. I have attempted to be open about my reflections and projections with regard to analysis of the phenomena. Originally a term used within psychoanalytic practice (Freud, 1914), projection refers to an unconscious defence mechanism. Unwanted impulses (thoughts, feelings and behaviours) are attributed to another object, usually a person. This in turn ameliorates a sense of anxiety. Accounts of my reflexive experience are located in reflective sections throughout the thesis. I am engaged with IPA literature and on-line forums to maintain an appropriate understanding of the application of IPA. To exemplify research coherency, I have endeavoured to ensure that epistemological underpinnings are commensurate with the required knowledge construction of the phenomena as idiographic and embodied. The chosen methodology has hopefully enabled me to capture these qualities. The inclusion of the analytical steps, openness of the research process and reflexive comments illustrate my attempt to be transparent in the nature of knowledge acquired.

Impact and Importance

The HCPC (2010) advocates integration of professional and research skills to inform theory and practice. The acquisition of qualitative knowledge of empathy and self-compassion has a number of practical implications: 1. the possibility of theoretical advancement in which existing theories and positivist constructions can be developed to comprise of idiographic, intrapersonal and interpersonal datum; 2. findings can be employed to inform the way in which empathy and self-compassion are thought about and practiced within care settings at the level of delivery and 3. analytical findings can be elaborated and situated within current political agendas to advise policy makers and professionals involved in commissioning, regulating or developing services for people with ID and challenging behaviour.

3.2.3 ETHICICAL CONSIDERATIONS

The BPS Code of Ethics and Conduct (2006) and UEL ethics outlines respect, competence, responsibility and integrity as key principles. Approval was sought from the University of East London's Ethics Committee (see appendix 3) and registration completed (see appendix 4). To ensure that respect and integrity was provided to participants they were provided with written and oral explanation of the researcher role and purpose of the research (see appendix 1). Interviews were arranged at a preferable location. Participant safety was considered and interviews were arranged at the participants' place of work where peers and senior staff were present to offer support if required. Consent was sought at various stages including the initial recruitment phase and in response to any unexpected material presented during interviews. A written consent form was provided (see appendix 2). As the nature of the research is reflective, participants were informed of implications for wellbeing and given details of a local counselling service.

Capacity to consent was checked using guidance set out in the Mental Capacity Act (2007). Legislation states that one's ability to provide informed consent is dependent on the ability to understand, retain, weigh up and communicate back information related to the decision in question. At the time of interview participants were asked to clarify what they understood about the research topic and the impact it may have on their wellbeing. Capacity was believed to be important given the likelihood of exploration of intense emotional experiences which may elicit distress, and in regard to context in which vulnerable adults are present and dangerous behaviours can be displayed. The weight of disclosure of risk was conveyed and that reported experiences or incidents of malpractice would be disclosed. Participants were informed that they could withdraw from the research at any time.

Participant material including consent forms, audio recordings and written materials were kept in a lockable space at the researcher's home and destroyed after use. Electronic data were stored on a lap top in a coded file in line with the Data Protection Act (2003). Pseudonyms were used to protect confidentiality as suggested in professional practice guidelines (Bor & Watts, 1999). My management of the project and data was reflected on throughout and reviewed in research

supervision. Competence was considered and a contingency plan to seek guidance where this may have been required.

3.2.4 SAMPLE AND INCLUSION

Sample

Smith et al, (2009) argue that the aim of IPA is to explore a homogenous group in depth. No one person's experience is privileged above another however converging and diverging accounts can be considered in order to develop a picture of the phenomenon and inform future research. A purposive approach was implemented to select participants who were likely to have undergone the phenomenon under investigation with an aim to provide insight into their experience. The homogenous features of participants are outlined in the inclusion criteria.

Inclusion Criteria

Participant criteria included the following:

- The participant is currently in a role providing daily support to individuals who live in 24 hour residential services whom have been diagnosed with an ID and exhibit challenging behaviour. This was pertinent to identifying support workers in contact with the relevant population and to enable exploration of a broad range of experiences. Limitations in shared activities and contexts could reduce the richness of accounts available.
- The person is male. This criterion was included in light of research that indicates men in particular struggle to validate and express their feelings (Kingerlee 2011) and can influence empathic practice (Neff, 2007). This was of importance in light of the likelihood of exposure to stressful environments and the additional complexity of both interpreting and validating experiences of others.

- The participant is involved in supporting people with ID in aspects of their personal care, domestic activities, personal skills development and community participation. This outlined specific roles likely to involve a high prevalence of social interaction, contact and interpersonal experience.

- The participant has been working in the role for a period of at least 6 months. This was in order to access support workers who have had at least some experience in which to foster a rapport with people but more likely to be working in the capacity of a support worker without additional senior duties.

- The participant is a full time contracted member of staff rather than working for an agency. This was to increase the likelihood of in depth personal experiences with people with ID.

3.2.5 PARTICIPANT RECRUITMENT

I am connected to a local ID network (Kent Challenging Behaviour Network) in which codes of practice are being developed for services that provide support for adults with ID and challenging behaviour. This enabled recruitment through liaison with local commissioners and service managers. Information sheets were sent to residential organisations electronically outlining the purpose and role of the research. Participants were asked by their service managers if they wished to participate in the research and provided with the research literature and consent forms. I was able to recruit a total of 8 participants from three different ID residential services.

PARTICIPANT DEMOGRAPHIC DATA

Table 1: Demographic data

Participant	Ethnicity	Age	Years working with adults with ID and challenging behaviour	Years in current service
Jack	White British	29	11	3
Fred	Nigerian	50	4	4
Samuel	White British	26	5	3.5
James	White British	41	14	10
Frank	Black African	26	5.5	4
Derek	White British	38	13	1.5
Mark	White British	27	1	1
Mike	White British	20	2	2

Table 1 present's participant demographic data. The mean age of participants was 32.1 years. The mean duration of working in ID settings was 6.9 years and the mean time in current post was 3.6 years.

3.2.6 DATA COLLECTION

Data was collected by means of semi structured participant interviews (see appendix 5). Semi structured interviews allow for greater coverage of psychological subject matter and enable exploration of novel areas elicited by the participant. This can provide rich data for analysis (Smith & Osborn, 2010). Interviews facilitate participant rapport and can be helpful in the exploration of relational issues pertinent to the phenomena under enquiry. The schedule was informed through evaluation of literature and developed following consultation with my research supervisor and a pilot interview. The schedule adopted a funnelling approach in which participants were given opportunity to report broad experiences of being with people with ID followed by increased guidance to explore accounts of relational, interpretative and introspective emotional experience. This facilitates emergence of related and nuanced data that can inform the overall analysis of participant transcripts and their

reported experiences of the phenomena under investigation (Smith, 2011). The use of a semi structured interview allows the researcher to engage in a dialogue with the participant about their perception of their world and be flexible in light of responses.

1 pilot interview was conducted followed by 7 further interviews. IPA guidance has indicated that 5 or 6 interviews are a reasonable sample size for projects (Eatougth & Smith, 2006). Notwithstanding current trends in qualitative research, in this study the inclusion of a larger sample allowed for possible participant withdrawal. It offered a greater range of data for exploration, which was helpful given my lack of research experience.

The use of a pilot interview enabled participant feedback and revisions to be made. This can include the level of difficulty and tone (Smith & Osborn, 2010). Following the pilot interview, I reduced the length of the schedule and clarified the terminology of questions. This was because a participant reported difficulties understanding the language used and a sense of feeling "lost" when lots of information was requested. Moreover, I learnt that sensitive data could be better elicited through process of participant self-reflection. Consequently, this shaped my tone and approach in interviews, I think I expressed more sensitivity to material and became less directive. Questions became less direct and were simplified in an effort to minimise the impact of my preconceptions of the phenomena, and how they may be experienced.

Verbal prompts were provided in response to participant difficulties with engagement. This did happen on occasion, and intervention consisted of either rewording questions or encouraging reflection and elaboration of previous accounts offered. Interviews lasted for approximately an hour and were audio recorded for transcription. IPA does not require detailed transcription of prosodic features as the focus of analysis is semantic (Smith & Osborn, 2010). Past qualitative researchers have advocated checking with participants the accuracy of transcribed data to ensure credibility (Elliot, 1999). I summarised interviews at the end with participants to clarify agreement with prevalent themes or topics that emerged, and to check understanding. I chose not to check with participants' analytical notations. Yardley (2000) argues that qualitative theories and methods can be complex for participants to understand and lead to potential complications in analysis. Furthermore, it is important to consider how such interpersonal barriers may influence researcher-

participant relationships and inhibit willingness to be open to and engage with research findings when differences in interpretation emerge (Bloor, 1997).

3.2.7 ANALYTICAL PROCEDURE

Analysis was informed by the process described in detail in Smith and Osborn (2003) available in student handbooks. Smith (2004) argues for the importance of adapting and developing guidelines. Furthermore, he articulates how the personal analytic procedure undertaken at various stages of the research determines the quality of the work produced. In this section my procedure is presented.

1. The procedure began with the transcription of interviews. Themes informed by the research questions were highlighted. This proceeded to lengthy reading and re-reading of individual transcripts. There was a focus on the use of language and initial interpretation of the meaning of the participants' communication.

2. Transcripts were then printed and exploratory notes and comments written. This was to develop identified themes and to aid interpretation of relevant material (see appendix 6). Once predominant themes were identified analysis moved to a greater level of abstraction.

3. At this stage analysis involved sustained and effortful engagement with transcripts. Descriptive analysis involved focus on descriptions of what participants said about their experience and identified key ideas and subjects that emerged. Linguistic analysis explored use of participant language including shifting tenses and choice of words, metaphors and phrases used to describe aspects of accounts of experience. This included acknowledgement of non-verbal expression experienced in the interview. Finally, interpretative or conceptual analysis involved interrogating and conceptualising material at a more psychological level. This process involved questioning meanings and challenging what's happening within the participants' accounts of their experiences (London IPA Group, 2014). The function of these approaches

was to get "experience close" (Smith et al 2009). IPA adopts the position that that there is no direct access to pure experience or reality.

4. Initial findings were shared with my supervisor and research cohort to ascertain clarity and credibility (see appendix 9). Emergent themes were explored looking for connections between them. They were clustered based on the nature of reported emotional experience or possible relational process identified. Further analysis focused on looking for conceptual understandings and meanings inherent in accounts of participants' experiences. This iterative process was repeated across all cases. Thematic links could then be explored between participants (Smith & Osborn, 2010).

5. The next stage comprised of identification of theoretical and thematic connections across all cases. Convergences and divergences between individual and group cases were noted and analysed. Themes were clustered within related domains (see appendix 7). The emergence of related subthemes sharing qualities led to the rise of superordinate themes which captured specific focal areas of the phenomena. These were then ordered in such a way as to provide a coherent and logical overview of participant accounts (see appendix 10). Thematic domains were then tabulated and the table is presented in the analysis chapter.

6. The final stage of analysis occurred in the writing up of the research in which themes were translated into a narrative account (Smith & Osborn, 2010). Convergences and divergences were expanded on, leading to the final revision of themes. Each theme was explained and illustrated by verbatim extracts and interpretation from transcripts. Care was taken in the level of interpretation offered as at times there was lack of clarity in articulating themes in conjunction with limited grounding in extracts. The following chapter presents the narrative account of research findings.

3.3 Reflections on the analytical procedure

I found the initial process of the analysis novel and exciting. There was a sense of limited restriction and the freedom to immerse myself in what I understood or interpreted about the accounts offered by participants. I then noticed how I experienced a cathartic relationship with the data and at times felt confused and unclear about where my analysis was coming from; was it emerging from my own experiences of working and being with people with ID? or was it situated within participant accounts? I found research supervision helpful in orientating me to the research question and grounding my interpretations within participant quotations. This approach gave me confidence in bracketing off some of my own judgements and beliefs about the experience of empathising in care settings and struggles in engagement with self-compassion. On reflection I wonder whether my personal difficulties in expressing distress when in my previous role as a support worker were somehow connected to struggles in both the elicitation of self-compassionate material and identification of related concepts within transcripts. In light of my concerns with regard to how I might be influencing the analysis, I decided to write up individual in depth analytical accounts or narratives of what I had found within participant transcripts (see appendix 8). This process enabled me to gain a greater insight into the individual features and nuances of participants and their reported experiences. Although time consuming, I felt that I had gained a greater sense of the participants and how they tried to make sense of their experience.

I started to realise the enormity and complexity of the research task and began to feel less confident. I attempted to be accountable for my sense of vulnerability and lack in competencies by attending training workshops and engaging in peer research groups and on-line IPA forum groups. A sense of my fore-understandings (Heideggar, 1963) emerged which was both useful and confusing; I sought to use my knowledge and experience to inform the design of the research but equally did not want my beliefs to distort, limit or restrict potentially rich data. In retrospect, I think on occasion I failed to manage these elements successfully. This was evident perhaps not only in my experience of interviews, but also my reflections of the analysis.

Further complications arose when there was a feeling that participants would endeavour to understand me or yearn to express ideas, sensations and emotions but would struggle to bring about the words required to articulate their experiences. Times like these elicited my internal supervisor (Casement, 1985) noting a need to adhere to sometimes subtle distinctions between qualitative interviewing and therapeutic technique and motivations. Despite these challenges what was advantageous was that it enabled me to reflect on my senses and experience of transference. I have considered how fortunate I am in the modest acquisition of these skills and how difficult it might be for support workers when seeking to understand powerful feelings yet not possessing the theory and practice to both situate and make sense of confusing interpersonal experience.

In consideration and management of dilemmas like these I found supervision to be helpful not only to unpack what I was experiencing but also to challenge and critique the work I was doing. It emerged that my prior occupation in the application of empirical sciences to assess and formulate client's behaviour often led me down the path of thinking about participant accounts as reflecting real constructs that exist in the world that could prove or disprove my theories. I struggled when considering reality critically which both surprised and frustrated me. I have measured myself to be an open and curious person and perhaps under certain pressures and within particular contexts these qualities are less present.

CHAPTER 4

ANALYSIS

Overview

This chapter presents predominate themes that emerged from transcripts. Analysis of 8 interviews revealed 4 superordinate themes and 9 subthemes. Each superordinate theme consisted of between 2 and 3 subthemes. This is represented in Table 2. A detailed discussion of themes will form the focus of this chapter. Each theme will be illustrated and supported by verbatim extracts from interviews conducted. I will attempt to encapsulate the lived experience and meaning making of participants to do justice to their contributions and appropriately frame the research question within IPA methodology.

It is my intention to offer an in-depth idiographic illustration of how male support workers interpret and respond to people with ID; with a focus on processes of understanding and relating. It will also explore reflections of what these experiences might mean. Although, participants' talk can only represent accounts, it was anticipated that accounts would reveal how processes of relating are understood and whether they enhance or inhibit self-compassion. Extracts, comments and themes were selected based on their relevance to the research focus on the experiences of empathic practice and self-compassion in male support workers. The essence of recurrent themes was considered and the extent to which extracts provided the most powerful illustrations of any single recurrent theme.

The accounts provided by James and Mike were not included in great detail within the analysis of data. This was due to difficulties in interpreting data to produce in-depth narrative accounts. In review of both accounts, identification of situated moments or features of empathy and self-compassion were sparse, and linguistic and conceptual analysis was problematic. This seemed partly due to participant difficulties in engagement, and a tendency to seek confirmation about their ideas, or ask questions about my views, in contrast to describing their own.
Exclusion is not uncommon in the final analysis. Alternatively, some accounts can be used to assess or parse the prevalence of themes across the group (Hefferon & Gil-

Rodriguez, 2011). The tabulation of converging themes is presented in appendix 7. In light of this, IPA quality criteria were examined (Smith, 2011). Sufficient sampling was taken from the corpus to show the density of evidence for each theme. This requires that there are extracts from at least 3 participants from each theme from a sample of up to 8 participants (Smith, 2011).

4.1 Table 2: Illustration of analytical themes

Superordinate themes	Subthemes
Making sense of the others inner world	Interpretation based on knowledge and observation Relating without language Direct Empathy
Processes that enhance empathic practice	Holding people in mind Reflexivity
Tensions and conflicts	Uncertainty Intrapersonal tension
Management of distressing feelings	Managing reactions Taking responsibility

4.2 SUPERORDINATE THEME 1: MAKING SENSE OF THE OTHERS INNER WORLD

This superordinate theme illustrates ways that participants interpret the experience of people with ID. It emerged participants would often contextualise their experience within concepts drawn from academic theories and ideas, moving on into a more experiential account from direct observation. Participants' alluded to how they may enter the inner world of people with ID and relate to their experience, which appeared to be enhanced by thinking more deeply about the experience of being with the person. This yielded accounts of perceived non-verbal experiences of relating, followed by accounts of what it would be like to be a client.

4.2.1 SUBTHEME 1: Interpretation based on knowledge and observation – "I just picked up books and read"

This sub theme relates to participants' references to their knowledge base and observations that informed the way they understood the presentation and experience of people with ID. Many participants appeared to ground themselves in literature and drew on what they understood as facts about people with ID and first-hand experience of what they could see.

For example, the accumulation of knowledge appeared important to Jack and fundamental to the process in which he made sense of client's presentations. On a number of occasions diagnostic categories framed with an empiricist medical model informed Jack's thinking about the challenges he may experience, as outlined below:

"I just picked up books and read and read and kept reading and it gave me a lot of knowledge and that was very helpful at the time for, you know coz I used to work with people with mental health problems as well as on the autistic spectrum and being able to understand that the person is showing so much distress is actually because there's something going on internal for them" (Jack. 3, 52-58)

In the extract above Jack describes a process in which he seems to have immersed himself in literature; it appears his motivation was guided by how "*helpful*" this was in understanding complex presentations. The use of past tense suggests that he does not presently experience an urge to gain knowledge from "*books*" but remains open to apply knowledge to make sense of observed distress for example, the theory that there is "*something going on internal for them*".

Jack discussed an individual that appeared to struggle to form relationships with support workers as a result of their challenging behaviour, he stated:

"He's non-verbal, he's on the autistic spectrum he struggles very much with all sensory input that's coming in, really struggles with all that sort of stuff, and I said, you know, you know he's not a monster, he's a person, (laughs) he's clearly not being supported right. That's it, or we've not got it right yet" (Jack. 7, 131- 135)

Attributing challenging behaviour to a diagnostic origin seemed to aid Jack's ability to make sense of the client's difficulties. Multiple sense making processes seem to be

in play suggesting interpretation can be an effortful and challenging task; Jack considers how interpretation may lead to negative and dehumanising labelling such as "*monster*" and evaluates how well he understands the person by the way in which they respond to support offered. Use of the term "*we've not got it right yet*" suggests a desire to make sense of the person's sensory struggles and a view that he and other support workers have a responsibility to provide the "*right"* support. This implies at times perhaps Jack minimises the responsibility of people with ID and maximises the responsibility of others. Consequently, focus on sensory problems appears to increase a sense of understanding the client's "*struggles*" yet perhaps reduces acknowledgement of challenges that support workers encounter. It might restrict exploration of other influences that may contribute to the client's difficulties. His gentle tone and laugh experienced in his delivery suggested an air of optimism in interpreting the needs of people with ID.

Below Samuel interprets an emotional state of enjoyment by observing the facial expression of "*smiling"*. This appears to be couched in the understanding that people with ID experience a level of self-awareness. This is illustrated by a sense of them knowing their environment is "*different*". Samuel seems to reflect on personal memories to help make sense of how he and the client may be feeling. This suggests that when he interprets emotional states through a process of direct observation, he may then participate in reflective processes to more broadly make sense of the context, person and himself.

"When you're going on holiday with someone you support and seeing their smiling and they know it's different and they're enjoying it, it makes me happy, a lot more happy than it does (pause) taking my kids away for a week. Don't get me wrong of cause I enjoy it, I'm not saying I don't enjoy it but I chose this job and I say to my partner all the time, I chose this job so if I've got to go and sleep there that's what I chose to do, if I've got hours that aren't suitable for us, that's what I chose to do, you know so…" (Samuel. 10, 325-330)

In the extract above Samuel seems to evoke a high incentive to provide care. This is illustrated by his self-sacrifice of personal time and acceptance of working inconvenient social hours. I wonder if Samuel's incentive is reinforced by the happiness he reports in situated events such as holidays. He pauses when

contrasting family and client holiday experience perhaps illustrating a process of thinking. This may be to verify that Samuel believes he has accurately conveyed his understanding of the impact of being with people with ID. This insinuates that he may have had limited opportunities to reflect and discuss how he understands clients.

Both Jack and Samuel appear to assume responsibility engulfing themselves selflessly in their roles. There are differences in the way in which they seek to interpret people with ID. Jack appears to reflect on his knowledge of ID and interpersonal experience in contrast to Samuel who seems to place emphasis on his observations of people with ID and his personal experiences.

Below Fred describes how being with a person with ID has led to a sense that he is able to interpret when something is "*wrong*" based on the person's observed presentation, for example when he "*puts his head down*". Perhaps this illustrates a reliance on visual cues to gain understanding. His reference to the person wanting "*to do something*" suggests Fred understands people with ID to be autonomous, at least within particular contexts.

"When you are talking to him and he puts his head down, that means something is wrong… when his head is down, that means there's a problem he wants to do something strange and show a kind of behaviour" (Fred. 3, 55-59)

This sub theme presents accounts of how participants use observation and ID literature to inform their understanding. The participants seem to be relatively confident in strategies used with no explicit evidence of doubt in their accounts. It be suggested that this is in response to the need to interpret situations quickly and parsimoniously given the nature of the setting. There appears to be an undercurrent of personal responsibility that flows within these extracts in which the responsibility of people with ID is somewhat diminished. Conversely Samuel and Fred's extracts allude to the perception that people with ID are self-aware and in some ways autonomous. Accounts offered seem to negate reference to cultural and social experience of people with ID with increased emphasis on interpretation of affect or choice. Further to interpretation based on external information participants also seem to reflect internally on their relational and intrapersonal experience to inform what they understood about the experience of people with ID. This appeared to occur

when verbal language was limited or a greater depth of understanding was being sought or reported.

4.2.2 SUBTHEME 2: Relating without language – "It felt like he knew"

The unique experience of being with people with ID appeared to facilitate a process of non-verbal relating or relating without verbal expression. There was a general sense that participants were largely active when trying to connect in this way.

In the extract below Mark describes his experience of feeling "*connected*":

"One of our guys is nonverbal, profound learning disability and sometimes you really feel that connect, maybe it's because he doesn't speak and can't talk erm and so you can feel the connection there when he sort of looks at you, you know each of his looks can be a bit more purposeful than his action" (Mark. 17, 347 – 351)

Mark conceptualises his experience of connection as one which is "*felt*" and underpinned by the nature of a "*look*"; the weight to which Mark places the importance of a look in contrast to other actions can be illustrated in the way he articulates how it is more "*purposeful*". Arguably the affective experience of connection may be elicited and or associated with the person's lack of verbal communication. Although interpretation is not explicit per se Mark reports a sense of "*connection*" when eye contact is made. This echoes the use of observation to aid understanding.

Reported experiences of non-verbal relating also seemed to assist Mark to theorise how a person with an ID may view the motivation of support workers, for example incentive to become their keyworker. This is outlined in the extract below:

"It felt like he knew, like he was aware that it might be the reason (financial gain), *you know that it could be the reason why a person might take up a keyworker role in itsself and that might have been quite worrying and it made me feel, no I'm gonna prove you wrong it's the reason why, and he knows, he definitely knows now that I have his best interests at heart." (Mark. 14, 281-286)*

In this case Mark has constructed a complex relational interplay in which his interpretation of the client's thoughts and feelings influence the way he thinks and feels. Subsequently this guides his future behaviour. The urge to prove one-self and demonstrate that he has the person's "*best interests at heart*" appears strong. A possible sense of being tested seems to lead to efforts to communicate an understanding of the person's worry. This is illustrated by trying to offer an alternative relational experience to the one perceived to have been interpreted. Mark's motivation to achieve this aim is articulated when he states *"I'm gonna prove you wrong"*.

In the extract below Frank constructs his understanding of emotional experience as a kind of affective intuition. He describes a sense of emotional connection in response to tone of voice:

"So we are able to understand things like that, when they're not feeling well you can see it by their confidence sometimes, you can feel it by the way they talk" (Frank. 11, 223 – 225)

Furthermore, Frank seems to attribute weight to his feelings to help him inform decisions:

"so if it's not a very big decision that you are going to make, like giving medication that is when you can go on how you feel but that is like offering a drink or offering him the spa things like that like maybe what you feel, yeah so sometimes it's really difficult" Frank. (13, 264 – 267)

In the extract above there is a sense that Frank has mixed confidence in how accurate his feelings may be about a person's emotional state or difficultly. Perhaps this is due to limited cues. Lack of confidence is highlighted by his reluctance to make "*big*" decisions based on experiences of emotional connection. In contrast Mark appears to be guided more willingly by his emotional experience.

There was also a sense of ambiguity in Derek's accounts. Nonetheless this did not prevent him from exploring a possible position of the other, this is present in the extract below:

"Well, rare in the sense that, that banana took a long time I mean you know eating for ages and he was like, look you've been feeding me for all this time, why should I bother now?, maybe he was thinking that or whatever he was thinking but you know with persistence, to change something that's been in place for years, I mean some of the guys I've supported they're in their 60s they've gone through institutions, they've gone various services and they've got learnt behaviours…..that you know, probably will never change, so breaking those barriers to develop skills can take time for certain people so I guess that's why I've got a handful or small bag full of amazing moments erm, but then that's my own experience, someone else might have loads for all I know, sometimes it takes time to change something because it's been in place forever ago you know" (Derek. 21, 442 – 454)

The rarity and value of sharing moments of meaningful change is captured in the way Derek refers to experiences such as these as a "*small bag of amazing moments*". This evokes imagery of a handful of stones or gems, something that is precious to hold on to. Derek considers people's histories when evaluating how they may progress perhaps signifying the importance of shared "*amazing moments*". This echoes possible processes of personal reinforcement. Derek seems to attribute an internal voice to the person with ID to help interpret their experience. This strategy contrasts the emotional approach employed by Frank and Mark. However, despite their variability, both approaches appear to elicit a deep sense of understanding and relational congruence, in some cases emotional connection.

Given that participants report on their experiences of trying to understand and relate to people with ID when language is not present it is perhaps unusual that they did not discuss the impact of body language or other non-verbal cues. For example, the use of mirroring to convey a sense of understanding. The more participants thought about the way they related to and interpreted people with ID, it emerged there was a possible process whereby they would position themselves directly into the perceived experience of the person.

4.2.3 SUBTHEME 3: Direct Empathy – "It's vital to put yourself in that person's position"

Direct empathy[5] can be understood as situating oneself in the position or experience of the other in order to engage empathically (Luff, 2010). This appeared to largely be an active effortful process that emerged from accounts in exploration of relationships with clients. Interestingly participants did not always offer accounts of direct empathy within situated moments and settings. In contrast they seemed to reflect more broadly on how facets of clients' lives might be experienced through a process of empathic comparison. This seemed to lead to an interpretation of what it might be like to be directly in the position of a client.

Direct Empathy – *"put yourself in that person's position"*

Jack appeared to adopt a heartfelt and firm belief in the idea that to empathise with people with ID it was important to do this directly, reflecting on how a given situation or setting may impact upon you. He stated, *"I think it's vital to put yourself in that person's position and actually figure out and try to understand where they're coming from" (Jack. 1, 12-14)* In this extract Jack advocates that there is a requirement to "*figure out*" and "*understand*" the person's experience. There is a sense of seeking to identify with the feeling experienced. He articulates that effort is needed suggesting that he is aware of how he engages with clients in this way. He goes on to talk about how this process is difficult by reporting, *"you know put yourself in that person's position and try to do that for a second" (Jack. 2, 39-40)* The temporal element in Jack's phrasing suggests that empathising may be fleeting and challenging.

Jack also talked about how understanding concerns of parents of people with ID is aided by his own reflection of family experiences, for example, *"I can imagine the*

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[5] Luff (2010) explored forms of empathy of care home staff working with older people. She argued that lived experiences of empathy are constructed in different ways. She postulated a theoretical dichotomy in which staff might engage with others by directly placing themselves in the situation of the person (direct empathy) or indirectly by placing a loved one into the situation of the person (indirect empathy).

feelings are, what's going to happen now for my child? So I understand that" (Jack. 21, 424, 425)

Similarly, Samuel reflected on imagined life experiences to gain understanding. In the extract below he attributes a negative emotional state to a person who engages in self-injury based on how he may experience such behaviour:

"it's not gonna make him happy it's gonna make problems for them surely? If I punch myself in the head everyday I'm sorry but I'm gonna have problems down the line" (Samuel. 6, 167-169)

Although Samuel indicates that the person is not happy, there is a sense of doubt in his interpretation, illustrated by the inclusion of the word "*surely*". It's as if Samuel is asking a question to seek confirmation. He appeared to struggle throughout the interview to reflect on client's experiences.

Below, Mark seemed to draw on his sense of family values to relate to a client who appeared to struggle purchasing gifts for relatives. Perhaps a process of direct empathy occurs through interpretation of difficult situations that relate to your values or experiences. This might facilitate understanding of how specific situations or dilemmas are directly experienced. Mark's application of the term "*cling onto*", illuminates the elusive and transient quality of this possible process.

"You know he likes to get a good deal and not to pay over the odds. But yeah with his family he definitely feels for, and that related to me because I'm a very family orientated person (okay) and if anything that gives me something to cling onto at times…. and perhaps it will come out that you know, you feel for other people, and perhaps understand how they feel, and that might affect your decision making and how you approach things for the future" (Mark.15, 305 -312)

Direct empathy through comparison – "we're all human beings"

Samuel seemed to reflect on his life experiences to understand the position of clients. This comparative approach appeared to be helpful to make sense of the presentation of people with ID, and to empathise more directly with their difficulties, for example:

"I've grown up with everything I am and they've grown up with everything they are, we're all human beings, but it's just things that click, it's the things that make them do weird things and I don't mean this in a nasty way I just think things like banging, hitting, grabbing, you know not basically getting what they want so..if we don't get what we want we accept it, sometimes (laughs) if they don't get what they want I don't think they know how to accept it, you know so... I've lost the question" (Samuel. 2, 43-48)

Samuel's loss of focus towards the end of his statement suggests he struggled to engage with the research focus and interview process. Samuel's accounts were experienced as emotionally loaded and I was struck by the emotive weight and impact that engulfed Samuel when he talked with me about his experience of visiting an old institution. In the extract below he spoke with a melon-conic tone appearing unaware of his changing presentation:

"I do a lot of ghost tours and things like that that had people with special needs in and I go and do a lot of them and I can be walking around the buildings sometimes and you can see how the room was built and see there used to be a padded cell, and you think Jesus I wonder if he ever had that, one of the guys we support and then I feel sad and I can come to work and look at him when you know when he's not looking around and think I hope you wasn't because standing in the middle of that cell and I can say that to whomever I want erm, (pause) you can feel that it's not right, to imagine, hang on if that door was shut I couldn't escape then and you know it's sad, it's sad" (Samuel. 13, 408 – 415)

This moment was poignant and although did not seem related to the research focus there was a sense that space was needed for Samuel to articulate his thoughts. His experience of imagining being in a "*padded cell*" appears to have a profound and enduring impact on how he empathises with lived experiences of people with ID. The intensity of this experience is apparent in the way he talks about his feelings in the first tense as if it is being lived in the present moment. This appears to guide Samuel in the way in which he empathises with clients, illustrated by the way in which he recalls the event at a later time when at work.

Frank also appeared to adopt a comparative approach in empathising with client challenges. He seemed to draw on experiences of uncomfortable acquaintances to conclude why some clients might "*push it*" with staff:

"service users know who to push it with sometimes if you know what I mean, they will always try but it's not like they will get it but they will always try (smiles) if you know what I mean but some will just, I don't know, like me and you we may not like somebody so they have that as well…. just some people they just don't like them, it doesn't mean they have done anything wrong to them or something they just don't like them" (Frank. 9, *187 – 191*)

These accounts illustrate the possible process of direct empathy or empathy by comparison to gain a sense of directly being in the shoes of a client. It emerged that relating to possible inner experiences/states could elicit uncomfortable feelings such as feeling "*sad*". This seems congruent with the likely outcome of positioning oneself in the experience of distress of another. In Jack's accounts he appears to view direct empathy as challenging and requiring effort, for example, "*try to do that for a second*". Perhaps this difficulty is connected with problems accessing and relating to the inner world of people with ID. When personal experience is lacking this seemingly results in a need for greater use of imagination, which necessitates a level of self-awareness, self-belief, motivation and effort.

This superordinate theme outlines possible ways participants seek to interpret, understand and relate to the experience of people with ID. Application of external information to guide interpretation based on knowledge and observation is prevalent amongst participant accounts, particularly in the context of observed distress. Experience of being with people with ID seems to foster a sense of confidence in the interpretation of thoughts and feelings. Conceivable processes of non-verbal relating appear to be important in the interpretation of thoughts and feelings. This occurs with both verbal and non-verbal people with ID. This form of sense making is seemingly contextualised within a broader more personal framework. It would appear reflective process is an important aspect of seeking understanding. It was further revealed the more participants engage in reflective processes the greater the sense of congruence and significance of shared experiences and their meanings, "*like a small bag of amazing moments*".

4.3 SUPERORDINATE THEME 2: PROCESSES THAT ENHANCE EMPATHIC PRACTICE

Further to possible active and specific ways of understanding clients, participants also seemed to think about them in a broader sense, couched within curiosity and interest. This became noticeable in more wide ranging exploration of clients and relationships. Participants seemed unaware of how the way they thought about and reflected on their relationship with people with ID increased opportunities for interpersonal connection. They did seem to identify how their attitudes and behaviour had changed as a result of relational experiences.

4.3.1 SUBTHEME 1: Holding people in mind – "Always in the back of my mind"

Participants seem to construct their experience of understanding people with ID largely from a reflective and distanced position. This emerged through lack of accounts offered in which idiosyncratic situated experiences of understanding were communicated. Alternatively, it transpired participants would be stimulated or engage in thoughts about their relational experience, memories or events. This appeared to inform understanding about their qualities and interests, and how clients might feel in particular situations.

The extract below illustrates how Samuel reflects on what he understands about a client's interests. Perhaps the use of emotive language "*love*" and *"loved"* mirrors the quality of thinking of someone when they are out of sight yet still in mind. It is perhaps important to acknowledge how this thought may have been intrusive, as Samuel was not with the client at the time. This implies that he may not always be in control of his thoughts about people with ID.

"When I go out Ben, I can go out and see something and think, man would he love that and my Mrs will go, "what you on about now?" And I'll go "oh I'm on about so and so at work, he would have loved this" (Samuel. 12, 364 – 366)

Samuel's narratives also provided an account of his curiosity about how people with ID may experience their feelings. The extent to which Samuel reflected on the presentation of clients can be illustrated in the extract below:

"A very lot of things go through my mind you know, how it works for them, what makes them wanna do this, what makes them wanna do what they've just done, what's made them sit there and be from that person to go to that person" (Samuel. 2, 38-40)

In Samuel's account, he describes multiple questions that "*go through*" his mind suggesting that he is mindful and curious of the intentions of others. His sense of questions going "*through*" his mind evokes a sense of struggle to hold and place belief in his understanding. He seems to split client characteristics dependent on what they "*do*", for example, *what's made them…be from that person to go to that person".* There appears to be limited integration of the person.

Frank also appeared to think about people with ID when they were not present. This is illustrated below by his on-going thoughts about them whilst not in his work setting:

"like I was saying to you earlier when, even when you are on annual leave and then you just remember things that have happened at work and you just remember and you just start laughing. I worked with a service user before and she just went home for a week and she didn't come back for a week and then I started missing her because she just come around and say all sorts of stuff to ya and they just make you laugh you know" (Frank. 25, 509-515)

The extract above illustrates Frank's connection with affect as he thinks about the people he cares for. As he reminisces about time he has apart he reflects on how thinking about the client can make him laugh and identifies how he misses them when they are not there. These emotional experiences appear to occur without conscious direction but rather as a result of "*just remembering*" and in response to time apart.

Thinking about clients seemed to inform Mark's understanding. He frequently discussed his thoughts about a client, framing their presentation to enable him to "*accept*" and "*help*" him. This is illustrated in the extract below:

*"I think a lot about **** and how I can help him and just accept that there are certain things that he doesn't understand and he's not to blame, it's not him purposely trying to spite me by not achieving things we have set out, that's just a part of him and you know he does achieve things, you know small things here and there" (Mark. 8,166-171)*

The account of frequent thinking and possible holding in mind what is understood about the person seems to have enabled Mark to focus on the part of the person's ability to "*achieve things*" and to a lesser extent the part of "*spite*".

This subtheme appears to capture a process whereupon people with ID are kept in mind by support workers. The accounts suggest various ways this process may be experienced. Participants seem to think about people following exposure to external cues or as a result of ongoing curiosity and reflection of the person and the relationship. Lack of situational moments of relating suggests participants may not think about how they relate to or interpret people with ID during the process of interaction or day to day reflection. Exploration of themes of holding a person in mind led to the emergence of further reflective accounts. These accounts captured a process of evaluation and learning.

4.3.2 SUBTHEME 2: Reflexivity – "I used to say arr come on you're winding me up"

This subtheme explores accounts of reflexivity. It captures the process of reflection and in cases reflexiveness that informed participants of their experience and fostered individual and interpersonal growth. Accounts of possible reflexivity were variable.

At the start of Samuel's interview, he appeared to reflect on how his life experiences had shaped his interests in supporting vulnerable people, leading to a realisation of how *"precious"* life is:

"*Before I come into care, obviously I cared for my father in law who has Parkinson's disease and if things went on, my mum wanted to take it over because obviously she thought it was her role to do so..and I wanted to carry it on, but I never thought I would work in a challenging home like now….eventually when I managed to get here*

and I did see what it was, it made me want it more, you see? So erm, and seeing the people that I work with and seeing how they live their life made me realise how precious their life is and how precious my life is, the things I can do different, the things they can't" (Samuel. 1,15-23)

In the extract below, James seemed to acknowledge that challenges are experienced when trying to understand a client's distress. He appeared to report that thinking over what happened, can elucidate understanding, for example "*that is when you….see".*

Erm, its really hard to at the time but erm, afterwards I think you can see, obviously there was a reason why they become distressed and I think that is when, that is when you can actually see (voice stops and starts) that maybe someone who was with them at the time or something like that has not really understood that person you know more" (James. 23, 472-478)

Jack presented as reflective and thoughtful throughout the interview. He gave examples in which he appraised his feelings in the moment, *"I think ooh gorden bennet where does this come from?" (Jack. 12, 232 – 233)* and his behaviour post event for example*, "I recognise it in myself that sometimes it's not worth fighting that fight coz actually it's not that important" (Jack. 10, 203-304),* and *"I used to think, why are you doing that?" (Jack. 12, 249).* It is perhaps apparent that he values a reflective process and utilises this to inform development. When asked how he responds to stress in his interactions with people with ID Jack replied, *"I manage it by one experiencing, two reflecting and three I spose building my knowledge up" (Jack. 11, 214-216)*

Jack used his reflective capacity to inform how he might predict situations in the future and the adaptive influence this may have on his thinking, feelings and practice. In the extract below he appears to communicate an understanding of tensions within the context of his own individual value base:

"I used to say arr come on you're winding me up….it was only a toilet handle..don't worry about it actually, it's not that important…I suppose that's how I kind of manage it a little bit…it's not important to me" (Jack. 9, 169 – 178)

Mark also presented as reflective and talked about what he had "*learnt*". Adopting a curious position appears to have been helpful in determining what may be responsible for distressing a person with an ID and interpreting how they may be feeling. This is outlined below:

"I wonder what's going on in his head and why does he need to do that erm, yeah erm, and I've since learnt that sometimes because he feels out of control, sometimes because he feels unsafe, sometimes because he can't get something and that's the way that he has learnt to get the biggest response..erm but yeah, erm it's difficult to see it, it's difficult and it's hard to see that sometimes" (Mark. 27, 557 – 562)

In the extract above there is a shift from present tense in which mental curiosity is explored to past tense when Mark reflects on how experiences of behaviour have shaped his understanding. There is sense of struggle in interpreting cognition, affect and behaviour and a yearning to "*see*" perhaps illustrating an urge to understand the client's behaviour. Holding a person in mind is echoed, illustrated by Mark's "*wonder*" about "*what's going on in his (clients) head*".

This subtheme captures possible accounts of personal growth which enhance the ability to relate to the experiences of people with ID. For example, Jack's shift in apportioning importance to a *"toilet handle"* and understanding what things to let go: *"that fight…actually it's not that important"*. Mark reflected on his accumulated knowledge that certain behaviours were shaped as "*he (client) has learnt to get the biggest response*".

This superordinate theme explored mindful and reflective processes that seem to enhance understanding of people with ID. Participants seemed to hold client's in mind; some think about them following exposure to external or internal cues and others as a result of ongoing curiosity and reflection of the person and the relationship. Accounts of possible reflectivity suggest that thinking about what can be learnt from interpersonal histories can enhance personal growth and improve how the experience of people with ID is interpreted and responded to. Reflective capacity allowed for attempts to position oneself in the experience of clients to try to make sense of what they think, feel and do. Most participant accounts differ in the way they try to understand, interpret or relate to the experience of people with ID. This

suggests that processes of relating are unique to the person with an ID and the person supporting them.

Underpinning many of the subthemes across both superordinate themes there is a deep sense of responsibility in which participants appear to strive to understand and accept accountability for the way in which they instigate support. The responsibility or role of the person with an ID does not appear to be explicitly present in accounts offered yet a sense of autonomy permeates extracts. This suggests participants may not always be aware of the role or power that people with ID possess. The complexity of these issues appears to lead to a sense of ambiguity and uncertainty. It appears the combination of required effort, sense of responsibility, ambiguity and reflection on what distress might feel like can lead to a number of tensions and challenges. Participants alluded to a sense of uncertainty, victimisation and the imposition of political and organisational agendas.

4.4 SUPERORDINATE THEME 3: TENSIONS AND CONFLICTS

This superordinate theme outlines challenges that participants appeared to experience in the interpretation of people with ID and perception of their role. Consideration of the relationship and engagement with reflexive processes appeared to enhance understanding and permit greater range of interpretation. However, relationships experienced were often not perceived by participants to be reciprocal. It emerged that experiences of relating could lead to a sense of uncertainty. This seemed to be compounded by how participants understood the professional parameters of their role. Tensions appeared to be complicated by conflicts in personal beliefs and values.

4.4.1 SUBTHEME 1: Uncertainty- "No-one could tell me what it could be like"

This subtheme illustrates experiences of confusion and ambiguity that emerged from participant accounts in relation to their sense of being able to understand people with ID. Accounts seem to capture the essence of uncertainty in being able to interpret thoughts and feelings.

For example, Samuel appeared to experience a profound sense of uncertainty in his ability to interpret client's experiences. He seemed to adopt a view that perhaps people with ID themselves are unaware of their own thoughts and feelings, as outlined below:

"I could sit here and say to you I know what it would be like, but you can't even tell me what it would be like…No-one could tell me what it could be like, because I can't just go into his room and say "what's it like for you?" because one, it wouldn't be nice to say to them and two, maybe they don't know that themselves" (Samuel. 7, 196-201)

In the extract above Samuel identifies a dilemma in which if a person with an ID is unable to understand their own experience, how can their experience be understood by others? The extract evokes a sense of distancing from experience illustrated by lack of first person pro-noun and inclusion of "you" and "no-one" perhaps externalising his sense of confusion. There is perhaps a tone of frustration alluding to a feeling of loss in how to makes sense of this dilemma. Despite his confusing and uncertain feelings there is a curious and motivated part of Samuel that seeks to do so, he takes a leap of imagination to understand people with ID, illustrated in the extract below:

"Maybe he wants another cup of tea (both laugh) maybe he's just doing it you know coz we think he's happy and go just let him have another cup of tea, but that's what he must think, I can't say what he thinks but I think I wonder if he thinks I'm gonna let him have another cup of tea straight away, I bet that's what he's thinking" (Samuel. 7, 227-230)

In contrast to imaginative means to interpret people with ID, in the extract below Samuel articulates the absoluteness of being unable to understand the behaviour of people with ID:

"Learning from these people is hard, today he will eat porridge, tomorrow he may not, I can't tell you why he's not eating the porridge today, so I never ever learn that person, I just know how to be strong for them and support them in the way they need supporting" (Samuel. 5, 136-138)

There is a sense that at times Samuel believes there is no knowing or certainty in his understanding of the people he supports. Perhaps this is qualified by his perception there is no consistency or predictability. Despite lack of understanding and acquisition of knowledge Samuel adopts the position he is still able to offer "*strong*" support and "*in the way they need*". Interpretation of Samuel's experience evokes imaginary of a pendulum swinging from a confident sense in interpretation to a sense of complete hopelessness in understanding. This is perplexing and is an example of the difficulty I experienced trying to make sense of some of Samuel's accounts. On the one hand he is stating that he is unable to "*learn*" the person yet reports he can offer support they "*need*". Efforts to unpack Samuel's conceptualisation of learning about people had limited effect, *"Ummph, (sighs) that's a hard one really learning about the person because (slow speech) every day, every day is different" (Samuel. 4, 104-105).* Samuel's conceptualisation of each day as "*different*" elicits a quality of unpredictability and layer of confusion in his interaction with people with ID. I surmised that at times he was unable to articulate his thoughts in the depth he sought to. Difficulties in engagement perhaps mirror his struggles making sense of this dilemma. This was also experienced in the process of eliciting material and understanding Samuel's accounts, which at times was challenging.

The experience of uncertainty is echoed further in the extract below by Derek who describes how it can be "*difficult to know*". He seems to respond by doing the "*best*" he can:

"It's difficult to know what people with ID are actually thinking, some people will never really know the situation, so you gotta assume and diffuse it the best you can" (Derek. 9, 188)

Derek's account diverges from Samuels in the way he appears to accept that although at times he may never really "*know*" the experience of people with ID he is able to "*assume*".

Fred also described experiences of confusion. He told me that on one occasion, "*It wasn't very easy because of their behaviour.. you don't know the time that can change that they can grab someone beside you and what do you do? How do you stay collected and handle that situation?" (Fred. 2, 35-41)*

Above Fred's account evokes a sense of unpredictability, echoing Samuel's struggles with lack of experiences of consistency. He infers changing "*behaviour*" can elicit difficulties regulating feelings captured in his phrasing "*how do you stay collected*". There is an essence of emotional volatility. Fred went on to state that at times it was not possible to determine why people presented as distressed. It appears that when he struggles to understand a person with an ID earlier themes are echoed in which he reverts to his academic knowledge, practice and observation, as outlined in the extract below:

"we see that when there is a kind of behaviour like he is unsettled you can look at and say what is happening and say is it because it is happening because he is in pain, you can say maybe he is warm and maybe feel his body or offer PRN. And there are times we cannot really" (Fred. 10, 202-206)

Fred also talked about challenges addressing conflict when the person you are supporting has limited verbal ability, "*because he can't talk we don't know how he is feeling" (Fred. 10, 201).* Fred's account is poignant diverging from other accounts that advocate possible non-verbal processes of interpreting experience. There was however evidence of personal reflection in the way Fred seemed to think about past incidents of conflict, echoing themes of reflexivity:

"*when some people are here, he - just sits down, he's not doing any activities or engaged in anything - he just sit down and watch some tele. But the moment the person goes out of the house then he will start to go all other the place and staff say "stop it", so I don't know if its personal somehow…if you develop that, I don't know how…with people" (Fred. 10, 109- 195)*

This subtheme illustrates accounts of feelings of uncertainty and confusion interpreting people with ID. These dilemmas may be underpinned by an understanding that people with ID are unable to interpret their own experience and cannot be predicted. This context appears to inform practice leading to focus on observational and strategic responses. Despite challenges participants appear to believe they are able to provide the support needed; this seems to be achieved by drawing on a sense of responsibility within their role and by trying to do the best possible. I wonder if given the context of confusion and tension, drawing on a role of responsibility gives meaning to participants in their motivation to support clients and

tolerate distress. Dilemmas appear to elicit intrapersonal tensions in how relationships and participant roles are understood.

4.4.2 SUBTHEME 2: Intrapersonal tension – "I can't be a robot, its human support"

This subtheme emerged following identification of accounts of conflict participants appear to experience in their role and relationship with people with ID. Particularly in response to conflicting personal values and interpersonal conflict.

Jack's account captured a sense of tension working within the parameters of his perceived professional role. He described a working culture in which it is expected that people acknowledge their role as paid employees and adhere to a professional code of conduct. Conversely he communicated that emotional intimacy formed an important part of his work with clients, this is illustrated below:

"*If you're investing enough with that person you're gonna have an emotional attachment….we talk about professional boundaries…I don't think you can do your job properly unless you've got an emotional attachment*" (*Jack. 22, 447 – 451)*

Jack appears to manage this dilemma by ultimately adopting a professional position, "*I put my professional hat on sometimes, and that helps me rationalise what's happening" (Jack. 24, 502).* He appears to experience conflict in the degree he can attach to clients. There is a sense that Jack experiences a need at times to detach from relationships, perhaps to assume a more rational, distanced position commensurate with professionalism. I wonder how this process influences Jack's ability to interpret or relate to clients given his perception that to "*do your job*" you need an "*emotional attachment".* It's as if Jack views emotional connection as fundamental to fulfilling his role. Perhaps other methods of working inhibit his ability to form meaningful bonds.

Professional practice impinging on personal values seemed to be experienced by Derek. Tensions could be understood as the conflict he experienced in maintaining a professional role and being able to connect with clients in a personal way. In the extract below he explicitly frames his role as "*a professional job.. you're not their friend*".

"Derek: (draws breath) I think er its its about character of the person you're supporting, no matter how hard I try in this job, I can't be a robot, its human support with humans so there's gonna be human behaviour, you know the gentleman in there he loves his banter so can't help but dive into it and build a rapport because that's the way he is with you erm the same with other people and individuals that I've supported you warm to their character and that's how your relationship develops… but I spose that can be difficult because..you need to know if it's a professional environment, I've always found it really really hard erm like to not use nicknames say erm because it's a professional environment, it's a professional job you're not their friend" (Derek. 3, 46-60)

In the extract above Derek states he can't be a "*robot"* which suggests he experiences pressure to perform in an emotionless and mechanic way, contradictory to his own values. The concept of humanness appears significant captured by language such as "*human support"* and *"human behaviour*". Accounts were accompanied by fidgeting, deep breaths and increased tone of voice perhaps emphasising Derek's feeling of frustration. A sense of unease was experienced in discussion of personal values perhaps reflecting his discomfort in not being able to be himself.

The extract below builds on Derek's tensions adhering to service protocols. He describes how "*tough"* it is for his own character.

"I can't deny I do still find it difficult not to shorten a name or do a nickname or even sort of mate, because it's a professional environment" (Derek. 13, 256-258)

Derek communicates in the present tense how he still does "*find it difficult",* perhaps illuminating a deep sense of ongoing struggle and conflict he experiences managing the perceived parameters of his role.

Samuel also alluded to a sense of struggle. His construction of the tension between personal values and service guidance appears to elicit an almost punitive experience. There is something both innocent and passive in the way he struggles to tolerate adhering to rules and guidance. This is illustrated below when he describes having "*to do as I am told".* There is a sense of restriction that permeates Samuel's narrative:

"I'm here to do my job and I'm here to get them out on activities, I'm here so that they can get their own clothes, I'm here so they can go and purchase their money so they can go and get a meal out, that's why I'm here, to give them the best life they can have (pause) and er.. I have to make that decision, I have to do as I am told to do, and you know er if, if #### said to me and he would, I want to go out for lunch but like I say there's only so much you can do with them.. I just think there is more we can do for them" (Samuel. 8, 257-262)

Further to tensions couched within support worker roles participants also referred to frictions brought about by interpersonal contact. Jack seemed acutely aware of this difficulty. When discussing a client, he formed a secure bond with he stated, "*he would know when I was stressed so he would be on my case...we would just wind each other up" (Jack. 17, 337-340).* Jack's attribution of knowledge and control of behaviour to the person with ID echoes the sense of awareness and autonomy in people with ID. He appears to validate that experiences of being wound up are constructed interpersonally, illustrated by his phrasing; "*we would just wind each other up*"

Mark appeared to be deeply affected by behaviours which he appraised as being directed towards him. This is captured in the extract below:

"it took me three attempts to get him to go, because he was in bed the first two times, he was in bed, he didn't want to get up, eventually he did and we went and he enjoyed it in the end but he just thought, it's just Gatwick airport, I don't really want to do that and so you know when I spend some much time and effort for him when he doesn't want to do it, that's when it feels a bit personal and you sort of feel like, well I've really tired there **** erm, yeah it is difficult" (Mark. 12, 232 – 238)

Mark's conceivable experience of rejection appears to be compounded by the amount of "*effort*" exerted to facilitate client goals. Despite attempts to rationalise experiences of rejection Mark continues to question himself. The extract below suggests that experiences of rejection can lead to self-doubt:

"I think is it me, you know would he be better with different key workers? Somebody else? Or is that you know just you being you erm..." (Mark. 11, 211-213)

There is perhaps a tone of uncertainty in Mark's self-belief as a key worker. Perhaps the feeling of self-doubt in abilities is mirroring the experience of the client. I wonder how this is reflected in the way he empathises with others. For example, lack of confidence interpreting client needs leading to disproportionate focus on observational and behaviour driven interventions. Although Jack seems to also be subjected to aversive feelings these do not appear to influence his self-confidence. He appears to attribute the motivation of the person with an ID to be deliberate and harmful for example, "*he would know when I was stressed out*". He seems to construct the conflict as being shared between him and the person with an ID. Alternatively Mark seems to attribute more of a naivety or ignorance to the person with an ID. This subsequently leads to a possible increased sense of responsibility and ownership of the conflict. This may account for his deep examination of his competencies.

This subtheme has illustrated experiences of tension in the way participants perceive their role and relationships. They seem to struggle in their practice as a result of the conflict between personal values and beliefs and being professional. There is an essence of responsibility and drive to engage personally perhaps beyond perceived boundaries of professional conduct. This echoes earlier themes in the way participants draw on a range of interpersonal and reflexive processes to relate to the experience of people with ID. Emergent themes of relational conflict were also present in which participants reported "*stress*" or thoughts of being personalised by people with ID once a bond or attachment had been established. This issue is perhaps exacerbated by conflicting views on the autonomy and responsibility of people with ID.

This superordinate theme has presented the impact that experiences of confusion and tension have on participants within the context of their role, relating to people with ID and interpreting their distress. Participants reported difficulties in understanding thoughts and feelings in others which for some fluctuates from a sense of understanding to a sense of not being able to understand at all. Tensions were reported in the way participants seem to believe they should behave in their role and how this can conflict in how they would rather be in their client relationships. For some this could lead to feelings of possible restriction illustrated by the way in

which Samuel seems to seek more activities and Derek seeks more freedom in how he communicates and engages with people with ID.

Further tensions appeared to be embedded within relationships. Feelings of "*stress*" were reported by Jack, and Mark's account suggested possible amelioration in confidence. The depth of emotional experience present in participant accounts perhaps amplifies processes of direct empathy and holding people with ID in mind. Interestingly participants' appeared to not attend to their physiological experience when reporting intrapersonal tensions. Exploration of accounts of uncertainty, stress and conflict illuminated ways in which participants manage their emotional experience and sense of responsibility. Analysis of transcripts revealed variability in emotional awareness and a number of ways in which participants appeared to defend against a sense of distress. Accounts of possible processes of denial and minimisation were elucidated.

4.5 SUPERORDINATE THEME 4: MANAGEMENT OF DISTRESSING FEELINGS

Feelings of confusion, tension, sadness, stress and frustration emerged in interviews. Following explication of negative affect and uncertainty participants experienced it was revealed they seemed to react to a sense of distress in different ways. It also emerged some participants didn't seem to recognise the occurrence or impact of upsetting emotional experience. When distress was validated participants appeared to refrain from sharing their experience for fear that it may transfer to others, echoing underpinning themes of personal accountability and responsibility.

4.5.1 SUBTHEME 1: MANAGING REACTIONS – "Its part of the job"

This subtheme presents possible management strategies that participants utilised in reaction to intrapersonal and interpersonal tensions and negative affect. It emerged that some participants may appraise their experience based on factual and quantitative knowledge. This appears to enable rational interpretation of events and feelings in order to adopt management strategies. Other participants seemed less

aware or in denial of distressing feelings. The possible use of humour was also prevalent in accounts.

Intellectualising – "I know sort of logically I don't think ** is spiteful"**

Intellectualising can be understood as a process whereby a person may appraise events based on factual and quantitative knowledge at the detriment of establishing personal meaning or connection with affect. Analysis of transcripts elucidates accounts in which participants may intellectualise their experience both to interpret people with ID and ameliorate a sense of distress.

In the extract below processes of intellectualisation[6] are perhaps clear in the way Mark "*logically*" ameliorates the impact of spiteful behaviour by framing it as only "*part*" of the person. He appears to almost force himself to take this perspective as he has to "*talk*" himself "*round*" echoing experiences of tension:

*"Erm, quite often my first sort of thoughts are, you're making this decision, this isn't just your Asperger's or your learning disability this is just a part of you-you're purposely making this decision and I have to talk myself around because I know sort of logically I don't think **** is spiteful, I don't think **** is a bad person erm but this is just a part of him" (Mark. 11, 217, 221)*

Above Mark seems to initially attribute greater responsibility to the client but then moves towards diffusion of his sense of being spited by attributing the client's presentation to their "*learning disability*". This reaction elaborates further underpinning themes of amelioration of responsibility in people with ID within the context of interpersonal challenges. This is likely to be helpful in fostering an accepting and understanding approach and is perhaps a valued way in which to conceptualise people's personalities and behaviour. However, there is no identification, validation or exploration of how Mark felt when he understood behaviour to be "*spiteful*".

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[6] The term intellectualising is adopted in cognitive behavioural therapy (Beck, 1967) to describe a mental process in which factual and quantitative knowledge is used to evaluate experience (Teasdale, 2002). Over reliance on this mode of thinking is argued to lead to people becoming disconnected from their emotional experience and struggle with the interpretation of meaning of events (Wills, 2013).

Commensurate with Mark's account, Fred's validation of distressing emotional experience appears limited. In the extract below there is a sense that he rationally manages his "*stress*" by contextualising his experience as "*part of the job*". This seems to result in distancing from his affective experience and opportunity to clarify feelings and seek support. The intensity of Fred's stress is illustrated by the vivid and powerful picture of someone being "*on his neck*", the neck being part of the body which allows us to breath and survive. Possible lack of awareness of the impact of stress is perhaps present in the way in which Fred seems to believe he can "*just relax*".

"The behaviour they present at times is interesting in the sense that the word interesting in that you are like okay, you have been with somebody for a while and you know that the next thing, if I leave this person the next person they are going to do, now you know it. So when you do it I just smile, because that is what's going through my mind (joint laughing). The next thing that there is, is where they are going, and that is the interesting aspect of it, the stress aspect of it is that er you are just er, look this guy has been on my neck since the time I resume this place, for the past six hour he has been doing this and doing this and I say oh I think I'm tired. But at the same time because we know that that is the reason we are here, we just have to relax and its part of the job" (Fred. 19, 392-403)

Conceivable processes of intellectualisation in reaction to negative affect converge between Mark and Fred. Both appear to react by rationalising and compartmentalising their experience. Mark seems to rationalise "*spiteful*" behaviour as being "*part*" of the persons *"learning disability"* in order to make sense of his experience, engage in his role and connect with the person. Fred perhaps compartmentalises his experience of "*stress*" as part of his "*job".* He rationalises his negative experiences as contextualised within his role, being "*the reason*" he is "*there".* At other times participants seemed to be less forthcoming or not aware of negative emotional experience.

Denial – "It doesn't really affect me"

In contrast to rationalizing experience there were times participants appeared to be unaware of the impact of their distress.

For example, although Fred acknowledged both negative and distressing feelings he appeared dismissive of the impact they may have on him and his relationships. He presented as confident in his posture and tone in discussion about experiences of stress and stated, "*it doesn't really affect me*" *(Fred. 17, 356).* Below he goes on to tell me:

"*At the same time it doesn't affect me working with the other service users because we have er, a plan each day for what exactly we want to do with them from this period to this period, so I will say do it just to move them on and make sure they are doing what they are supposed to do*" *(Fred. 20, 348 – 352)*

In the extract above Fred appears to minimise the potential impact of stress within his relationships by stating that it doesn't affect his ability to work with other clients. He reverts to a rational process of following support plans further elaborating possible processes of intellectualisation and compartmentalisation in participant reactions to a sense of distress. This approach also echoes strategies endorsed by a sense of client unpredictability.

At other times participants appeared to contradict themselves in how they understood stressful experience. Mark appears to be of the view that he manages his stress well yet reports physical discomfort. He has some understanding that "*showing*" how he feels might help him yet his account suggests that he chooses otherwise. "*Stress"* is communicated as embodied "*physically*" and "*builds up",* illustrated in the extract below:

"*Yeah, well as I say I think I'm quite good at dealing with stress and perhaps not showing it, but you know countless times I've gone home with a headache and I've had to lay in a dark room, you know it sort of, you know physically it builds up rather than me showing it so much erm*" *(Mark. 23, 465-469)*

Both Fred and Mark's accounts suggest subtle awareness of transition in mood and affect. They demonstrate agency in how this experience is managed. Mark's account suggests a sense of responsibility that may inhibit emotional expression. This further elaborates the deep sense of responsibility that participants seem to experience. Conceivably accounts suggest naivety in acknowledging the impact that emotional distress may have on client relationships and on physical and mental health.

Humour – "I think I joke it off"

The use of humour to manage experiences of distress seemed prevalent amongst participants and took various forms. Some focussed and articulated use of humour in reaction to negative affect. Others seemed less aware that they were using humour within the context of their distress.

Samuel discussed use of humour. He acknowledged a process whereby he tries to make others laugh. He appears aware of the limitations of this strategy and how he is not consistently able to use humour in response to how he feels. Despite this cost potential lack of humour seems to be outweighed by the benefit of joking which may take his *"mind"* away from how he is feeling. This is illustrated below:

"I think I leave it, I try to leave it at the door. There's been times I haven't been able to obviously you know erm but, I think I joke it off. I can come in here and make people laugh that takes my mind off it. You know" (Samuel. 14, 443-445)

Above Samuel communicates leaving his experience by *"the door"* perhaps echoing themes of responsibility. This phrasing evokes imagery of clothing or baggage something that is emotionally opaque and can be removed and picked up at a later time.

In contrast, Fred appears unaware of his application of humour to frame physically challenging behaviours emitted by people with ID as outlined below:

"A funny thing like, you know grabbing is funny coz we are just talking now and my head is just now and the next thing I will do is just to maybe grab your trousers! You know I funny (laughs)" (Fred. 4, 73-75)

Fred's humour permeated the interview throughout. He did not explicitly talk about his use of humour as a means to contextualise challenging behaviour or respond to dilemmas, however he would often smile, chuckle to himself, laugh or share laughter with me. There seemed to be a sense that Fred would frame challenges he encountered with humour. In response to my enquiry about the challenges of thinking ahead Fred responds:

"Yes, you just…I think it's just part of the job because if you don't think ahead of them they will beat you're planning (joint laughing) they will beat your experience or whatever you call it!" (Fred. 21, 429 – 431)

Although challenges are validated in his initial response, Fred starts to laugh which leads to me laughing also. He appears to use humour to diffuse the difficulties of thinking ahead and the seriousness of our discussion. He goes on to frame thinking ahead as a kind of friendly competition with clients, for example "*they will beat your planning*" (*Fred. 21. 229-430)*

This subtheme presents a number of possible ways participants seem to react to experiences of distress. It would appear to manage distressing thoughts or feelings they may rationalise and compartmentalise their experience perhaps to identify helpful ways of understanding and relating to clients. This seems to reduce opportunities for validation and expression of feelings. In other cases, participants appear to acknowledge a transition in how they feel but deny its impact, again reducing opportunities for validation and expression. Finally, the explicit and implicit use of humour is used in reaction to distress and conflicts, again leading to avoidance of emotional expression. A strong undercurrent of individual accountability for the management of distress seems to flow through accounts which led to the emergence of a possible and specific way in which participants take responsibility for how they feel. This was perhaps captured in the way in which participants strove to engage in interviews even when struggles were experienced. They paid particular focus on how they endeavour to meet the needs of people with ID yet minimised material reflecting on their own needs. This position may have been intensified by context, as interviews were conducted in the participants' workplace during their working hours.

4.5.2 SUBTHEME 2: TAKING RESPONSIBILITY – "Problems should stay at home"

This subtheme explores participants' sense of responsibility in the management of their emotional experience. In exploration of reactions to mental or emotional

distress it emerged participants would often seem to take strong accountability for their experience, possibly to avoid distressing others.

Hiding – "I used to put myself, pretend I was an actor"

There emerged a process whereby participants appeared to acknowledge a change in their feelings but would refrain from sharing this experience with others. Participants seemed to position themselves differently in how they thought about and made sense of this process.

Below Samuel provides a description of how he believes his feelings interact with the feelings of others. Conceivably he gives importance to hiding his sad feelings for fear of sadness influencing others, for example:

"I don't show that I'm sad, because I feel that they can pick it up, the sadness I feel they can pick it up and you can't ask me why I know but I can feel it" (Samuel. 13, 423-424)

In the extract above Samuel is perhaps unable to quantify how he believes feelings are transferred; he seems to adopt an introspective approach to his interpretation of emotions. This is illustrated by the way he communicates that he can "*feel*" the process. Samuel's reflections echo themes of reflexivity and relating without language. His sense of sadness as being a phenomenon that others can *"pick up"* suggests he constructs his sadness akin to something aversive like infections that can be picked up, caught and have negative consequences. It also evokes a sense that Samuel's experience of sadness is something that can be physically detached. This echoes Samuel's earlier constructions of feelings being left *"at the door"*.

He continues to explain how his personal values articulated as "*morals"* may influence how he exhibits his feelings within the emotional boundary of the work place. This is outlined in the extract below:

"It's not nice, its not nice because I believe that your worries should stay at home, your problems should stay at home you should never bring them to work, not into this sort of job anyway. You know in the back of your throat or whatever, if you stand there and think about what, why your sad, yeah you can't because other people get

to see it and you're coming into somebody's house, you know its morals" (Samuel. 14, 433-437)

The notion of an "*emotional boundary*" also emerged in an account provided by Mike. This is exemplified in his report of how he "*blanks out*" his mind and attends to his mood "*after work":*

"Yeah blank it out your mind and think I'm at work now, that's the way I do it, erm come in to work while handovers being done and if I'm in a bad mood don't talk to no one really, just say hello, say hello how are you to the service user and that's it really until handover is done, see who I am working with and then that's it now, I've got to do the shift, do the shift and do the work and then that's it and I don't think about my bad mood and I can attend to it after work" (Mike. 23, 464-470)

Below Mark possibly notices his stress but appears reluctant to express feelings. He perceivably believes that it is "*his problem"*. Mark seems to advocate how ownership can help him "*take the time"* to "*deal*" with his feelings. His use of the word "*deal*" evokes a sense that he may experience feelings as aversive to be dealt with or a kind of burden. A strong sense of accountability permeates his account:

"I do notice myself getting stressed and that's why I think I've got good dealing with it and not erm, you know making anyone else's problem, I think then probably not become more patient but perhaps that's how it seems because I will just take the time to deal with it and not make it anyone   else's problem that's what I focus on, not making it anyone else's problem because it's me that's got to deal with it and I will deal with it" (Mark. 24, 493-499)

In the extract below Jack describes how he used to pretend to act in a role to avoid eliciting stressful interpersonal contact:

"I used to put myself, pretend I was an actor is the best way I could describe it, and put myself in a role, so I'm playing a role and that's how I used to manage that stress because I would, I would be over enthusiastic about certain things, that okay are not important to me but are very important to him, and that's how..coz if I wasn't over enthusiastic as soon as my facial expression changed and I would be like uoogh, I wouldn't you know, he would pick up on it straight away, straight away and then his anger, anxieties would be raised" (Jack. 15, 312-320)

Jack seems to inhibit expression of his feelings by playing a *"role"* perhaps both to manage stress and reduce the likelihood of elicitation of anger and anxiety in the person he is supporting. Participants appear to adopt the position that it is potentially aversive for others in the event that their experience of distress is directly expressed. There is a possible undercurrent of personal accountability and drive to manage feelings independently from others.

This superordinate theme illustrates the complexity of participant reactions to aversive emotional experience. There appears to be a variety of processes in play in which participants rationalise, deny the impact of or use humour to cope with how they feel. In most cases there is a strong sense that participants seem to choose to inhibit their emotional expression in order to protect others. This includes people with ID and the broader social network within the workplace. This may lead to lack of opportunity to validate and communicate distress to others. Ultimately it appears that the way participants contain and manage their emotional experience allows for engagement in a range of positively biased interpretative approaches. Negative facets of client's characteristics and behaviours are diminished and reinforcement is experienced in the context of fulfilling a sense of responsibility.

4.6 OVERVIEW OF ANALYTICAL FINDINGS

The process of trying to understand the experience of clients with ID seems complex and challenging. Limited accounts of situated moments of cognitive and affective processes perhaps suggest struggles in monitoring and reflexivity. However, participants appeared to engage in a range of strategies to try to understand clients. This was often underpinned by a possible sense of responsibility in their role which was somewhat mirrored in the intense altruistic engagement in interviews.

Limited affective or situational cues and experiences of distress seemed to endorse distancing and application of theoretical and observational strategies. Application of academic knowledge and senses, particularly sight and hearing were seemingly complemented by reflective, reflexive and affective processes which appeared to allow for a greater level of emotional attunement and imagined sense of the person's inner world. For some this meant a sense of fulfilment in their role. Participants

seemed to reflect on their relationship to think about what they have learnt about the person's needs and methods of communication. Conceivably they imagine what the person is thinking in particular situations with an aim to extrapolate meaning behind their behaviour. They also tried to put themselves in the position of the client to make sense of how they are feeling or what they might be thinking. Participants appeared to move from a position of observer to one of participant in interpretation of relationships, feelings and their meanings. A sense of connection or understanding seemingly held personal meanings for participants often leading to a sense of achievement or realisation.

It was revealed that being mindful of clients and establishing strong relationships led to a deep understanding of them. However, the development of an attachment to someone with an ID appeared difficult to tolerate. Themes of stress, self-doubt and confusion were revealed in the way participants' appeared to think about their interpersonal experiences. They seemed to report how relationships were not reciprocal and expressed doubt in their abilities to understand clients. Patterns of intrusive thoughts were illuminated. Motivation to provide care seemed conflicted by organisational policies and procedures, illuminating further dilemmas. There was a sense of depersonalisation of the experience of support workers and restricted opportunities to develop meaningful relationships. It is interesting that given the level of reported stress it was often the case there was a tendency not to share distressing feelings for fear of contagion. Transference of negative affect seemed to represent failure to be responsible and accountable.

The extent to which distress was validated is unclear, some participants noticed a shift in their feelings but was not reflected on in much depth. During interviews participants directed and elaborated more deeply issues of client distress in contrast to their own. There was a sense of misconception in how effective coping strategies were in ameliorating painful feelings. In relation to this, there seemed little awareness of how lack of self-care may potentially influence one's ability to understand and connect with people with ID, for example low frustration tolerance and problems thinking clearly or without judgement. It may be that assuming a position of responsibility, diminishing the responsibility of people with ID and using denial, humour and other defences enables understanding and toleration of a challenging and dangerous work context. Ultimately, doing what is perceived to be

possible to achieve, and what is thought to be morally correct and symbolic of the role of the support worker. These findings are unpacked and discussed further in the following chapter, along with the influence of context.

4.7 Reflections on conducting the analysis

 At the start of the analysis initial clustering of themes appeared to elucidate contradictions in participant perspectives and hidden meanings in how their emotional experience may be conceptualised and managed. Explication and elaboration of possible defences and aspects of self- concept that participants did not appear to have insight into, raised questions for me about theories and models that guided my research. I also reflected on how the framework of research is not designed to be therapeutic. I was conflicted about what to share post analysis individually with participants. I returned to the theory and literature to inform my decision not to member check findings (Yardley, 2000; Bloor, 1997), but rather share the findings as a whole. I then found I started to doubt my analytical interpretations. In supervision it was suggested that my analysis of participant accounts was often too descriptive or overly interpretative, I did not know how to strike the right balance.

During the iterative process of analysis, I found it a challenge not to reduce themes prematurely but equally also to prevent them becoming too vague and generalised. I found it difficult to avoid fitting quotes into existing understandings of how empathy or self-compassion might be understood or function. There was a sense of concern about being able to develop rich descriptive and conceptual accounts of experiences which might shed light on current research. I wondered, to what degree can meanings attached to people and their experiences, be understood, interpreted and analysed. At times the complexity of the task led to a sense of demotivation and self-questioning, for example, how was I to try to make sense of such a vast array of data? how could I identify and communicate unique personal experiences in a valid and theory driven way, and with clear links to the research aims? were my superordinate themes conceptual enough? were my clusters correct? perhaps most disconcertingly were my thoughts about whether I was being true to the epistemological positions of hermeneutics and phenomenology, did I really understand how to acquire knowledge on this epistemological paradigm?

As the analysis progressed so did the level of my uncertainty. I would often feel confused and overwhelmed by what I was reading or my interpretations that transpired from accounts. I felt alone and immersed in the world of my thoughts. As each thought passed by I felt less grounded and became more disconnected from the research aims. Synthesising data was a struggle and my confidence began to further ameliorate. Supervision was supportive in the exploration of how perhaps I was not empathising with myself but rather striving to understand and develop the research study. I wondered if this mirrored feelings of support workers who may not empathise with their own experience. This was revealed in accounts that alluded to the strong influence of responsibility inhibiting validation of distressing affect when trying to meet the needs of clients. Perhaps, in some contexts provision of attachment behaviours (Gilbert, 2013) conflicts with our ability to be sensitive and committed to ourselves.

What struck me about these reported experiences and how I related to the research material was the depth of my involvement with participant accounts and how emotional I felt. I acknowledged a sense of pressure and desire to try to create something new, something meaningful that could assist support workers and people with ID in their relationships. There were days I felt physically sick and stuck, not knowing which direction or prose to progress with the study. I wondered did my analysis lack nuanced accounts of self-compassion perhaps because related material was too painful for me to experience, or was I in denial? was I being responsible for participants so that they did not become overtly distressed or was I protecting myself? was I interpreting correctly or failing to capture the nature of human fragilities?

CHAPTER 5

DISCUSSION

Overview

The present study was developed to explore how male support workers interpret and respond to people with ID with a focus on inquiry into processes of understanding and relating. It also explored reflection of what these experiences might mean. Grounded in participants' reported experiences, I aimed to explore how processes of relating were understood and whether they enhance or inhibit self-compassion. I considered how support workers respond to their own experience of distress. IPA methodology (Smith & Osborn 2008) was utilised to meet these research aims.

The primary research question in this study was:

What are the experiences of self – compassion and empathic[7] practice in male staff supporting adults with intellectual disabilities and challenging behaviour?

This question was explored via further subsidiary questions:

- How do staff interpret the experience of working with people with ID?
- What meanings do experiences of interpretation or relating hold for staff?
- What aspects of the relational experience enhance or impair empathic practice?
- How do staff respond to their own experience of distress?

This chapter explores key findings in respect of the above questions. I will seek to determine how participant meanings may be understood in the context of research,

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[7] Given the history and breath of definitions and understandings of empathy, for the purposes of discussion I will situate and interpret research findings predominantly through a psychological lens. It is beyond the scope of this thesis to explore and critique epistemological concepts of empathy as indeed differences even within the phenomenological and positivist traditions are present, (Zahavi, 2010). Furthermore, the intention of the study was to explore not explain experiences of empathy and self-compassion as understood by participants in ID and challenging behaviour settings and to apportion openness to their constructions and interpretations.

theories and frameworks pertinent to the discipline of counselling psychology. The significance of the study, methodological considerations, suggestions for future research and clinical implications will subsequently be discussed. Throughout I have striven to acknowledge and explore my position in the way in which I have accumulated and discussed emergent data. Reflections are presented in this chapter and intermittently throughout the thesis, commensurate with the reflective process (Kolb, 1984) that underpins counselling psychology practice.

5.1 Psychological concepts that emerged from the analysis

The themes presented in the analysis draw upon constructs within the literature base of empathy and self-compassion. Emergent concepts are in dialogue with, and linked to, the extant literature. In particular, further elaboration of the role of the working relationship in understanding others and significance of the capacity to be reflective. What was striking about identified themes was the complex ways participants seemed to consider processes of relating, relationships and their sense of wellbeing. Participant reflections and approaches appeared to be variable, heavily influenced by context and by possible perceived struggles in the management and holding of conflicting views and experiences. A curious finding is the apparent lack of motivation to attend to experiences of distress in a compassionate way. In this section, I will evaluate the main concepts that emerged from the data set including: 1. the role of reflexivity in understanding people with ID; 2. internalisation of the relationship; 3. impact of the relationship on self and 4.the roles of altruism and responsibility. Given the discovery of unexpected themes it has been necessary to consider additional literature to help contextualise and make sense of the findings. This is usual within IPA practice.

5.1.1 The role of reflexivity in understanding people with ID – from observer to participator

Both Superordinate Theme 1: Making sense of the others inner world, (page 53) and Superordinate Theme 2: Processes that enhance empathic practice (page 64) illustrate the dynamic and transient quality of relating and understanding people with

ID. This is perhaps most clearly conveyed by the way in which participants seemed to move from a position of observer to participator when empathising with clients. The subtheme "interpretation based on knowledge and observation" outlines accounts of understanding based on academic theory and sensory feedback from an observer position. The subtheme of "reflexivity" identifies how, although constrained by dilemmas of managing professional boundaries and personal defences, most participants appeared to consequently engage in a process of intrapersonal reflection. Couched within attribution theory (Fiske & Taylor, 1991) intrapersonal functioning refers to self-directed thoughts and emotions (Weiner, 2000). In the case of the participants, this included consideration of what has been learnt about experiences of being with the client they are supporting and how this has influenced their approaches, thinking and feelings. Accounts were presented which illuminated changes in personal beliefs and values, for example, Jack's realisation that he did not need to apportion importance to environmental damage caused by clients and feel frustrated when this occurred (page 67) or be pulled into unhealthy patterns of relating (page 75). Considering that the research focus was on how support workers interpret the experience of people with ID and what aspects can enhance empathic practice this was a somewhat novel finding.

It would appear, therefore, that variability in reflexive thinking may influence how we empathise. This is relevant to the exploration of processes that may impair empathic practice. Participant accounts suggest that reflexivity enhances understanding and authenticity within the relationship. In the subtheme "reflexivity", participants described how they reflected on their practice and had evaluated why they might be drawn into conflict or struggle in their role. Participants who appeared to be less reflective seemed to struggle to understand and communicate facets of practice. This was acknowledged explicitly by participants in the interview debrief and was implicit within their accounts. Transcripts posed challenges in the identification of empathic thinking, feelings and behaviour. Variability in intrapersonal reflection appeared to be in relation to how their client work was understood, rather than lack of congruence with the research focus. These participants seemed more often to be aware of observational cues and sensory feedback. They struggled to simultaneously reflect in the moment on their experiences and what it might mean. It is, however, important to consider how interpretation of accounts are inextricably

bound by context. For some participants the formal nature of the interview may have influenced incentive to articulate particular aspects of their experience.

Neuropsychological ideas (Lamm et al, 2014) indicate that regulation of one's egocentric perspective may be crucial for understanding others. In other words, our awareness of self, our learning and the role we play within our relationships may be a significant factor in how we empathise with others. Purposeful reflection is thought to lead to a deeper understanding of issues, improve judgements and critical thinking (Cirocco, 2007). Bolton (2005) has proposed reflective practice enables a shift in attitude, relationships and values. Each of these concepts can be applied to the role and experience of support workers in the way they might relate to and emphasise with people with ID. Taken together, these ideas offer a pluralistic and in-depth understanding of how we might conceptualise and experience empathy. Perhaps this illustrates how integration of disciplines can be useful in thinking about psychological concepts and their meanings. Interpretations in the subtheme "reflexivity" suggest that, following reflection upon their thoughts and behaviour participants seemed to be able to adopt a more tolerant and open position in their understanding. For instance, in the way Mark reflected on his learning that observed behaviour may be contingent on cognitive functioning (page 67) and how Jack evaluated what is important (page 67). These experiences may inform future practice and foster capacity for self-care. For example, by re-framing emotional tensions as intersubjective rather than intrapersonal, and facilitating capacity to adopt different positions in understanding challenges. This perhaps elucidates the dynamic nature of empathy.

Critical and self-reflective capacity has been explored within nursing settings and has been found to enhance practice (Kuiper & Pesut, 2004; Williams, 2001) but is difficult to teach due to unclear definitions and lack of evidence based strategies (Kuiper & Pesut, 2004). Both active repeated guidance facilitated by a process of critical questioning (Williams, 2001) and learning journals (Bolton, 2005) have been argued to foster these competencies. At a micro level, interviewing participants about their experiences in detail did appear to elicit reflective (thoughts about experiences and what could be learnt) and reflexive processes (questioning of own attitudes and values). This echoes the idea that context may influence how people think about or communicate their experience of empathy and self-compassion. My prompts may

have been helpful in generating more in-depth and focussed responses, but, equally the type of accounts provided may have been contingent on a sense of being judged or pressure to acquiesce.

Notwithstanding the influence of context, the development of simulation theory (ST) within cognitive psychology proposes that one's own mental apparatus is used to simulate the psychological and neuropsychological experience of others, thus facilitating predictions and explanations of actions (Harris, 1995). This is, perhaps, congruent with the idea that intrapersonal reflexivity can inform learning and understanding about our relational transactions. This highlights possible potential interventions within care settings for the opportunity to acquire skills in reflective practice. The concept of self-differentiation or acknowledging and using one's own being as a means to inform understanding has already been postulated to facilitate empathy (Sartre, 1943). However, this has arguably been in isolation of acknowledgement of other interpretative processes. In contrast, a number of possible empathic approaches, often integrated, were revealed within participant accounts, further illustrating the conceivable dynamic quality of the phenomenon. These are outlined in the subthemes of "interpretation based on knowledge and observation", "relating without language", and "direct empathy". What emerged was the way in which thinking about the experience of the relationship could enhance these practices. This finding is now considered within psychodynamic theory.

5.1.2 Internalisation of the relationship

Analysis of participant accounts suggested important elements in empathising with people with ID is contingent on both reflexive and reflective processes. Superordinate Theme 2: Processes that enhance empathic practice and sub themes of "holding people in mind" and "reflexivity" described how reflecting on client relationships appears to enhance understanding. Although discussed in psychoanalytic literature (Lamb, 1979; DeGroef & Heinemann, 1999), idiographic understandings of relationships with clients with ID and their meanings have been scarce, particularly within the context of empathic practice. To perhaps understand this further, it might be useful to consider contemporary psychoanalytic

understanding of relationships, which are mostly embedded within attachment theory (Bowlby, 1979) and object relations theory (Kernberg, 1976).

Attachment theory offers an understanding of personality development and behavior in close relationships and seeks to explain differences in people's emotional and relationship patterns. Object relations theory emphasises the importance of early human interaction and the conscious and unconscious experience of self as embedded within interpersonal relationships (Kernberg, 1976). The theory posits that relational experiences lead to unconscious drives that internalise these "object relations" and consequently guide understanding and interpersonal actions. This can perhaps be illustrated in the way Mark's account of ongoing reflection on his relationship with a client, leading to an understanding that challenging behaviour is not personally directed towards him (page 66). Additionally, Frank's experience of missing a client, and facets of their personality seemed to elicit positive affect, and a sense of normalisation of the relationship (page 65). His transient emotional experiences appeared to occur without conscious direction, but rather as a result of "*just remembering*", (*Frank. 25, 510-511).* Although IPA does not focus on interpretation of the unconscious per se, psychodynamic theory appears useful to explain the data.

These accounts suggested a process of "holding" relationships (objects) in mind wherein ideas about others are held within our relationships and include experiences of the context in which our relationships are formed (Britton, 1955; Bick, 1968). What emerged from participant accounts and is captured in the subtheme "holding people in mind", is possible reflective activity which considered, in depth, thoughts and feelings about client relationships. The way relationships were intimately held in mind seemed to inform and transform how participants might interpret and relate to the experience of clients. It is suggested this reveals a dynamic and multi-faceted quality to empathic experience. Situating this finding within the extant literature, it has been theorised that the richness of representations of internalised objects elaborated by experience across varying situations, time, settings and contexts can enhance empathic understanding (Preston & de Waal, 2002). The findings revealed that participants would appear to think about clients when they were not at work and make links with items or activities that they believed might be of value to them. Other accounts illuminated situations or environments that participants thought may well be

experienced as distressing for clients (page 62). These concepts are relevant to the area of inquiry that places focus into how staff interpret the experience of people with ID and what aspects of the relational experience enhance or impair empathic practice.

5.1.3 Impact of the relationship on "self"

Superordinate Theme 1: Making sense of the others inner world and Superordinate Theme 2: Processes that enhance empathic practice, put forward intrapersonal concepts that may facilitate understanding people with ID. However, what also emerged was that internalising experiences of the relationship and reflecting on what this might mean could be difficult to tolerate, and at times, upsetting. Accounts of stress, self-doubt and confusion were revealed and captured in Superordinate Theme 3: Tensions and conflicts (page 69) and sub themes of "uncertainty" and "intrapersonal tension". These areas of exploration were pertinent to the inquiry of experiences of self-compassion and empathy, processes that may enhance or inhibit empathic practice and how staff might respond to their experience of distress.

Participants reported tensions and dilemmas in their understanding of clients. These were variable and dynamic within individual accounts offered across the data set. Samuel reported confusion in his ability to interpret people with ID (page 70) and Mark's account seemed to suggest frustration in the perceived lack of reciprocity within relationships (page 75) and a personal sense of limited competence (page 75). Identification with people with ID is thought to influence self-worth (Lamb, 1979) and can be understood as transference, a process in which latent meanings are played out in the relationship (Bateman & Holmes, 1995). Possible experiences of transference can be couched within participant accounts of a sense of incompetence in struggling to understand their role and clients. As a recognised marginalised group within society (Fryer, 1993), it is possible that people with ID have been treated in such a way that would lead to feelings of low self-worth (Hodges, 2003).

It was revealed that participants appeared to experience tensions and dilemmas within a triad of relational dynamics, not only with people with ID but also within the context of organisational expectations (page 75). This was revealed, in the way in

which personal boundaries are managed and the quality and nature of support offered. Participants expressed frustration at the extent to which they could inform the way care was provided. It is perhaps in this area that evidence to support reflective capacity to recognise their own emotional experience and meaning was difficult to identify within narratives. This finding illuminated struggles participants might experience articulating or responding to their experience of distress. It is, however, important to acknowledge that context and the experience of holding conflicting positions in mind might contribute to this difficulty, regardless of capacity to be reflexive.

The concept of emotionality forms one facet of emotional intelligence (Heffernan et al, 2010) and includes an awareness of the emotional perception of self and others, capacity for emotional expression and empathy. Studies have found a correlation between emotional intelligence and self-compassion (Heffernan et al, 2010). Allowing oneself to try to understand or sense the experience of a person with ID is likely to lead to distress as this process may often occur in emotionally loaded settings and when a sense of vulnerability may be high. This perhaps provides further support for the advancement of opportunities for development of reflexive and reflective capacity for support workers with the aim of enhancing a sense of self, acknowledge distress and conflicting views, and engage in self-compassionate approaches.

Prompted by inquiry into how staff respond to their experience of distress led to Superordinate Theme 4: Management of distressing feelings (page 77), and sub themes of "managing reactions" and "taking responsibility". This yielded accounts of how participants might make sense of and respond to distressing feelings. These findings are now discussed within the concepts of altruism, responsibility and emotional contagion.

5.1.4 Giving meaning to experience and practice

It seemed that participants were motivated by altruistic values to persevere in trying to understand the inner worlds of people with ID. Altruism has been contextualised within philosophy (Lipps, 1907) and quantitative research (Batson et al, 1987) as a

feature of empathy. The drive to understand people with ID also seemed to be fostered by a deep sense of responsibility. Themes of responsibility permeated participants' accounts across all themes. Beliefs in, and feelings of, responsibility are reported to be powerful in leading people to respond to other's needs or in refusing to harm people. They can lead to helping even when circumstances do not focus responsibility on a person (Staub, 2013).

Staub (2013) argues that a responsible orientation may be fostered by vocational practices such as experienced by care providers. Consequently, this can lead to values that ascribe to helping others. The subtheme "managing reactions" described accounts of how participants may rationalise and compartmentalise their experience, perhaps to identify helpful ways of understanding and relating to people with ID. Cognitive patterns such as rationalisation may be underpinned by deep cognitive structures or schemas (Beck, 1976; Young & Rafaeli, 2011). Social mentality accounts of empathy suggest that "self-other" schemas develop to guide people to seek specific roles (Gilbert et al, 2006). Operations of mentalization in care-giving have been formed into three groups; insightful, one-sided and disengaged (Koren-Karie et al, 2002). Insightful interaction is thought to involve trying to understand experience as the person would see it and consider who they are, for example, a child. The care provider makes efforts to explore feelings and motivations from this position (Koren-Karie et al, 2002). Participant accounts suggested that perhaps care-giving mentalization may operate and illustrated a number of instances in which clients' vulnerabilities were identified by support workers and guided their understanding of them.

Considering what it might be like to experience impairments in cognitive functioning and ability to regulate emotions and behaviour, may also account for the possible concept of diffusion and perhaps conflicting accounts of client responsibility revealed within the analysis. It is hypothesised that perceiving people with ID as less able enabled support workers to make sense of experiences of challenging behaviour and the purpose of their role. Conversely, Psaila and Crowley (2006) have suggested that being treated as child-like may restrict opportunities for people with ID to experience reciprocal roles. This could, perhaps occur, when support workers adopt care-giving roles at the cost of recognizing client strengths and attributes. The

experience of taking on the responsibility of others yielded accounts of contradictory views, frustration and distress. However, a sense of responsibility appeared to provide a means to respond to negative affect. Couched in schema theory, diffusion of client responsibility could tentatively be interpreted as over-compensatory responses to maladaptive schema's that are underpinned by a sense of impaired autonomy and performance or other-directedness (Young & Rafaeli, 2011). Holding these ideas lightly, this perhaps further illuminate's potential vulnerabilities and needs that support workers might experience.

5.1.5 Responding to distressing feelings

The way in which support workers approach self-care is likely to be inextricably linked to experiences of relating and governed by personal resources, values and context. They appeared to use their sense of responsibility in the role to avoid expression of distressing feelings for fear of transferring negative affect, a process that has been termed emotional contagion (Scheler, 1973). Concerns about emotional contagion are prevalent in the subtheme "taking responsibility". IPA allows for the tentative abstraction and analysis of what may be hidden from participant awareness. Responses of intellectualisation and denial are arguably revealed within participant transcripts. This suggested use of intellect to avert acceptance of distressing experience. These responses may inhibit self-care. Germer (2009) has proposed that self-compassion requires a non-intellectual and accepting approach. He argues that experiences of isolation may evoke anxiety and prevent self-care. There is physiological evidence to support this theory and studies have suggested emotional systems cannot operate simultaneously. Threat focused systems that create anxiety as a means of protection prevent activation of the resource seeking and soothing (self-compassionate) systems (Gilbert, 2013). Thus, fear of transferring negative affect could lead to problems engaging with self-compassionate approaches. Participants limited expression of feelings are congruent with research findings that suggest men struggle to validate and communicate distressing affect, resulting in difficulties being compassionate towards self (Kingerlee, 2011). Analysis of accounts also suggests that the challenge of holding contradictory views in mind,

intrapersonal, interpersonal or organisational, further exacerbated this issue. The residential setting (context) in which support workers think or talk about their practice and wellbeing may, therefore, influence capacity to be self-compassionate, or at least narrative accounts of this phenomenon.

Neff et al (2007) has hypothesised the possible impact of self-compassion is maladaptive in, for example, the context of war situations. The notion of conflict is relevant to challenging behaviour settings and perhaps distressing feelings are minimised or managed through a process of inhibition. Inhibition of distressing affect may be perceived as useful to maintain professional conduct and could also be couched within a sense of responsibility and perhaps altruistic motivation. Hochschild (2003) hypothesised that care providers may believe it is not professional to experience negative feelings and that emotions should be managed instead of expressed. These perceptions may be complicated further by the influence of cultural, language and ethnic differences in the understanding and expression of language (Eid & Diener, 2001). Perhaps this signifies the extent to which context may influence how people understand and respond to their needs.

Interviews were held at the participants' place of work. Consequently, participants may have experienced political pressures to conform to a particular social model of a support worker as promoted within the culture of their organisation. Fear of being perceived as incompetent in this role has been identified in previous literature (Lloyd & Williams, 2003). Exploration of practice is likely to have illuminated differences in how participants believe they work and what they believe is expected. Situated within the context of exploring personal experience, this may have elicited anxiety. What was revealed in subtheme "managing reactions" were themes of contradiction in which experiences of stress were both acknowledged and denied. This might convey the dilemmas and challenges support worker's experience in expressing negative affect within the context of their role. Somewhat paradoxically, inhibition of distressing feelings may reduce opportunities to use emotional responses to interpret the feelings of people with ID.

It is understood that both external environmental and internal cognitive threats activate the threat focused system and release of cortisol (Gilbert, 2013). Inhibiting emotional expression might then also offer support workers a sense of personal

protection both in their interaction with professionals and with clients. This process may occur beyond awareness.

The findings from the present study have yielded psychological concepts that contribute to current understandings of empathy and self-compassion. Reflexive activity and context have been identified as key in facilitating these phenomena. Reflexivity is perhaps stunted by lack of opportunity to engage in reflective practice, and further mediated by managing conflicting understandings of clients, the support worker role and organisational demands. This is complicated further by the context of the workplace, and the way in which a deep sense of responsibility appears to drive support workers to accept accountability for the actions of people with ID. This might be with the aim of minimising the impact of interpersonal tensions or identify with perceived organisational values. Furthermore, accounts suggested reluctance or confusion in the expression of upsetting feelings, perhaps as a result of concerns of emotional contagion. Physiology may also influence capacity for self-soothing. These notions influence the acknowledgement of distress and engagement in self-compassionate approaches.

5.2 Reflections on bringing the research together

The final stage of the analysis was perhaps the most challenging. Following multiple drafts, I felt confused when trying to discuss the core concepts that had emerged. In depth discussion with my research supervisor guided me to realise that at times I was focusing perhaps too heavily on findings and methods of relating in contrast to meaning, and how illumination of interesting concepts does not need to be couched within quantitative paradigms. Subsequently I was able to stand back and think about the data in a different, more tentative and open manner.

I reflected on how much of my early clinical work was underpinned by positivist approaches to research and practice and that perhaps this was making it difficult for me to understand and work within a more phenomenological framework. I also realised I had become overwhelmed by the process of writing up the thesis. Ironically during the final phase of the analysis I appeared to again to have struggled with being self-compassionate. This perhaps further elucidates how values and context

might influence how we relate to ourselves and make sense of uncomfortable experiences. The dilemmas of holding contrasting views in mind for example, working within the parameters of academic writing and attempting to do justice to participants' and their accounts, seemed to have made it difficult for me to pause and allow myself time to process the experience and act on what might be helpful for me. Nonetheless, with gentle guidance and a focus on meaning and sense-making, I was able to modestly transform themes into a narrative account. This was largely influenced by accepting that I could only get "experience close". Additionally, that extracts did not represent a concrete reality that would consistently validate a property or structure of the phenomena of empathy and self-compassion.

The psychological concepts discussed in this section will now be considered within the context of the study design and potential flaws in the research process.

5.3 Assessment of evaluation criteria

This study has yielded some interesting and useful findings in relation to the research questions. However, these need to be thought about in the context of the design of the research. Qualitative research requires assessment to demonstrate validity (Smith, 2011; Yardley, (2000). This can be accomplished through assessment of key evaluation criteria including sensitivity to context, commitment and rigour, coherence and transparency and impact and importance (Yardley, 2000).

Sensitivity to Context

I have provided a comprehensive literature review in which to situate current knowledge and practice pertinent to understanding empathy and self-compassion, people with ID, support workers and clinical practice. I have considered the nature and role of policy and clinical theories, and identified social pressures, such as relational tensions with people with ID, and organisational protocols that may influence the way support workers make sense of their role, construct their experience of empathy and respond to distress. The challenging work context and its impact on well-being is echoed in previous research (Hastings, 2002; Burns, 2005;

Lobban, 2007; Howard et al, 2009; Jenkins, 1997). Furthermore, I have reflected on my relationship with participants and implications for the way emergent themes were constructed. For example, a possible difference in power differential, and my flow of questioning. These ideas are explored further in the following section (5.2.1).

Commitment and Rigour

The process of writing this thesis has resulted in a period of prolonged engagement with the research material. The completion of multiple drafts, on-going literature reviews and engagement in research supervision has enabled me to revise my interpretation of the emergent themes and their meanings. Perhaps most significantly, in my understanding of my role in the research process. In an attempt to obtain meaningful and relevant data, careful thought was applied to the criteria for sample inclusion. This included ensuring maximum coverage of work features that increase the likelihood of emotional contact with clients (specification of role and duration of employment) and contexts which might elicit a need for emotional expression (work setting and responsibilities). However, in using these inclusion criteria the age range was quite large and differences in life experiences were not considered in any great depth. Moreover, the sample obtained was predominantly white British, and cultural differences were not explored, illustrating a limitation to this research.

In efforts to safeguard a rigorous and focussed approach to analysis, I always went back to the research questions and tried to work within the parameters laid out in the IPA method. Identified themes were compared to existing literature to ensure relevance to the phenomena either in extension of existing theory or findings, or acquisition of knowledge that enhances current understanding. The role of context and integration of cognitive and phenomenological accounts of empathy has helped to interpret accounts of a myriad of tensions and spot light the depth and range of empathic practice

Coherence and Transparency

The phenomenological and hermeneutic epistemology that underpins IPA methodology has enabled descriptive, linguistic and conceptual explication of accounts of empathy and how support workers seem to construct their vulnerabilities and responses to them. Themes revealed contribute to an evolving qualitative research base. Interpreting accounts from these perspectives has illuminated useful insights into the complexities of relational and emotional experiences in ID settings. Furthermore, how constructions of these experiences might enhance or inhibit empathic practice and self-compassion, for example how holding multiple conflicting ideas in mind and fear of emotional contagion may restrict empathic practice.

I have endeavoured to be open about my role in the research, and outlined how I understand my contributions and thinking in various reflective accounts throughout the thesis. A pivotal aspect of the process was the interview phase. I recognise that my approach developed as the research progressed. The experience of the pilot interview was significant in a number of ways. Firstly, it assisted me in recognising the importance of openness and freedom in the way participants' articulated accounts of their experience, secondly to be mindful and considerate of what is said, and thirdly in the impact of complex terminology impinging engagement.

The pilot interview yielded a number of relevant themes pertinent to inquiry that were useful to include in the final analysis. A shift in rigid questioning to framing interviews within the context of empathy and self-compassion, perhaps led to more rich, autonomous participant accounts, but may have omitted opportunity to focus on and unpack nuanced elements of experience. I also found that empathising with personal struggles revealed during interviews, at times reduced my capacity to encourage reporting of deeper and more conceptual accounts. I believe this to be linked with concerns of eliciting distress. In light of this, in 5.3.1, I have accounted for how some themes associated with managing distressing feelings might have been shaped by my awareness of cultural expectations and personal experience of support work.

I experienced fluctuation in participant engagement and focus. When participants appeared to struggle, it was helpful to focus back on their earlier narratives in attempts to both direct the interviews, and foster opportunity to construct more complete

accounts of experience and their meanings. Increasingly I found a need to be sensitive to material that was perhaps not clearly linked to the research question, but for participants seemed to be congruent with the context of the interview. It was necessary to provide gentle prompts, but time for participants to discuss aspects of their lives. Post interview, all participants declined support to access local counselling services. Perhaps this further exemplifies the sense of resilience that support workers experience in their role, and possible difficulties in expressing vulnerabilities.

Impact and Importance

The acquisition of qualitative knowledge of empathy and self-compassion has a number of implications. Firstly, it provides an evidence base to critique empathic practice and self-compassion in ID settings and explore these concepts in relation to clinical models and frameworks that inform service provision. Secondly evaluation of these concepts has potential for systemic interventions within care settings and at the level of delivery and thirdly psychological concepts that emerged from the analysis can be situated within counselling psychology practice and high light practitioner competencies that are well suited to working in this area. For example, promoting reflective practice to examine confusion and tensions, and theoretical critique and integration to guide implementation of complex clinical models.

Overall evaluation of key criteria suggests sensitive, transparent and in depth engagement in the research process. However, limitations are acknowledged in the evolving nature of interview techniques, the researcher – participant relationship and in the orientation of participants to the research focus. In relation to this, identified concepts and ideas are extrapolated further in the reflective comments that follow.

5.3.1 Methodological Considerations and Reflective Comments

Further to the assessment of evaluation criteria, in this section the following areas are discussed: 1. IPA methodology and researcher experience; 2. participant

capacity for reflection and understanding of language; 3. the interviewer – participant relationship and 4. the researcher's values and beliefs.

IPA methodology offers interpretation of accounts of experience and cannot claim to identify a tangible construct of a phenomenon. Thus theoretical generalizability needs to be taken cautiously. Empathy is a complex, multi-faceted phenomenon with a rich history in a variety of disciplines. The present study offers one interpretation of possible understandings of accounts of empathy within a particular discipline, context and homogenous group, in this case, male support workers. Inclusion of men and/or woman may have resulted in different patterns of interpretation and analysis.

My limited research skills and novice application of IPA will have played a part in the construction of knowledge. This is relevant in: 1. my expectations of participant knowledge and capacity for communication; 2. my choice of questions and 3. My approach in interviews to guide participants and prompt elaboration of their reported experience.

Potter and Hepburn (2005) reported how researchers can place unreasonable demands on participants by assuming they are able to know and communicate details of their practice within psychological frameworks. It became apparent that participants seemed to struggle to articulate complex facets of their emotional experience and to reflect on situated moments of empathy and self-compassion. Variable reflective capacity or a sense of vulnerability may have restricted accounts of embodied sensations and access to the meaning participants gave to their experiences. This was evident in my struggle to identify and examine accounts of distress and how this related to the direction of self –care. I, perhaps naively, thought that most participants would have reflexive experience and feel comfortable to be reflective in an interview setting.

Exploration of empathy and self-compassion also seemed to pose difficulties for participants in their use of language to convey experience. This is not something I originally considered in much depth. I drew on my experiences of support worker training believing this would be practicable and reliable enough to inform the research design. There was a sense that participants would struggle to bring about the words required to describe their experiences. Studies have suggested linguistic resources and cognitive language play a part in how participants articulate their

perceptions, opinions, beliefs and attitudes (Henderson, 1991). In retrospect, I believe my fore-understandings Heideggar (1962) could have disproportionately directed the language used in my schedule, the nature of prompts and overly broad use of psychological terms.

This issue was exacerbated further with participants whose first language was not English, (n=2). I recall incidents of impasse typified by prolonged looks and a feeling of being stuck, as if participants were seeking guidance or direction. Language can construct, transform and symbolise the meaning of shared intersubjective experience. Problems finding words or understanding language due to cultural and ethnic differences impacted on both my experience of the researcher participant rapport and the construction and understanding of our experience. This issue is complicated further by the degree to which language can be understood as representational of subjective experience (Willig, 2008).

Particular words used by the participants, such as "stress" may be interpreted or understood incorrectly when context and issues of cognitive language are not considered (Potter & Hepburn, 2005). Despite these challenges, moments of impasse enabled me to explore my intrapersonal experience. The interpretative struggles and leaps of imagination that can lead to a sense of shared understanding and authentic connection sometimes only occurred within these contexts. What became apparent was how close I felt to accounts of confusion and connection with a felt sense of deep responsibility. I contemplated whether, at times, I experienced an almost cathartic encounter living through past experiences and reinforcing my beliefs and ideas that services struggle to facilitate effective interpersonal support, and that support workers are emotionally robust. This is likely to have had an impact on the way in which I constructed interviews and sought to elaborate particular facets of experience. I questioned whether I was looking to affirm my own knowledge rather than explore phenomena that may arise from the research.

I have reflected on the researcher – participant relationship and considered how participants might have felt uncomfortable discussing aspects of their role and emotional resources in the context in which they worked. Political pressures and power dynamics (given my possible perceived professional role) may have foreclosed openness and willingness to divulge personal and professional

experiences. Conducting interviews at participants' place of work perhaps was practicable and facilitated recruitment. However, this may have increased the political and personal pressures that participants might have experienced in being with me. It is possible that reflection on intimate experiences of relating, emotions and sense of identity created anxiety. Theorists have argued that a sense of safety is important when making decisions and judging the nature of interactions (Gilbert, 1989). In response to particular questions, feelings or thoughts, participants may have felt reluctant or conflicted in their engagement with me. Additionally, they could have been complexities in how participants understood their identity as a support worker and what they believed was appropriate to share. Membership categorisation, for example, institutional identity, has been recognised to influence how people position themselves within the area of inquiry and articulate their experience (Baker, 2001). It is conceivable that participants could have been concerned about what the outcome of the encounter might mean for them, and for the service more broadly. These issues might have influenced narratives provided, particularly around experiences of vulnerability and any steps taken to address negative feelings and other tensions.

Upon re-reading the transcripts I have noticed how much impact the researcher – participant relationship had on my interview approach. When I experienced increased congruence, or felt in some way connected to what the participant was saying I experienced, a more natural flow of engagement and exploration. In contrast, when I had a sense of distance or dominance, I was less likely to clarify what the person was saying. When interviewing one of the participants, I had a sense that he positioned himself implicitly as experienced and knowledgeable in his field. At times he appeared distracted and almost bored. I experienced the interview as uncomfortable and felt tension. This led to somewhat clumsy exploration of interpersonal and intrapersonal themes and, perhaps, compliance in the types of narratives offered. I think at times the participant may have also experienced a sense of discomfort and, at the end of the interview, his feedback was, "it was okay" but "good to chat". Although emotional topics and themes appeared to be restricted, he was, nonetheless, able to offer a number of rich examples that helped to illustrate how his experience of feelings, both positive and negative permeated his role in his understanding of his relationships and emotional experience with clients. Perhaps,

this illuminates the challenges of holding contradictory views and experience. I was unable to identify these important themes until the analytical phase of the research. This might suggest how my experience of feeling disempowered inhibited my ability to notice meaningful and sensitive efforts to communicate experience. Perhaps this dynamic is experienced when supporting people with ID and challenging behaviour, for example, in the context of feeling disempowered or uncertain. My preconceptions of how I think support workers may deny or withhold their feelings perhaps impaired my ability to capture a sense of human fragility and emotional insight.

Finally, my pre-conceptions are likely to have influenced my analysis, such as my attention being drawn to certain aspects of transcriptions based on my lived experiences. This was both useful and confusing, perhaps mirroring identified dilemmas situated within accounts. I sought to use my knowledge and experience to inform the design of the research but, equally, I did not want my beliefs to distort, limit or restrict rich data. This dilemma can be illustrated by my views (borne from experience) that quantitative and scientific approaches to evaluating client progression can, at times, lead to focussing on challenging behaviour and rigid practices. Perhaps I failed to notice positive experiences or support available within positivist domains. In retrospect, I think often I failed to manage these dichotomous elements with the fore-sight and grace required. This was evident not only in my experience of interviews but also my reflections of the analysis. For example, my struggles in identifying subtle facets of self-compassion in the knowledge that this is an area I myself have found difficult to engage with in care settings. Analytic observations can lead to under-analysis of material when elements of text or talk are not considered (Potter & Hepburn, 2005).

I am also aware of how my judgements informed the way I presented myself to participants and had to cautiously monitor these feelings during analytical phases of the research. At times, I noticed myself drifting and feeling annoyed when material did not initially seem compatible with my inquiries. These thoughts and feelings were, however, useful in subsequent interpretations of data. For example, it appeared some participants spoke in a more monotone tone when discussing guidelines, procedures and policies. Perhaps this illustrated their lack of interest or

thinking about the nature of interpersonal transactions as routine and with reduced emotional validation and expression.

In consideration of what can be interpreted from the data set, and in light of limitations in the research design, recommendations for future research will now be outlined.

5.4 Recommendations for future research

These findings provide a foundation for further investigative work, potentially in the following areas:

- Given the homogenous sample and unique setting, it may be useful to explore accounts of experiences of empathy and self-compassion with other groups and in different settings to investigate how different cultures and contexts may influence understanding and practice. This might include the use of both male and female participants and inquiry into the experiences of empathy in family systems and contexts. Additional settings could include respite services in which the amount of time and contact with clients is significantly less than in residential care. There is also scope to consider the impact of age and ethnic origin in relation to life experiences, and how this may influence how people construct accounts of empathy and self-compassion.

- Accounts of responsibility permeated participant accounts and may conceivably result in diffusion of the perceived responsibility of people with ID. In light of current person focused key initiatives that promote independence and autonomy, such as Valuing People Now (DOH, 2009), perhaps this dichotomy warrants further investigation. A related area of inquiry might be examination of the correlation between perceptions of responsibility and capacity to be self-compassionate. Additionally, how ideas about self-compassion are understood and the impact of context in influencing willingness to express vulnerabilities.

- Future research might benefit from greater consideration of context in relation to the power dynamic between the researcher and participant. The location of interviews and participant understanding of the expertise and role of the researcher, and the research aims, requires sensitivity. Neutral locations and detailed explanation of the function of the research, and the role the researcher is playing within this process, may assist in achieving this.

- Focus on a specific quality or facet of empathy or self-compassion could permit the development of a more structured interview schedule. This is likely to be useful in maintaining participant focus, and perhaps increasing opportunities to unpack in detail relevant nuanced accounts of experience. An open approach to signs of struggle, and validation of possible discomfort might give participants and the researcher confidence to explore in greater detail emotional vulnerabilities. Exploration can be couched within the context and parameters of a more structured interview schedule, and its key focus areas. However, this should not restrict flexibility, which can facilitate the elaboration of important features of accounts.

- Mixed method approaches could allow for assessment of the prevalence of variables that may influence empathic practice and self-care. Examples might be length in relationships, verbal ability of clients and type of challenging behaviour. Variables could then be explored in more depth adopting a qualitative approach. This process of inquiry could unpack further underlying themes and meanings about particular qualities of the relationship that complement or constrain how support workers empathise with clients and with themselves. IPA might be useful in exploring these idiographic experiences. Discursive approaches (Willig, 2001) could be helpful in developing an understanding of the linguistic resources available to support workers and how their use of talk enhances or inhibits how they relate to people with ID, exercise reflexivity and ability to assert power within their roles. Future inquiry might benefit from working with participants to develop reflective skills that may assist them to articulate situated experiences and access in more depth thoughts and feelings. Additionally, prompts could be used, such as social

stories in which to facilitate perspective taking and alternative way of reflecting on experience (Haggerty et al, 2005).

Reflecting on my role in the construction of knowledge, I acknowledge a number of limitations in the themes that emerged from the analysis and ways in which future research might improve the validity of data. Whilst researcher beliefs and values are integral to the process of qualitative research, my lack of experience in the field and in the application of IPA methodology was likely to have influenced the analysis. Nevertheless, there are a number of potential implications for training, supervision and service delivery that can be proposed. It is hoped that epistemological congruence, quality evaluation processes and situating findings within the extant literature will enable meaning and value to be abstracted from participant accounts.

5.5 Study Significance and Clinical Implications

It could be suggested that there are a number of clinical implications that have emerged from this study. These can be usefully situated within counselling psychology values, theories and methodologies. In this section, the significance of what was revealed within participant accounts will be explored and framed within possible applied practice. Approaches have been developed with the objective to contribute to existing models of service provision. In particular, systems for support workers, specialist care frameworks and psychological training. Given that IPA research places emphasis on the identification of variability within accounts and that the sample size is relatively small, proposals should be viewed tentatively.

5.5.1 Training and Supervision

Seeking to understand human experience from a phenomenological perspective, wellbeing and potential underpins core values of counselling psychology practice (Strawbridge & Woolfe, 2010). Explication of accounts of role confusion, relational conflict and experiences of distress transpired providing scope for training and supervision for support workers. Systemic intervention can form part of the role of the counselling psychologist (Orlans, 2003) and is commensurate with practice

guidance outlined in the Learning Disabilities Services Stepped Care Approach High Intensity Interventions (DOH, 2008).

5.5.1.1 Training

Challenges managing dilemmas brought about by conflicting views is revealed within accounts. Support worker training could be offered with emphasis on examination of the ambiguous nature of the role and how best to understand it within the context of the organisation, current policy and government agendas. This may help to ameliorate role confusion. Exploration of interaction with people with ID and methods used to interpret and respond to a range of presentations could also be considered. This would involve discussion of the following key areas:

- The unique experiences of relating and how this converges with, or diverges from, organisational guidance, models of support or personal values.

- The impact that interactions with people with ID may have on thoughts, feelings and behaviour. For example, how holding contradictory views and feelings can present interpersonal and reflexive challenges and how this may enhance or inhibit support and self-care.

- Exploration of negative affect stimulated by thinking about or being with clients and development of a range of evidenced based strategies that may reduce distress and enhance self-soothing. Current strategies include schema recognition and behaviour experiments (Young & Rafaeli 2011), meditation, compassionate mind imagery, monitoring of cognitive patterns and compassionate writing (Gilbert, 2013). Consideration would be paid to the need for defences and management of negative affect. Storey et al. (2012) have theorised that interventions targeting defence mechanisms can be problematic. They advocate deepening understanding of why mechanisms are employed in order to identify and explore settings that can elicit distress.

- Present to support workers the possible identified methods that may be used to facilitate understanding of people with ID, for example, observation, relating without language and direct empathy. Collaboratively explore inclusion and expansion of these methods in practice. Consequently, facilitate groups to review these experiences, evaluate progress and address difficulties.

5.5.1.2 Mental Health Awareness Training

Additional training might involve mental health awareness to target concerns of emotional contagion, normalise distressing experience and explore negative stigma. This would be with the aim of promoting a less guarded emotional culture and increasing confidence in seeking help.

5.5.1.3 Mindfulness Based Groups

These interventions could be complemented by mindfulness groups (Kabat-Zinn, 2005) with the intention of improving reflective practice and reducing difficulties experienced in the management of stress. Approaches include teaching attentional strategies that can improve emotional regulation (Siegel, 2007). Mindfulness based approaches have been applied in care settings and found to be helpful in ameliorating conflict and strengthening the relationship (Singh et al, 2006).

5.5.2 Supervision

Supervision is a process believed to improve skills and enhance confidence (Wheeler & Richard, 2007). Models vary across settings ranging from review of behaviour measures to multi-dimensional reflection (Freshwater, 1999). Despite participant reflection being identified as important in enabling understanding of clients and clinical supervision being advocated by professional bodies (CQC, Supporting information and guidance: Supporting clinical supervision, 2013), limited reflective space was revealed within participant accounts. This suggests little or no access to supervision that enables support workers to evaluate and reformulate their

experiences. This is consistent with findings in a psychodynamic study conducted by Storey et al (2012), which also proposed inadequate opportunity to reflect, leading support workers to repress painful experience or displace them into the organisation.

Psychological consultation and modelling in which to develop reflective and guided discovery focussed supervision or groups (Freshwater, 1999) may offer an appropriate space for support workers to explore relational and emotional struggles and signpost self-care. Reflection requires attention to experience. This process is thought to underpin self-compassion and facilitate "care" rather than "cure" (Germer, 2009, p.33). Integration of bespoke self-reporting tools or administration of the self-compassion scale (Neff, 2003) could be trialled as an additional means to prompt reflection of experience and monitor change. Supervision or reflective groups could also be offered to senior staff and registered managers. This might be important in order to support how managers empathise with support workers and with the emotional complexities of challenges encountered. Support workers' projections may lead to powerful feelings that could be difficult to understand and contain. Adopting compassion and understanding in the way supervision is offered and the way supervisees care for themselves is likely to encourage empathy. Research has indicated that children who are exposed to kindness, nurturing and compassion (including boundaries) during their development are more likely to display empathic tendencies in adulthood (Gilbert, 2013). Perhaps compassionate values and approaches within supervision, training and service culture can, at some level, elicit a similar outcome.

5.5.3 Service Systems, Models & Clinical Frameworks

There are tentative implications for the development of service systems, policies and advocated approaches to service provision. These recommendations could work towards enhancement of both the practice and wellbeing of support workers, and promote congruence within their relationships with clients.

5.5.3.1 Service Systems

Organisational policies outline principles to guide practice (Policy and Procedures Resource Manual, 1998). Development of policies and procedures to facilitate staff support groups could promote wellbeing and reinforce concepts that emotional distress is not necessarily pathological and does not need to be experienced in isolation. Sharing, examining and being with people that experience the same struggles are thought to be meaningful in the processing and management of distressing experience and reducing a sense of shame (Greenberg et al, 2008). Additional groups or activities in which support workers and people with ID are able to discuss together (where this is possible, ethical and appropriate) their shared experiences could facilitate increased openness and identify areas of difficulty that may enhance or impair rapport and trust. Neff (2003) posits that connecting with others is a form of self-care thus interpersonal activities may orientate and foster self-compassionate thinking and experiences. Emotional dialogue could be encouraged to both normalise and model effective emotional regulation and social problem solving. This approach may foster reflective skills and perhaps elucidate intersubjective themes that could be examined within therapeutic groups consisting of both support workers and people with ID. In consideration of the way context informs the construction of knowledge and how we might apply our theories and ideas, experiential and shared learning may benefit both parties. A cautious and reflective approach would be required. This is necessary given the possibility that clients whose histories are upsetting may mirror those of support workers. Consequently, support workers may be subject to their own experiences of distress or exhibit secondary traumatic stress symptomology (STSD) (Figley, 1995b, p.7). Sparse STSD research has been conducted in ID settings.

Analysis of participant accounts suggested lack of dialogue between managers and senior staff and support workers. Specifically, themes of role confusion, difficulties balancing professional and personal practice and critiques of aspects of service provision were identified. Developing policies in which to improve open communication and share knowledge and experience may enhance professional working and enable support workers to access the information or support they need. Consequently, this might begin to ameliorate tensions that can influence the way support workers understand, negotiate and empathise with organisational aims and

people with ID. Potentially, it could improve focus on the relationship and foster self-confidence and morale. Interventions may provide means to foster relationships that are supportive, consistent and attuned which is believed to be fundamental to caring professions (Howe, 2000).

5.5.3.2 Service Models & Clinical Frameworks

Service models provide a framework that enables joint understanding between commissioners, professionals, service providers and people with ID about the nature and expectations of care provided. PBS[8] (PBS Coalition, 2015) is one such framework adopted in current practice. Integration of the significance of the support worker relationship within existing models of PBS could be emphasised and include the following:

- Emphasis on the human element in the way complex behavioural plans are implemented. Although types of social mediation may reinforce contingencies that can elicit and maintain challenging behaviour, it is perhaps important to remember that it is the person not the behaviour that is being supported; is it not human to have a difficult day?[9] Cooper (1967) has argued that it is important to distinguish between behaviour that has assessed contingencies or explainable biological processes and behaviour that occurs and is influenced between people. This is important as different presentations require different or more integrative approaches. Pitonyak (2002) offers a relational account of challenging behaviour and central to his theory is that all behaviour is meaningful. He suggests that the aim of intervention is to encourage support workers to listen to the function of difficult behaviours. This process may help to accept the mutality of the common human condition (Lovett, 1996). Concurrently, I agree that the process of listening and accepting the idea of the global nature of human fragility may guide support

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[8] Positive Behaviour Support (PBS) is a values led approach that is based on applied behavioural analysis and person focussed approaches. It uses data driven processes to inform practice (PBS Coalition, 2015).
[9] Positive Behaviour Support (PBS) is a values led approach that is based on applied behavioural analysis and person focussed approaches. It uses data driven processes to inform practice (PBS Coalition, 2015).

workers to understand, relate and support people with ID in a more compassionate and sensitive way.

- Facilitate a level of creative innovation based on personal and unique relational experiences, and the nature of the relationship. Freedom to be adaptive may allow for the growth of both people with ID and support workers. Complementary approaches such as person centred planning (DOH, 2001) advocate that provision of care for people with ID should be a continuous process of creative problem solving based on action to strive towards better outcomes (Towell & Sanderson, 2003). Elsewhere in the literature Mansell and Beadle–Brown (2003) have suggested that the full range of skills support workers possess are not always recognised or used. Experiences or approaches could feed into service planning.

- Attribute greater weight to the significance of the support worker, their qualities and how forming relational bonds can complement existing models of support, for example, person centred approaches such as active support. Person Centred Active Support (PCAS) forms part of the broader provision of Person Centred Planning for people with ID. PCAS provides a framework for support workers to follow with an emphasis on providing meaningful daily support and engagement and fostering autonomy and relationships, (Felce,1988).

Application of interventions could be enhanced by recognising the need for a range of support systems to be available to support workers, particularly within the domains of supervision, reflective practice and peer group support. In their critique of person centred planning in its strategic context, (Mansell & Beadle-Brown 2003) the authors express the importance of support for staff in the form of mentoring and informal support groups. Each clinical intervention or battery of interventions suggested would need to be considered in relation to the nature of the role of the support worker, service context, organisational philosophies, applied research, current best practice guidance and, most importantly, with respect to the individual needs and formulation of the person(s) with ID.

5.5.4 Utilising research findings to inform practice in the broader ID community

Liaison with local services, commissioners, ID networks and psychological conferences could assist in the dissemination of research findings and sharing of research ideas and proposed applied interventions. Distribution of psychological knowledge and theory and contribution to clinical practice are key aims of counselling psychology (Monk, 2003). It may advance how the provision of care for people with ID and challenging behaviour is approached and stimulate debate with regard to current frameworks and political views adopted within services. It has been recognised that counselling provision has historically been limited in ID populations (Burke, 2014) and that there is a need to promote access to mental health services.

5.5.5 Clinical Training in Counselling Psychology

Integration of complementary cognitive and psychodynamic theories may enhance existing understandings of empathy and self-compassion. This position sits well with the pluralistic philosophy and formulations that are a central tenet of counselling psychology (Strawbridge & Woolfe, 2010). Significant is the notion of the importance of the therapeutic relationship and, in particular, use of empathy, a key focus of this research. Numerous studies have indicated that a positive therapeutic alliance increases good outcomes (Gilbert & Leahy, 2010) and is related to the establishment of bonds (Bordin, 1979). Bonds can be formed by supporting clients to feel safe and understood, and empathy and compassion are thought to be fundamental to this process (Gilbert & Leahy, 2010).

The notions revealed in this study offer potential areas in which to advance counselling psychology training and practice including: 1. elaboration and exploration of the range and nature of barriers to empathy, compassion and self-compassion; 2. building on theories of empathy that are fluid, dynamic and contextual (Preston & de Waal, 2002); 3. extending understandings to comprise of theories of holding and reflection of the relationship (Britton, 1955); 4. highlight the significance of reflexivity and 5. examination of the role and context of cognitive and possible unconscious defences that may influence empathic practice and self-care.

5.5.6 Implications for counselling psychology practice

The discipline of counselling psychology enables intervention at a range of conceptual levels including primary (structure and systemic), secondary (training) and tertiary (counselling) (Palmer & Gyllensten, 2010). These levels can be thought about as a continuum, in which the proposed clinical recommendations span across the breadth of provision. Moreover, this research has revealed the context in which support workers relate to people with ID is likely to influence the way in which they empathise and engage in self-compassion. The bridging and pluralistic approach of counselling psychology, and openness to different traditions (Orlans, 2003), is well positioned to work with contexts and systems. Drawing on the proposed recommendations I will now expand further on specific features of counselling psychology that marry well with clinical provision in ID services.

It seemed time and space to identify and make sense of difficult relationships and feelings was limited. Reflective groups could be useful but require consideration of potential support worker vulnerabilities. Developing and maintaining an appropriate frame (Gray,1994) and validating the parameters of disclosure and nature of comment is likely to be helpful in maintaining a contained safe haven (Bowlby, 1979). Collaborative emotional exploration can then occur. This can be linked to therapeutic frames established in counselling therapy.

In addition to these challenges, it emerged that expression of feelings and help seeking was problematic. Counselling psychologists are well placed to provide psychological education on a range of mental health issues and draw on current literature to promote well-being (MIND, 2013) and self-compassion (Gilbert, 2013; Neff, 2011).

Although training may be helpful, the challenging work context experienced by support workers and managers may restrict capacity to empathise with the standpoint of others, notice emotional dimensions of events and situations, and address consequent complexities. Sparse opportunities to examine these difficulties were reported. The provision of clinical supervision by reflective practitioners can assist reflective practice in these areas (Scaife, 2010). Reflective practice is a core quality of counselling psychologists, along with emotional resilience and skills in conflict resolution and mediation (Palmer & Gyllensten, 2010). These qualities are

likely to aid the management of emergent tensions within groups, in the provision of clinical supervision and engagement with service providers. Moreover, principles of cognitive behavioural theory are likely to be useful in the exploration of patterns of thinking, and how this may lead to conflicting ideas when self-beliefs and service or client values are contradictory. The model provides scope to explore perspective taking and work towards ameliorating interpersonal tensions.

Primary level intervention with service providers is believed to have more enduring impact than other interventions, particularly in relation to long term management of stress (Cartwright & Cooper, 2005). This would suggest evaluation and modification of systems that underpin staff support and practice might be significant in enhancing empathic practice and self-compassionate approaches. This requires an evidence based approach. Evidence based practice is a framework advocated to guide psychological assessment, treatment and intervention (Corrie, 2010) This is likely to assist with the analysis of existing systemic interventions. A number of theoretical skills can also be applied.

Counselling psychologists are adept at comparing, contrasting, critiquing and integrating theory (Gilbert & Orlans, 2010). This provides a strong foundation to evaluate multiple models that inform service delivery and identify connections between them. For example, elements such as autonomy, holistic perspectives and lived experience, associated with humanistic therapy (Rogers, 1980) can be situated within key principles and values of person centred frameworks such as PCP (Magito-Mclaughlin, 2002). Systemic theory (Stanton & Welsh, 2012) can be utilised to evaluate organisational functioning such as observing patterns and trends and the interaction between them (Capra, 1996). Recent research supports the idea that a sense of "felt" security can be experienced in the interaction between varying levels of service provision. Providing a safe haven and fostering an empathic approach with managerial teams, can transfer empathic values to support workers, promoting empathic engagement with clients (Collins, 2015).

5.6 Conclusion

The aim of this research study was to explore how male support workers interpret working with people with ID and what meanings these experiences of interpretation or relating hold for them. It was considered how support workers respond to their experience of distress. Although not specifically testing theories of empathy, adopting IPA methodology the present study offers a modest nuanced contribution to existing understandings of empathy and self –compassion. This new knowledge builds on existing theories that hold that empathy may be a dynamic, transient process involving a process of object internalisation that is influenced by reflexivity, values and context. Analytical findings elucidate a range of possible empirical and experiential modes of understanding and relating. The way in which support workers understand and respond to their experience of distress was explored. Accounts of difficulties in the identification of perceived roles and values, distressing relationships and validating emotional experience were revealed. Often, these appeared to be couched within dilemmas in experiencing contradictory views and what they might mean. It is hypothesised that underpinning these struggles is an undercurrent of deep responsibility and thoughts and actions associated with feelings of threat, anxiety and isolation. These dilemmas were perhaps compounded by practices that limited reflection or were not resourced to offer reflective space and supervision. What was also revealed was how the notion of holding contradictory views and experiences in mind could influence expression of, or capacity for, self-care. Emergent themes of contradiction and confusion perhaps echo the elusive and evasive nature of empathy and self-compassion.

There are limitations in the construction of knowledge. These include use of a homogenous group, my limited research experience, possible participant struggles with reflexivity and articulation of experience and, possibly, participant defences in response to the context in which the research interviews were conducted. Despite these concerns, I believe research findings inform the basis of a range of interventions that can be connected with and situated within existing theory, evidence based practice and related to a corpus of studies. I contend that the process and outcome of the research adheres to principles of the scientist – practitioner model. Emphasis has been on the synthesis of scientific theory and understandings and what these mean in relation to practice (Strawbridge & Woolfe,

2010). This may be helpful to project findings into the scientific community of applied psychology and lend itself to theoretical debate and practice based application.

5.7 A Final Word

My aim has been to produce a piece of applied work that could inform the way counselling psychology supports ID services. I believe that emphasis on positivist approaches to providing care to people with ID has disproportionately focussed on the weight of outcome measures and behaviour reduction. The value of natural science and quantitative evaluation is not disputed, rather, I am arguing that there is a lack in the validation of idiographic experience and values and how this informs the way in which people relate. I have sought to capture elements of how empathy and self-compassion might be understood and practiced through exploration of lived experiences of a range of relational encounters, beliefs and processes.

The research findings appear to elucidate the need for emotional support within a peer and supervisory capacity for people working in care settings. It may bode well to strive towards empowering support workers and people with ID by encouraging reflection and an awareness of the importance of relational bonds and the role we take within them. I now grasp the complexity of the phenomena of empathy and self-compassion and the modest contribution I can only try to present within the context of my research findings. However, I feel privileged in being able to offer something, albeit small and not without limitation that could be valuable and meaningful to others. Perhaps this illuminates both the strength and weakness of qualitative research and of my own understanding of both my competencies and fallibilities, an understanding of what it means to be human and to engage in a process of trying to explore humanity in others.

5.8 Reflections on the research journey

In writing up this research I have begun to realise the importance of process; knowledge is perhaps something that needs to be earned, effort is required to make sense of what we don't understand. This requires focus and attention on our

thoughts, feelings and the things we do to navigate and overcome these challenges. I understand now the value of process and interpretation in qualitative research and how particularly within IPA methodology this iterative approach is commensurate with its phenomenological and hermeneutic underpinnings. What has been significant for me is the sense that focus on individual sections of the write up felt fragmented and disjointed, yet this was required before I was able to understand the research and interpret its conclusions. I needed to make sense of and process the parts in order to see the whole. Emergent themes and meanings are perhaps most visible to me at this juncture, nearing the end of completion.

I have considered how these approaches and experiences mirror facets of the therapeutic process and notions of parallel processes (Doehrman, 1976). This concept seems to be infused within the research; struggles appear to be manifest in the experience between the objects of researcher and research, researcher and participant and participant (support worker) and client. I have learnt that the role and emotional experience of support workers is much more complex than I imagined and I did not expect to experience such a strong blend of loyalty, connection, compassion and annoyance towards participant narratives and accounts. This has led to the realisation that I dearly value working in ID settings, and provides incentive to continue to learn and grow as a practitioner within this field.

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APPENDICES

Appendix 1: Information Sheet for participants

<p style="text-align:center">PARTICIPANT INVITATION LETTER</p>

<p style="text-align:center">RESEARCH PARTICIPANT INVITATION LETTER</p>

<p style="text-align:center">UNIVERSITY OF EAST LONDON</p>

<p style="text-align:center">School of Psychology
Stratford Campus
Water Lane
London E15 4LZ</p>

The Researcher

Ben Renton

Email: benrenton@hotmail.com

       ben.renton@insightpartnership.org

<p style="text-align:center">Consent to Participate in a Research Study</p>

The purpose of this letter is to provide essential information to help you decide whether to participate in my research study. The study is being conducted as it forms part of my training on the Doctorate in Counselling Psychology, at the University of East London.

<p style="text-align:center">Research Project Title</p>

<p style="text-align:center">"Experiences of self-compassion and empathic practice in male staff supporting adults with intellectual disabilities and challenging behaviour"</p>

<p style="text-align:center">Research Summary</p>

There is growing research in the field of counselling psychology to try to understand processes that enable people to relate to each other and to develop caring relationships. Using an interpretative approach to analyse qualitative interview data this study seeks to explore the experiences of male care staff supporting adults with intellectual disabilities (ID) and challenging behaviour. Interviews will be carried out with male staff who work within challenging behaviour services with specific focus on the thoughts and feelings that have been experienced in interaction with vulnerable adults. There will also be exploration of how staff understand and respond to their feelings in their work setting. Research findings may help to better understand processes of "relating" to vulnerable adults who challenge services with implications for staff training and service development.

As a participant of this study, you will be asked to take part in a semi structured interview with the researcher. Interviews will last for approximately 1-1.5 hours and will be audio recorded for transcription.

If you experience discomfort/distress during or after the study, please do not hesitate to raise this and I can then provide you with further assistance and refer you to professional bodies like the UEL Health and Wellbeing services and/or Chaplaincy, and/or local services, for further help and support.

After the interview you will be offered time to talk about your experience of the interview and raise any concerns. You will be given verbal information on what will happen to your data.

Confidentiality of the Data

To ensure anonymity you will be provided with an Identification number (ID), this number should be kept as a reference. Personal details are not recorded for the purpose of the study; however, some essential information will need to be collected to ensure suitability for you to participate. However, if you choose to withdraw from the study, you are required to give your ID number to the researcher, so that you can be identified and so your data can be deleted.

Data will be kept safe in a password protected folder, where only the researcher can access it. Additionally, the ID number or/and your details will not be written anywhere on the final write up. Once the study is completed audio data will be deleted however electronic transcripts may be retained for 3 years in the event of developing the research further. The research study may be published.

Please note as part of my duty of care as a Counselling Psychologist in training any material discussed that eludes or explicitly refers to risk to your-self or others will be disclosed to your line manager or if required other relevant professional.

Participant Inclusion Criteria

The following criterion is required in order to participate in this study;

- You are male

- You are currently involved in a role in which you provide daily support to individuals who have been diagnosed with an intellectual disability (ID) and whom exhibit challenging behaviour (challenging behaviour can be defined as behaviours which significantly impact on opportunities to access the community and community based living settings and pose a risk of harm to the person or others)

- You will be involved in supporting people with ID in aspects of their personal care, domestic activities, personal skills development and community participation

- You will have been working in that role for a period of at least 6 months and for a maximum period of 24 months (*flexibility here*)

- You will not have worked in a care position before your current role (*flexibility here*)

- You are a full time contracted member of staff

- You will be available to participate in the study between July and November 2013 (to be revised as required)

Interviews

Interviews will be arranged at a time and location preferable to yourself, although guidance may be provided to avoid factors that may make participation difficult.

Disclaimer

It is not obligatory for you to take part in this study. You have the right to withdraw at any time either during or after, you have agreed to participate. No disadvantage will occur if you decide to withdraw and there is no obligation to provide a reason for your withdrawal. Any data that has been gained will be destroyed.

If you are able to participate then you will be asked to provide the signed consent below to your line manager, once this is provided you will be contacted to arrange a time and place for the interview and to ask any questions that you may have. Please retain this invitation letter for reference.

Thank you for your consideration.

Yours sincerely,

Ben Renton

Counselling Psychologist in training

Appendix 2: Participant Consent Forms

CONSENT FORM

(See pro forma in the ethics folder in the Psychology Noticeboard on UEL Plus. This should be adapted for use with parents/guardians and children.)

Research consent form

Research title: "Experiences of self-compassion and empathic practice in male staff supporting adults with intellectual disabilities and challenging behaviour"

Researcher details: Ben Renton Counselling Psychologist in training.

Student No. u1124704.

Institution: University of East London.

Participant:

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have read the Participant Invitation Letter (attached to this form) and understand the information that is included. I have had the opportunity to ask questions and have had them answered to my satisfaction. I am aware I can continue to ask questions throughout my involvement in the study and that I can withdraw at any stage of the research process. I understand that consent will be checked with me before, during and after the interview.

I understand that I will be offered time after the interview to discuss my experience and raise any concerns. I am aware that the researcher is bound by duty of care to disclose any information which alludes to risk to my-self or other people. I voluntarily agree to participate in this study. I am not giving up any legal rights by signing this form. I will be given a copy of this form**.**

_____   _____
Print name   **Signature**

                                                                           _____
                                                                           Date and time

Appendix 3: UEL Ethics Committee Approval Form

ETHICAL PRACTICE CHECKLIST (Professional Doctorates)

SUPERVISOR: Kendra Gilbert   **ASSESSOR:** Sharon Cahill

STUDENT: Ben Renton   **DATE (sent to assessor):** 09/05/2013

Proposed research topic: Experiences of self-compassion and empathic practice in male care staff supporting adults with intellectual disabilities and challenging behaviour

Course: Professional Doctorate in Counselling Psychology

1. Will free and informed consent of participants be obtained?   YES

2. If there is any deception is it justified?   NA

3. Will information obtained remain confidential?   YES

4. Will participants be made aware of their right to withdraw at any time?   YES

5. Will participants be adequately debriefed?   YES

6. If this study involves observation does it respect participants' privacy?   NA

7. If the proposal involves participants whose free and informed

   consent may be in question (e.g. for reasons of age, mental or

   emotional incapacity), are they treated ethically?   NA

8. Is procedure that might cause distress to participants ethical?   NA

9. If there are inducements to take part in the project is this ethical?   NA

10. If there are any other ethical issues involved, are they a problem?   NA

APPROVED

*YES

MINOR CONDITIONS:

*But can you add on participant letter that you may publish the material from the study

REASONS FOR NON APPROVAL:

Assessor initials: SC   Date: 20th May 2011

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

SUPERVISOR: Kendra Gilbert   **ASSESSOR:** Sharon Cahill

STUDENT: Ben Renton   **DATE (sent to assessor):** 09/05/2013

Proposed research topic: Experiences of self-compassion and empathic practice in male care staff supporting adults with intellectual disabilities and challenging behaviour

Course: Professional Doctorate in Counselling Psychology

Would the proposed project expose the <u>researcher</u> to any of the following kinds of hazard?

1   Emotional   YES

2.   Physical   NO

3.   Other   NO

         (E.g. health & safety issues)

If you've answered YES to any of the above, please estimate the chance of the researcher being harmed as: LOW

APPROVED

YES

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: **SC**   Date: 20th May 2013

For the attention of the assessor: Please return the completed checklists by e-mail to ethics.applications@uel.ac.uk within 1 week.

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.

UEL
University of
East London

www.uel.ac.uk

School of Psychology

Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966   fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk   web: www.uel.ac.uk/psychology

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The University of East London has campuses at London Docklands and Stratford
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853

POSITIVE ABOUT DISABLED PEOPLE

Appendix 4: UEL Research Registration Letter

Ben Renton
13 Carnation Crescent
Sittingbourne
Kent
ME10 4RY

Date: 29 July 2013

Student number: 1124704

Dear Ben,

Registration as a Candidate for the University's Research Degree

I am pleased to inform you that the Research Degrees Subcommittee on behalf of the University Quality and Standards Committee has registered you for the degree of Professional Doctorate.

Title of Professional Doctorate: Professional Doctorate in Counselling Psychology

Director of Studies: Kendra Gilbert

Supervisor/s: Amanda Roberts

Registered Thesis Title: Experiences of self-compassion and empathic practice in male care staff supporting adults with intellectual disabilities and challenging behaviour

Expected completion: According to your actual date of registration, which is **1 October 2012**, your registration period is as follows:

Minimum 33 months, maximum 60 months, according to a part time mode of study.

Your thesis is therefore due to be submitted between:

1 July 2015 – 1 October 2017

I wish all the best with your intended research degree programme. Please contact me if you have any further queries.

Yours sincerely,

Dr James J Walsh
School Research Degrees Leader
Direct line: 020 8223 4471
Email: j.j.walsh@uel.ac.uk

Cc: Kendra Gilbert, Amanda Roberts

Appendix 5: Interview Schedule

Interview Schedule

Draft interview questions

1. What is it like for you working in care settings?
2. How do you attempt to build a relationship with people with ID?
3. How does this process help you to understand the person's thoughts and feelings? (prompt for examples)
4. What helps you empathise with people with ID
5. What might influence this process? E.g. CB
6. How do you feel when trying to relate to vulnerable people?
7. What are you aware of?
8. What feelings do you experience in your work setting?
9. How do you respond to these feelings?
10. What do you think is the outcome of being aware and responsive to your thoughts and feelings in your work setting?
11. What is your understanding of self-compassion? (provide example if required, for example a way of caring for self and recognising, responding to your feelings)

Pilot interview questions

1. It has been argued that finding ways to try to understand how someone experiences their world can be helpful when interacting with people with ID and challenging behaviour. What do you think about this?

2. How do you attempt to understand the experience of people with ID?

3. How does this process help you to relate to the person? (prompt for examples)

4. What might influence this process?

5. How do you feel when trying to relate to vulnerable people?

6. What are you aware of?

7. What is your understanding of self-compassion? (provide examples if required, for example a way of caring for self and recognising and responding to your feelings)

8. What feelings do you experience in your work setting?

9. How do you respond to these feelings?

10. What do you think is the outcome of being aware and responsive to your thoughts and feelings in your work setting?

Final interview questions

1. What is it like for you working in a care setting?
2. What do you think about when you are interacting with people with ID?
3. How do you feel when trying to relate or interact?
4. How do you try to understand their thoughts and feelings/experiences?
5. What are you aware of, notice and feel in your body?
6. What feelings do you experience in your work setting?
7. How do you respond to these feelings?

Interviewer Notes

- ***Offer gentle prompts where needed, but allow for pauses***

- ***Notice body language and tone***

- ***Encourage elaboration***

- ***Adopt a curious and open attitude***

- ***Summarise***

- ***DO NOT INTERPRET***

Appendix 6: Example of Transcript Analysis

COMMENTS	LINE	TRANSCRIPT 7– P 7 MARK – EXPLORATORY ANALYSIS AND EMERGING THEMES	EMERGENT THEMES
TENSIONS IN ROLE VS ENJOYMENT IN ROLE	1	Ben: To begin it will probably be helpful if you could just give a broad	REFLECTIVE/MINDFUL
	2	description of what its like for you, has been like for you working in	
	3	care?	PERSONAL STANDARDS & VALUES
HIGH PREVALENCE OF EMOTION WORDS	4	Mark: Okay, well I started out in my position as a leading co-ordinator	
	5	erm, which essentially means I am responsible for running the shift,	
	6	erm medication, allocations first things, and I deal with petty cash.	
	7	Generally there can be a lot of stress that comes with that and it does	
	8	at times feel like I don't really get to work with and support as much as	
	9	I like the people I am working with and see them as much as I can.	
	10	(Pause). Erm and sometimes it feels like you can't be there erm as	
	11	much as you want to be and listening as much as you like you. That's	
	12	the kind of moan about that kind of position. The actual caring side is	
	13	erm a side which I have decided I enjoy very much and erm. (Pause). I	
	14	don't know if I can ever kind of leave that entirely, erm and especially	
	15	the kind of guys that I work with because basically they've taken to me	
	16	very well and I've taken to them very well, so its erm… yeah, its, its, its	
	17	been a surprise buts its nice that its happened.	
	18	Ben: Ahem	
	19	Mark: (Pause). Erm we have currently 11 men at the service varying in	
	20	terms of level of challenging behaviour and learning disabilities sort of	
	21	conditions that they have erm and it definitely takes a lot of skill to sort	

1

	22	of work from one person to the next, they're desperately different and	TENSION WITHIN RELATIONSHIP
	23	this can sort of be difficult to er change your skill set dependent on	
	24	who you are talking to, I'm sure I'm not the only person who has sort of	
	25	let themselves down by not changing their skill set and being stressed	
	26	with that one person and then carrying that over to the next person	
	27	and perhaps not dealing with the situation in the best way, but do try	
	28	really hard not to do that erm (pause) yeah. I don't know if there is	
	29	anything else that perhaps you wanted to hear?	
	30	Ben: I noticed that you mentioned it would be difficult to leave now	
	31	you've had the experience of working in care.	
SENSE OF CONFUSION INTERPRETING CLIENTS THOUGHTS	32	Mark: Yeah, (pause) especially, I mean mostly because I've created	
	33	quite a strong bond with erm all of the guys there really, some more	
	34	than others, some sort of its, some of the guys there it would be hard	INTERPRETATION IS CONFUSING
HUMOUR	35	to know if they liked you or not, sometimes (laughs) erm but erm I	
	36	would like to consider myself somebody that has tried their hardest	
	37	erm especially to facilitate the guys with things they want or need erm	
EVAULATING CHALLENGES	38	and I think they see me as someone who does do things for them and	
	39	erm not do things for them such as do everything for them all the time	
	40	but you know facilitate them with the things that they erm deem	
RELATIONSHIP- BOND	41	important erm..	
	42	Ben: Uhem	

BEING PULLED IN BY OTHERS UNCONSCIOUS DYNAMICS OR PROCESS?	43 44 45 46	Mark: …and so that when I am there, theres a number of names and faces who tend to gravitate towards me (laughs) which can be stressful when you're trying to do petty cash and things like that but erm yeah I have definitely created a strong bond with some of the guys	ATTACHMENT & SEPARATION
	47 48 49	and erm it would be really difficult to, I've spoken to my wife funnily enough who occasionally has thoughts about moving to Australia and erm somewhere hot because she gets fed up with the weather here	
SEEM AS VALUED BY OTHERS	50 51	but you know found myself saying, you know I don't know if I could (laughs) erm which is erm opened my eyes massively because after	
ATTACHMENT: STRUGGLE TO LEAVE	52 53	only a year there that's, its frightening to find I am now tied down (laughs) and I won't be able to leave! Erm	
	54	Ben: Frightening	
ATTACHMENT: UNDERSTANDING AND KNOWING- THESE TAKE TIME	55 56 57	Mark: Yeah (laughs boldly) well not frightening (pause) not frightening so much as I didn't think I would end up getting that much attached yeah.	
	58 59	Ben: Can you talk to me a bit about what you mean by the attachment by the bonds?	
	60 61	Mark: Erm (clears throat) yeah I think that when you spend time, a lot of time with anyone you end up getting to know that person,	
	62 63	understanding, I think that for erm, especially in the setting that they're in, in that they live in, it can be difficult to know that they are always	

STANDARDS	64	being looked after, thought about enough and cared for enough and
	65	sometimes it does cross my mind that perhaps they do get neglected
INTRINSIC VALUES – DESIRE TO CARE FOR OTHERS	66	and that worries me a bit so I think I can't let that go on without...well I	HOLDING PEOPLE IN MIND
	67	think that it creeps into your mind that are they always being sort of
	68	thought about enough and are people taking the time to do things like
MINDFUL OF CLIENTS NEEDS	69	brushing their teeth, not always for them but you know encouraging
	70	them to do so, especially those who don't necessarily have the
	71	capacity to understand why they've got to do those things erm, and
	72	they're easily missed erm and then you worry do the carers even
SEEKING TO UNDERSTAND	73	brush their own teeth let alone erm encourage them to do it when erm
	74	they would rather be taking toil or be getting home early or sitting and
	75	watching tele (light laugh) erm
COMPASSIONATE	76	Ben: Umm, can you think of an example that kind of thought went
	77	through your mind?
	78	Mark: Last night, yeah I mean it was a bit (more rapid speech) a bit on
	79	shift yesterday, we were a bit short staffed and it was, well we were
	80	very short staffed and there were lots of people sharing and erm
	81	clients which would always be shared and when that happens there is
	82	a lot to do for that one carer. Erm and so you know you are bound to
	83	think where I can fit this all in? Where can I cut corners? Erm and
	84	there are certain staff members who would if they weren't prompted,

PROBLEMS – "CREEP" SOMETHING SINISTER OR HIDDEN? AVERSIVE WORK CULTURE	85	guided or instructed you know can you please do that now before they	INTRAPERSONAL TENSION
	86	go to bed or whenever erm, that doesn't mean to say that happens but	
	87	I do worry about it quite regularly and so you know I constantly	
	88	mention it to people (laughs) and they probably don't like me for it but	
	89	that's just what happens (voice becomes quiet) yeah. **THINKING?**	
	90	Ben: I wonder where that worry comes from? why it's a regular worry?	
	91	Mark: We've had erm a number of people at the moment at the dentist	
BEING PULLED IN TO HELP? IS PARTICIPANT AWARE OF THIS? IS IT A CHOICE?	92	that has sort of highlighted problems but its not only oral hygiene, it	
	93	could be anything, I've noticed one of our guys he's got psoriasis on	
	94	his erm well numerous places all over his body and you know there	
	95	are days that I notice it is particularly dry erm this particular person	
	96	does like to bath a lot and this tends to dry it out but he does have a	
CARING & COMPASSIONATE VALUES	97	whole cupboard of moisturising cream that could easily be applied ten	
	98	times a day and his skin would never look dry, erm but yeah I find	
	99	myself when I'm not working with him spending five minutes with him	
	100	putting his cream on, and when I am working with him making a point	
	101	of doing it numerous times and you know its not always easy to point	
	102	your finger when you've not been there but when you notice those	
	103	things start to creep in and people not doing what they should be and	
	104	not taking the time to care, you know its basic things, its very basic	
	105	things you know we do in this service erm and these guys their time is	

HIGH STANDARDS	106	not always taken up with work and you know on the whole they have	
	107	time to do these things, they should be doing it right (pause) yeah,	
VALUES – DIFFERENCES IN VALUES	108	those sort of things do bug me a bit I spose. So they are basic human	
	109	conditions that we should all have. I spose I've noticed that I have not	
	110	verbalised all that before to anyone.	
REFLECTING ON EXPERIENCE	111	Ben: How do you make sense of that, that you've verbalised it today?	REFLECTIVITY
	112	Mark: Well its always a feeling that goes in my head about telling them	
LIMITED OPPORTUNITY FOR EMOTIONAL EXPRESSION?	113	have they done that erm, but I'm only really just sort of realising now	
	114	how big a part that sort of plays… now that I am telling you about how	
LIMITED OPPORTUNITY TO DISCUSS FEELINGS, RELATIONSHIPS	115	I think about it I spose.	
	116	Ben: Hmm, are there certain feelings that go along with that as well?	INTERPERSONAL & INTRAPERSONAL TENSIONS
	117	Mark: Um, yeah I spose worries about what if it doesn't happen and	
	118	what if it continues not to happen..my erm key client has the capacity	
	119	to understand near enough anything erm he has Aspergers and he	
FEELINGS IN HEAD – THOUGHTS OF EMOTIONS?	120	finds certain things difficult, you know empathy is near enough a	
	121	completely foreign concept to him erm, so he can very well brush his	
	122	own teeth and he knows that he should but he still needs reminding	
	123	because he likes to do other things, he doesn't want to do it. Erm and	
	124	so its not just that its shaving its bathing its everything and its very	
	125	difficult to get him to do it and so you know for some of the other guys	
	126	who can't physically do it themselves you know they need the support?	

FRUSTRATION	127	Ben: And how you do respond to those feelings?	
	128	Mark: Normally I will go and ask them if they have and I'll probably ask	
	129	the service user as well, "have you done it?", and actually most of	
SOCIETY VALUES VS INDIVIDUAL VALUES	130	them are surprising very honest about telling you if they have done it,	INTRAPERSONAL TENSIONS
	131	you know they know they're supposed to do them but they will still sort	
CONGRUENCE EXPERIENCED IN INTERVIEW	132	of tell you, "no I have not done this", (joint laugh) which is fantastic as	
	133	you have a fail safe, erm a floorless system where you ask the person	
	134	who is working with them "can you do it" and then you ask the service	
LAUGHING TOGETHER – WHAT IS THE IMPACT OF THIS ON ANALYSIS?	135	user "have they done it", yeah erm	
	136	Ben: And I heard you mention a bit about your key client there and I	
	137	wondered if you could tell me a bit about your relationship with the	
	138	client?	
	139	Mark: Yeah his 23 and has aspergers, he has a mild learning disability	
TENSIONS	140	and he fixates on certain things or he obsesses about certain things at	
	141	certain time and they tend to sort of change gradually. Because of his	
	142	aspergers he lacks empathy massively to the point at which	
	143	sometimes its extremely frustrated when you are trying to convince	
ARGUE ON BEHALF OF CLIENT? ADVOCATING	144	him to do something, which to be fair is normally something society	
	145	deems appropriate for a way he should act. He finds it so very difficult	
PROJECTION?	146	to act in that way, in his words he doesn't understand why he needs to	
	147	do that. He does on occasion really try to do things that fall within the	

CULTURAL VALUES & IDEAS	148	lines of social acceptability but erm because he doesn't understand the	
CLIENT AUTONOMY	149	reasons why and I don't necessary think he has the capability to	REFLEXIVITY
	150	understand why theres room for learning it, for him I think it would be	
OPENED EYES- GROWTH & LEARNING	151	mimicking, I don't think it would be understanding. I might be wrong,	
	152	could be completely wrong but erm I think working with him closely for	
REFLEXIVITY	153	the past year has really opened my eyes to how sort of our relationship	
	154	tends to be, he does value our relationship but it tends to be what he	MANAGEMENT OF DISTRESSING FEELINGS
TENSIONS IN MEETING NEEDS OR SUPPORTING CLIENT GOALS	155	wants not necessary what M needs. Now that's quite hard to, because	
	156	for me I focus on M's needs but for M he focuses on what he wants	
	157	and actually you know what it comes to do is that its not his needs that	
	158	come into play at all, which is how I erm sort of cope with it really	
	159	because I have everybody else trying to, not putting pressure on me	HOLDING PEOPLE IN MIND- E EMPATHY?
	160	but hoping that M strives and reaches his goals but actually M doesn't	
COPING WITH INTERPERSONAL CONFLICT – ACCEPTANCE	161	want a lot of things and actually he wants to play with his games and	
	162	can I facilitate that for him.. so yeah M has difficulty understanding why	
	163	he needs to achieve these goals and you know so far in his life he	
ACCEPTANCE – MANAGING STRESS?	164	always thinks "oh that will happen, I will do that when I'm older" but not	TAKING RESPONSIBILITY
	165	necessary understand he needs to change something about him in	
	166	order for that to happen and I find that very, and I think a lot about M	ATTACHMENT
EMPATHY A TRANSIENT PROCESS? DYNAMIC AND ONGOING WITHIN INTERNALISED RELATIONSHIP?	167	and how I can help him and just accept that there are certain things	
	168	that he doesn't understand and he's not to blame, its not him	

SPLITTING PERSON AS ADAPTIVE? COPING?	169 purposely trying to spite me by not achieving things we have set out, 170 that's just a part of him and you know he does achieve things, you 171 know small things here and there. But for example he struggles to get 172 out of bed, he stays in bed for long periods of time and perhaps two or 173 three times a week he will get up out of bed before ten o'clock in the	INTRAPERSONAL TENSION
DECONSTRUCTION OF PERSONALITY OR QUALITIES	174 morning and the rest of the week it might be seven or eight in the 175 evening and that's really hard to accept when you know there is so 176 much that he can achieve and the people that work in the service	MANAGING REACTIONS
TENSIONS	177 almost blank him for that and I mean he knows that he should get up	
FRUSTRATION	178 earlier and we have erm sort of a rule in the house that when he gets 179 up he should complete his morning routine, so his personal care you 180 know brush his teeth, have a bath before he goes out on activities erm	
REFLECTING ON IMPACT OF ACTIVITIES OR GOALS ON CLIENTS LIFE – OUTSIDE LOOKING IN, EMPATHISING?	181 and I think and also, its recently changed but before he used to have 182 to do his laundry and other things and I suddenly realised you know 183 that doing his laundry and cleaning his room was not important to M 184 and while we were supposed to be doing that it wasn't having a 185 positive impact on his life as a whole and so we changed it slightly and 186 talk to his carers doing laundry in his room while he's in bed with 187 perhaps an aim of getting him out of bed and perhaps making him feel 188 better about his environment because it's a bit cleaner and a bit tidier 189 and open the curtains to get a bit of light might encourage him to get	

SENSE OF PARTICIPANT VICTIMISATION – WHERE IS THE SELF CARE OR COMPASSION?	190	out of bed, give him a reason to which seems to have had some sort of	MANAGING REACTIONS
	191	positive effect and erm but on the whole its still still sort of lots and	
	192	when he does stay in bed and you've got something planned or you	
	193	want him to achieve something its erm, I find it hard not to sort of take	
	194	things a bit personally	
	195	Ben: Take it personally	
FRUSTRATION ADAPTING TO CHANGES	196	Mark: Yeah, when hes up and hes awake and hes happy, hes lucid	
	197	and aware so energised and he has aspirations and he will tell you all	
	198	these aspirations and then the next day they're missed they're gone	
UNCERTAINTY IN RELATIONSHIP & COMMUNICATION	199	and hes in bed and doesn't want to get up and hes tired and that's	
	200	hard not to think well you do, is that a personal…maybe personal's the	
	201	wrong word but sometimes it does feel like perhaps you were lying to	
	202	me, perhaps you didn't mean what you said and its almost likes hes	
MISSED OPPORTUNTIES	203	two people, you know when hes tired and in bed its very difficult to do	
	204	anything to get him up aside from his fifty pound and say "lets go and	
IMPACT "ON THE CHIN" PHYSICAL OR EMBODIED	205	buy something that you want" erm it is very difficult to maintain that	
	206	level of positivity and you know motivation to get him to do the right	
STRUGGLE	207	things and personally as his keyworker you have to take a lot of	
	208	disappointment on the chin and you have to pick yourself up and be	
EFFORT REQUIRED TO OFFER SUPPORT OR GUIDANCE – IMPACT OF CONFLICT ON EGO & SUBSEQUENT EMPATHISING	209	motivated for him and maybe that we had a PCP goal planned and I've	
	210	come in especially on my day off to do it with him and he doesn't get	

REFLECTING ON CHALLENGES AND WHAT THEY MEAN CONFLICTS IN SEPARATING PERSON FROM ASD & ID TO EVALUATE UNDERSTANDING INTERPRETATION BASED ON DIAGNOSIS?	211 212 213 214 215 216 217 218 219 220 221 222 223 224 225 226 227 228 229 230 231	up and out of bed and that feels quite personal and I think is it me, you know would he be better with different key workers? somebody else? or is that you know just you being you erm.. Ben: Erm it sounds like (cough) so when you have those different thoughts about him is it personal, is it that you don't understand erm how you do react to all of that? Mark: Erm, quite often my first sort of thoughts are, you're making this decision, this isn't just your Aspergers or your learning disability this is just a part of you-you're purposely making this decision and I have to talk myself around because I know sort of logically I don't think M is spiteful, I don't think M is a bad person erm but this is just a part of him and just you know he finds it extremely hard to get out of bed sometimes and you know (speech becomes more rapid) if it was a PCP goal that was amazing and really important to him, he probably would you get up out of bed and do it, but if its something mundane that perhaps betters his life in the long term that..for example we went to the airport to watch some planes because hes got a life goal, he wants to go to America and er that's massive for him, going on an aeroplane for that amount of time, going to America a place that he, you know he loves movies and games and they all come from America so he sees this as a heaven of a place erm (smiles) erm so we went to	TAKING RESPONSIBILITY INTERPRETATION BASED ON KNOWLEDGE AND OBSERVATION INTELLECTUALISING MANAGING REACTIONS REFLEXIVITY? INTRAPERSONAL TENSION

	232	Gatwick airport, now it took me three attempts to get him to go,	INTRAPERSONAL TENSIONS
	233	because he was in bed the first two times, he was in bed, he didn't	
	234	want to get up, eventually he did and we went and he enjoyed it in the	MANAGING REACTIONS
EFFORT	235	end but he just thought, its just Gatwick airport, I don't really want to do	
	236	that and so you know when I spend some much time and effort for him	
	237	when he doesn't want to do it, that's when it feels a bit personal and	
INTERPRETING CLIENTS THOUGHTS	238	you sort of feel like, well I've really tired there M erm, yeah it is difficult	
	239	but funnily enough I had some training recently about autism and erm	
EXPERIENCE FEELS PERSONAL	240	the lady she really opened my eyes about things that people just aren't	
	241	programmed to do, they just cannot physically do it, theres a woman	
	242	she spoke about that achieved academically greatly in her career and	TAKING RESPONSIBILITY
	243	she is very highly regarded yet she can't write sentences without	
	244	mixing up letters and no matter how many years, you know shes been	
PERSONALISATION OF EXPERIENCE – LACKING OF SELF COMPASSION	245	trying all these years and no matter how much she practices in her	
	246	head she just can't do it and that made me sort of realise that perhaps	
	247	M just can't understand certain things and I just have to accept that	
ACCEPTANCE	248	erm…which is hard to because you build up a relationship and anyone	
	249	I've had a relationship with before tends to you know feel emotionally,	
TRYING TO MAKE SENSE OF RELATIONSHIP WHEN IT DOES SEEM CONGRUENT OR IS NOT RECIPROCATED	250	understand how I am feeling and perhaps modify their behaviour but I	
	251	think perhaps M really struggles with that and when hes up he really	
	252	tries to do that and maybe sometimes that's why you think well you did	
EMPATHY COMPROMISED?			

	253 that that time why can't you do it this time? but perhaps...it feels like	RELATING WITHOUT LANGUAGE – INTUITION OR FELT?
	254 hes mimicking that behaviour because you know perhaps hes happy	
	255 and that time he wants you to feel happy...but you know when	
	256 something needs to happen, you know (voice quietens) sometimes its	
EMPATHISING BASED ON EXPERIENCE OF AFFECT	257 just a bit different.	REFLEXIVITY
	258 Ben: Um. Okay, you talked a bit about when you're building a	
RELFEXIVITY – THINKING ABOUT WHAT IS BEING SAID	259 relationship, I wonder how you go about that, building a relationship	
	260 with clients?	
	261 Mark: When I became Ms keyworker, you know I did work with him	
	262 before that it, M does respect his keyworkers and historically has done	
	263 so I've been told, erm and he does value them, erm but to start with it	
PROVING ONSELF – VALUES & RESPONSIBILITY	264 took a lot of..effort on my part, I was going in quite often on my days	
	265 off to help with PCP goals, erm I was spending a lot of time going in to	
	266 M and asking how he was and checking on him was there anything he	
SHOWING INTEREST – MOTIVATIONS	267 needed and just sort of this and that, erm proving to M that I do want	
	268 good things for him and you know, (takes a breath) **EMOTIVE** not that	
VALUES & STANDARDS	269 I don't do those things now but to start with on building that	
	270 relationship I think it was important to start to show him, show M my	
INTIMACY	271 interest with him and not necessary the extra 20p pay (laughs at self)	
HUMOUR	272 erm which he mentioned to me (speaking with humour) and said you	

SHARING EXPERIENCES AND TRYING TO COMMUNICATE THEM	273	get paid for being my keyworker and I said "yes M but that's not why I	
	274	took the role" (laughs)	
	275	Ben: What went through your mind when he said that to you?	UNCERTAINTY
	276	Mark: Er, I was surprised that he knew to be honest, I was surprised	
	277	that he knew erm, its part of the key worker role but I'm not exactly	
UNCERTAINTY & SURPRISE	278	sure where he picked that up from, I'm struggling to remember what I	INTRAPERSONAL TENSION
	279	said now..erm (pause)	RELATING WITHOUT LANGUAGE
	280	Ben: How did you feel when he said that to you?	
	281	Mark: It felt like he knew, like he was aware that it might be the reason,	MANAGING REACTIONS
	282	you know that it could be the reason why a person might take up a	
USING AFFECT TO UNDERSTAND OR INTERPRET	283	keyworker role in its-self and that might have been quite worrying and	
	284	it made me feel, no I'm gonna prove you wrong it's the reason why,	
	285	and he knows, he definitely knows now that I have his best interests at	
ANXIETY	286	heart. He does like to give the impression that he trusts everyone but	
	287	hes always second guessing what everyone says (brief laugh) that	
COPING	288	actions often contradict the wide picture a lot of the time and often	
	289	when he asks you a question that you might think he has no idea	
	290	about, if you answer it differently to how he would expect, he often	
HEART EMOTIVE LANGUAGE PERHAPS MIRRORING LOVE OR INTIMACY WITHIN RELATIONSHIP	291	steers it towards the answer, he already knows the answer and he's	
	292	testing you to see if you know it. So erm, yeah	

COMMON VALUES BRIDGING RAPPORT AND AIDING UNDERSTANDING SHARED BELIEFS – DOES THS BUFFER INTRAPERSONAL TENSIONS? INTERPRETATION OF CLIENT EMPATHY **CLING** – INSECURE, FRAGILE OR DESPERATE EFFORT & PAIN	293 Ben: Are there occasions that you've felt connected to him in some 294 way? 295 Mark: He, yeah he values family very much and I, it took me quite a 296 while to understand how he empathises with them and not other 297 people as it tends to be the case, he really thinks hard about they 298 might feel about things erm and yet doesn't with anyone else. He does 299 erm a bit, I don't think the will like that, but with his family he really puts 300 thought into, for example when we were buying Christmas gifts for 301 them, he struggles with his decisions anyway but erm you know he 302 really agonised over every person's gift because he really wanted to 303 give them. He still didn't really want to spend much money but that's a 304 trait he has, he doesn't like to spend much money on anything really. 305 You know he likes to get a good deal and not to pay over the odds. But 306 yeah with his family he definitely feels for, and that related to me 307 because I'm a very family orientated person (okay) and if anything that 308 gives me something to cling onto at times because perhaps you do 309 have (inaudible) and perhaps it will come out that you know you feel 310 for other people and perhaps understand how they feel and that might 311 affect your decision making and how you approach things for the 312 future. 313 Ben: Did erm, do you think he makes that connection as well?	INTRAPERSONAL TENSIONS MANAGEMENT OF DISTRESSING FEELINGS

	314	Mark: With his family or with me?	
	315	Ben: With you	
	316	Mark: Erm, I would like to think so but that are certainly times when it	RELATING WTHOUT
	317	feels like he hasn't, for example when hes choosing who he wants to	LANGUAGE
	318	do certain activities with he tends not to choose me to do those	
	319	activities with, for example you know PCP goals going to the zoo, or	
CONSIDERING THE NEEDS OF OTHERS	320	even when we're playing football and hes captain. He will not choose	
	321	me, even though, it sounds a bit big headed but I'm probably one of	MANAGEMENT OF
	322	the better footballers there and he tends not to choose me, things like	DISTRESSING FEELINGS
FEELINGS CAN BE USEFUL TO INTERPRET RELATIONAL DILEMMAS	323	that make me think first of all you're not choosing me, that's fine if you	
	324	sort of just haven't thought about it erm, but erm you know its regular,	UNCERTAINTY
	325	regularly it happens and I don't know, as I am his keyworker I make	
TAKING EVENTS PERSONALLY E.G. FOOTBACK	326	him question things that perhaps other people don't, or I give him a	
	327	hard time about things, perhaps say you've made a bad decision	
CONFLICTS BETWEEN PROFESSIONAL BOUNDARIES & INTIMACY OR CARING	328	there, so why have you made that decision? And perhaps put him	
	329	through his paces a bit so perhaps he really think about things and	
	330	perhaps next time that comes up.. that might be a part of it, but its hard	
	331	to make a gauge on it, but to me Ms quite an important person to me	
	332	and my wife, I'm having a baby soon so you know, I would like for you	
LACK OF CONFIDENCE IN ABILITY TO EMPATHSIS OR UNDSTAND	333	to sort of meet the baby and perhaps we can talk about that whenever	
CONTRADICTIONS			

	334	we're working together or just together or whatever. I think that M likes	
	335	the thought of that but I don't know how much he really values it.	
	336	Ben: What is it about that that you think M likes?	RELATING WITHOUT LANGUAGE
SELF DOUBT	337	Mark: I think there are certain people he looks up to perhaps who have	
	338	those sort of relationships and he likes to think that he does to and	
	339	that's perfectly normal-its just that sometimes I don't think that he	
HOW DOES THS IMPACT ON EMPATHY?	340	really connects with me the way I sort of want us to erm. I might be	
	341	completely wrong and get a wrong read off things, I hope I'm wrong	
VALUES & STANDARDS ARE HIGH	342	and that its stronger than I give him credit for.	
	343	Ben: You mentioned reading there, its that the sort of thing you might	
JUDGING	344	do with the people you're working with to try to make sense of whats	INTRAPERSONAL TENSION
	345	going on for them?	
	346	Mark: yeah, erm with all, yeah with all of the guys I've got an idea of	
SENSE OF CONNECTION POWERFUL IN NON VERBAL CLIENTS- MEANING AND EXPERIENCE OF BEING WITH THE CLIENT	347	how they perceive me erm even with someone with, one of our guys is	
	348	nonverbal, profound learning disability and sometimes you really feel	
	349	that connect, maybe its because he doesn't speak and can't talk erm	
	350	and so you can feel the connection there when he sort of looks at you,	
SENSE OF CONFUSION	351	you know each of his looks can be a bit more purposeful than his	
	352	action, although with M, although he talks a lot, I supposed the word is	
	353	its fickle, in that he doesn't often mean what he says, although he	
	354	perhaps wants to, he doesn't always mean what he says so its difficult	

	355	to understand or know if he's telling the truth and saying what he	
	356	believes or whether he thinks its what you want to hear, in fact you	
	357	know perhaps he's too intelligent (laughs)	
	358	Ben: Too intelligent	INTERPRETATION BASED ON OBSERVATION
	359	Mark: Perhaps (more laughing) for that purpose anyway yeah	
	360	Ben: So you were starting to describe some experiences there where	
	361	perhaps you felt connected to people who are nonverbal, are there	
	362	some experiences you had where they've been positive in terms of	RELATING WITHOUT LANGUAGE
	363	being able to support somebody with learning disabilities?	
EMBODIMENT OF EXPERIENCE	364	Mark: Erm, for me yeah. We've got a guy who is erm deaf, his got	
	365	downs syndrome, he verbalises but he can't speak in words and	
PURE OR CLEAN CONNECTION	366	actually, only certain words he can, its very difficult to have a	
	367	conversation with him, because he's deaf, well mostly deaf erm and	
REDUCTIONISM IN INTERACTING, RELATING OR COMMUNICATING?	368	you know when he does verbalise things its very difficult to understand	
	369	what he says because he's deaf so he can't hear what you are saying	
	370	and the effect of the learning disabilities and so on and so forth so	
	371	erm..with that particular person he gives you information back with his	
INTIMACY	372	body language, with his actions and you know I don't, its very difficult	
	373	to lie when you don't speak so you know what you're getting is pure	
	374	information as long as you are reading that properly so sort of erm..	

	375 Ben: Could you maybe give sort of an example something that's quite	
	376 clear to describe that?	
	377 Mark: Okay, so this erm, particular person we used to have a person	
	378 who used to target him and he did not like this person at all, but this	
SENSE OF BEING VALUED – UNDERSTANDING QUALITIES OF RELATIONSHIP CAN BE SUDDEN OR TRANSIENT?	379 person has moved on now from the service but er the person that sort	RELATING WITHOUT LANGUAGE
	380 of targeted him, but very often when that sort of person would come	
	381 back he would sort of hide behind you and sort of smile after you've	
	382 gone by and you know clearly valued you being there, well me being	
	383 there and knowing that I would protect him or look out for him and	INTRAPERSONAL TENSIONS
IMPACT OF INTERACTIONS ON CARE OF CLIETN – PERCEPTION OF CLIENT	384 that's, you know that was big for me when I realised that was	
	385 happening because suddenly I realised that this person valued me	
	386 quite highly, if only to protect them from you know the other client who	
	387 targeted him but but you know it goes further than that for anything	
PROJECTION	388 else happening, it would go the same way erm and that was big you	
	389 know and that was probably one of my first times, or one of the first	
	390 situations where I've actually been valued by the client, by the service	
TRANSFERENCE?	391 users you know so that's quite a long time ago now 5 or 6 months	
	392 since that has happened but that was a nice feeling to get that and the	
BONDING AND RELATIONSHIP – SIGNIFICANT IN UNDERSTANDING AND EMPATHISING WITH CLIENTS?	393 very first bond with that person, and probably since then I have looked	
	394 out for this person quite a lot perhaps even more than I would have	
	395 done had that not happened.	

	396 Ben: And that feeling you described, that feeling of being valued is that	
	397 embodied anywhere in your body, do you experience it anywhere in	
	398 your body?	REFLEXIVITY
	399 Mark: I notice myself, I'm a lot more open with this person because he	
	400 can't verbalise to him, I notice that I'm a bit more affectionate, not just	
PERSONAL GROWTH & LEARNING	401 with my body language but he tends to erm you know he tends to	
	402 come up to me and give me a cuddle and I openly accept that those	
	403 sort of gestures, which perhaps I wouldn't have done in the past or	
	404 with him more or necessarily anyone else and its opened up that bit I	
OPENED UP – FEELINGS OR VIEWS? IMPACT OF EVENTS CAN LEAD TO INCREASED INTIMACY	405 think	
	406 Ben: Okay and earlier you mentioned this kind of tension in your role	
	407 and you maybe kind of want to do some of the caring part of your work	
BODY LANGUAGE – OPEN	408 but that can sometimes be compromised with you role, I wonder if you	
	409 could tell me a bit more about that?	
	410 Mark: Erm, so from my induction process and onwards it was sort of	INTRAPERSONAL TENSION
PERSONAL & PROFESSIONAL TENSIONS	411 made very clear to me that the service users come first before	
	412 everything, and then sort of to have my belt and braces and I was	
BALANCING ADMIN & CARE	413 working for a while and then when I became the shift leader which was	
	414 the intention from the onset I suddenly realised how much less time I	
PAST EXPERIENCES INFORM NAUTRE OR TONE OF QUALITY OF RAPPORT	415 have to do the caring side and if anything taught me to budget my time	
	416 a bit better, but because of my role as shift leader you're responsible	

ORGANISATION AND TAKING RESPONSIBILITY	417	for everyone it always seems to be running the shift comes first and	
	418	they come second and its really difficult to balance the two, I have	
	419	obviously now developed the skills to ensure that the guys are well	
	420	taken care of while I'm running the shift but its certainly started to	
STANDARDS	421	really stress me out to know that I had to do both and if I put my client	
	422	or two clients whoever I am working with first before anyone else	
STRESS	423	running the shift that might well mean that nine others get put second	MANAGEMENT OF DISTRESSING FEELINGS
STRUGGLES	424	and you know vice versa and you know I think I struggled quite a lot	
	425	with that to start with and what I found once I was spending a lot of	
WHERE IS THE SELF COMPASSION? COPING STRATEGIES	426	time after the shift going back and making sure that you know their	
	427	room was clean and tidy, making sure that their laundry was done and	REFLEXIVITY
	428	that their files were filled out or updated all of those things that are	
	429	okay they are not all things that are really noticeable or important to	
MINDFULNESS	430	that person but they are important long term you know if I don't do their	
	431	PCP file and it gets to their PCP review and it will be like 'why haven't	
	432	you done this?" or whatever it is and you're their keyworker so that you	
	433	know all that runs through my mind quite regularly and that, it I deal	
	434	with the stress quite well I think, but you know when you are learning	
	435	everything and its new that stress is compounded because you're not	
	436	particularly au faire with everything so erm I wasn't doing my sort erm	
	437	job, I wasn't actually there for them the way I should be now I think I've	

	438	managed to sort of overcome that and find ways round to run the shift	
	439	and do the necessary you know when its supposed to be done and not	
	440	just in the shift, but yeah certainly a struggle to start with	
	441	Ben: I heard you mentioning there's lots of responsibility as well and	
	442	I'm wondering what's it like to have all that responsibility for the clients	REFLEXIVITY
	443	and for the staff?	
	444	Mark: Yeah its big, I mean sometimes its easy to forget how important	
	445	it is and you can be doing the meds and then suddenly oh, someone's	
CURIOUSITY	446	run out of those meds and its like okay they've run out of their meds	MANAGING REACTIONS & FEELINGS
STRESS	447	and on the face of it it sounds okay we can deal with it but if its	
	448	someone with their PRN medication and they can't get any until	
IMPACT OF EVENTS & IMPACTS OF STRESS	449	tomorrow and there is an incident and they need it or suddenly	INTRAPERSONAL TENSION
	450	everyone else can be in danger or that person is anxious	
	451	unnecessarily and that could upset the whole house and you think,	
FRUSTRATION IN BEHAVIOUR OF OTHERS – PERSONAL VALUES & STANDARDS	452	why couldn't someone just keep on top of that I tend to be quite	
	453	meticulous, not meticulous, I tend to think things through and I like	
	454	things a certain way erm, and with medication with petty cash those	
BELIEFS	455	sort of things it quite frustrates me when they have not been done	
	456	correctly and it adds to my stress if its happened and I've got to rectify	
	457	and if I'm busy trying to sort someone's activities I need to plan for	
	458	them and make sure people are on, so that, while that is going on I'm	

INTENSE IMPACT – "GOD" EXISTENTIAL REFERENCE?	459	thinking "god is this stress affecting me, is it going to affect the people	
	460	I'm working with?" or not even with everyone else, is my stress	
	461	affecting the whole team and then that's filtering down to the service	
	462	users and then they're going to have a bad day, you know all going	MANAGEMENT OF DISTRESSING FEELINGS
	463	through your head, it is a lot pressure?	
CONTRADICTION IN STRESS MANAGEMENT	464	Ben: Do you think that ever happens?	
	465	Mark: Yeah, well as I say I think I'm quite good at dealing with stress	
WHAT IS HE AWARE OF?	466	and perhaps not showing it, but you know countless times I've gone	
	467	home with a headache and I've had to lay in a dark room, you know its	DENIAL
	468	sort of, you know physically it builds up rather than me showing it so	
FEELINGS OF STRESS CAN HAVE PHYSICAL IMPACT?	469	much erm.	
	470	Ben: How do you go about coping with that stressful experience?	
	471	Mark: Erm, well I've sort of developed ways because the more I do	
	472	things the more I've done these things, you sort of more anticipate	
	473	when they're gonna happen erm, and how that might come about, so I	REFLEXIVITY
	474	spose now I've just sort of developed the skills to erm, not that it won't	
PLANNING	475	ever happen but when they do happen I can deal with it more	
INTELLECTUALISATION	476	efficiently and quicker and know how to. Where as with the staff it was	
	477	all new, and you know the petty cash was all out and the tin's down	
	478	and they need money for this, where do I go to deal with that? What do	
SELF CONSCIENTIOUS	479	I record that it's happened and who needs to know now?	

STRESS AS HIDDEN	480	Ben: Sounds like a lot of things	
	481	Mark: Well (laughs) yeah erm, yeah so you know a lot of the	
	482	operational issues I've worked out and don't have to sort of go and ask	
	483	someone erm you know and I also worry about bugging people	
	484	perhaps unnecessary erm but yeah I've worked a lot of those issues	
	485	out so I know where to go for things or know who to ask or who to	
	486	approach and if its something I can deal with myself then know how to	REFLEXIVITY
NOTICE CHANGES IN MOOD DURING INTERVIEW DURING INTERVIEW – STRESSED?	487	deal with it. Its taken a lot of practice I think, just learning to cope.	MANAGEMENT OF DISTRESSING FEELINGS
	488	(pause)	
	489	Ben: How do you recognise when you are becoming stressed?	
	490	Mark: Erm, (voice quietens) that's a good question. (pause). I think I	
	491	notice my patience diminishing erm rather than sort of shouting at	HIDING
FEELINGS HIDDEN FROM OTHERS TO AVERT DISTRESSING OTHERS – WHAT IS THE IMPACT OF THIS?	492	anyone or getting angry, I don't sort of tend to get angry at people so	TAKING RESPONSIBILITY
	493	you know I do notice myself getting stressed and that's why I think I've	
	494	got good dealing with it and not erm, you know making anyone else's	
	495	problem, I think then probably not become more patience but perhaps	
LIMITED SELF COMPASSION?	496	that's how it seems because I will just take the time to deal with it and	
	497	not make it anyone else's problem that's what I focus on, not making it	
	498	anyone else's problem because its me that's got to deal with it and I	
	499	will deal with it.	
	500	Ben: So the focus is on you dealing with it and not anybody else?	

LEARNING	501	Mark: Yeah, well it might be that I'm the only one I might ask someone
	502	to do something for me and they won't be aware of it or notice that I'm
	503	necessary stressed or sort of do it as a request. If something needs
	504	doing and they can definitely do it I will delegate but quite often these
	505	things if I am stressed its because of all these things that need to
	506	(inaudible) and I haven't necessary got the time, or enough time, or
	507	enough time to deal with them and that's perhaps when I get stressed.
	508	And you know we had a situation shortly after Christmas (increase in
	509	rate of speech occurs) where we were short and erm, one of the
	510	members of staff had a flat tyre in the van and needed to be out
	511	somewhere so we had that sort of looming and then the pantry door
	512	locked and it broke so we couldn't get into the pantry door for the
	513	fridge and freezer and it was getting towards lunch time, we didn't
	514	have enough petty cash in to send someone out so there was no food
	515	in the house and the activity that needed to happen couldn't happen
	516	because of the flat tyre erm and so that was, how do I deal with this,
	517	there's no person in the office and in the end I had to deal with it and
	518	luckily I had cash on me so I said right theres the money to go and do
	519	that, get lunch and phoned the place to cancel the activity which was
	520	not ideal but we had no way of getting them there and so I sort of dealt
	521	with it in the end. That sounded like quite an easy fix but it took me a

	522	long time to get to that sort of fix erm. And so that stressed me out and	
	523	I think you know that people must have been aware that I was	
	524	stressed because it all landed on my head erm but yeah I tried to sort	
	525	of think about the solutions rather than how bad the situation was sort	
	526	of, yeah	
ATTRIBUTE CLIENT DISTRESS TO ASD & ID	527		INTREPRETATION BASED ON KNOWLEDGE & OBSERVATION
	528	Ben: Hmm, okay. You have sort of talked about kind of stressful	
USE MEDICAL MODEL TO EXPLAIN OR MAKE SENSE OF RELATIONAL RUPTURES	529	experiences and times that have been sort of quite nice and feel	
	530	valued by the clients, are there other kinds of feelings that you	
	531	experience in the work place?	
	532	Mark: Erm, yeah I mean it can be erm (pause) quite difficult to see	MANAGEMENT OF DISTRESSING FEELINGS
DETACHMENT OF CLIENT'S DISTRESSING BEHAVIOUR	533	some of the scenes we have to see. One of our guys we have to get	
	534	things he wants or to gain control or just to stop something that he	
	535	doesn't want to be doing, like the laundry and things he screams at the	
	536	top of his voice for extended periods of time and I mean especially	
	537	when I first started that was harrowing like shocking to see somebody,	
	538	my first thought was why does this person need to do that? What are	
	539	these people doing to him? (laughs) for him to be acting this way, erm	DIRECT EMPATHY
	540	and you know its only after time that you realise that his anxieties are	
PUT SELF IN CLIENT'S SHOES TO MAKE SENSE OF EXPERIENCE – DIRECT EMPATHY?	541	brought on by his learning disabilities and erm perhaps the way he's	
	542	been treated in the past and it seems like he's always on a knife edge	

	543	of anxiety and it takes very little to tip him over the edge, erm and you	
	544	know after time I did realise from working with him myself while I was	
	545	being very nice to him you have to be, it wasn't something we were	
	546	doing, its just how he is and its very difficult even the most proactive or	
MEDICAL MODEL	547	person or people were still struggling to have a shift with him that didn't	INTERPRETATION BASED ON KNOWLEDGE & OBSERVATION
HOW ID IS COMMUNICATED WITHIN SOCIETY AND MESSAGES ABOUT CORRECT SUPPORT OR INTERVENTION	548	result in him screaming erm and then that also makes you realise how	
	549	much of the challenging behaviours come down to the right medication	
	550	and before being in this setting you, you know you see these movies	
	551	from Hollywood and everything and its just people who are dosed up	UNCERTAINTY
CULTURAL INFLUENCE ON UNDERSTANDING CLIENTS	552	because that's, you know you get this idea in your head that	
	553	everyone's just being dosed up to not be difficult, which is not the case	REFLECTIVITY
	554	and some people do really need this medication erm and so looking at	
MINDFULNESS OR CURIOUSITY ABOUT THE RELATIONSHIP	555	that for somebody that was new to it all, that was quite erm shocking	
	556	and that made me..erm… really question (speech slows down)	
	557	question.. a lot.. of things lately and wonder whats going on in his head	INTRAPERSONAL TENSION
INTERPRETING OTHERS IS UNCERTAIN & DIFFICULT	558	and why does he need to do that erm, yeah erm, and I've since learnt	
	559	that sometimes because he feels out of control, sometimes because	REFLEXIVITY
EFFORT REQUIRED TO EMPATHISE	560	he feels unsafe, sometimes because he can't get something and that's	
	561	the way that he has learnt to get the biggest response..erm but yeah,	
ADOPT BIOLOGICAL UNDERSTANDINGS WHEN OTHER INFORMATION IS UNAVAILABLE?	562	erm its difficult to see it, its difficult and its hard to see that sometimes.	

INDIVIDUAL DIFFERENCES	563 Ben: It sounds like you kind of learn about the person as well (yeah) its	
	564 interesting about what you said earlier as well about skill set and that	
	565 sometimes you feel the need to change, I think you said change your	
	566 skill set from working with one person to another but sometimes it	
	567 doesn't always happen in a way that you would like it too?	INTRAPERSONAL TENSION
	568 Mark: Yeah, well for example two of our guys they are very, both quite	
	569 demanding of time, they live in the same house and we've got three	
	570 separate buildings but they live in the same house. They're both quite	
DIFFERENCES IN APPROACHES	571 erm big personalities, they sometimes clash in personalities erm, and	
	572 they both respond very differently to instruction or depending on their	
STRESS & ANXIETY MAKE THINKING ABOUT INTERPRETATION OR EMPATHISING CHALLENGING	573 mood or whatever and erm if you're speaking with erm with one of the	MANAGEMENT OF DISTRESSING FEELINGS
	574 guys, hes very much erm, dominant, you cannot approach him anyway	
	575 physically, if hes being difficult you just cannot approach him physically	
	576 because he will not respond to that, that will escalate him massively	
	577 erm, whereas another of the guys it's the complete opposite, he asks	UNCERTAINTY
	578 to be held, he thinks its safer for him and everyone else if hes you	
	579 know held when hes being challenging and if you're dealing with one	
	580 of them and then the other in close proximately, you have to, they	
	581 could be one who is stressing you out and you could just erm, that	
	582 doesn't mean to say that you would just put your hands on him or	
	583 anything like that but you have to treat them in a very different way and	

	584	that could, one sort of care plan and thought process could definitely	
	585	sort of pass over to the other person and that could really upset them	
	586	and so at times of stress and anxiety you really have to think about the	
	587	way you are approaching different people, erm which can be really	
	588	difficult yeah, I don't know if there is anyone in the service that I have	
	589	approached perfectly every time and I mean that sounds like, that's	
LEARNING ABOUT CLIENTS & NOT GENERALISING APPROACHES	590	quite a big example that's quite an extreme example there can be just	
	591	times when you sort of are talking to someone normally and you sort of	
	592	talk to someone in the same way and it won't have the same	
	593	response...	
IMPACT OF DISTRESS FOR CLIENT	594	Ben: Have you experienced that?	
	595	Mark: Have I experienced that, yeah. Erm definitely say for example, I	
	596	can give you an example, (speech become more rapid) we were trying	
	597	to get one of our guys out for an activity and erm he was refusing the	
	598	activity saying he did not want to go out, saying that his tummy hurt. It	
NOTED HONESTY & OPENESS OF PARTICIPANT	599	took for a senior member of staff to be a bit more firm about it and say	REFLEXIVITY
	600	to him "you do want to go out ,we've been here before, you know you	
	601	enjoy it, you'll be fine when you get there", in a firm tone of voice erm	
HUMOUR	602	and leaving him no option of wriggling out of it, and he did and he	
	603	enjoyed it so I sort of took this on board and did the same thing with	INTRAPERSONAL TENSION
	604	him and this was when I was still quite new and I did the same thing	

CHALLENGES IN ADAPTING APPROACHES – ONE SIZE DOES NOT FIT ALL

PRESSURES OF SERVICE EXPECTATIONS ON INTERPERSONAL RELATIONSHIPS BETWEEN CLIENTS & STAFF | 605 | with that same person and it did work, (coughs) and it did work so I | |
	606	sort of tried this with someone else who he lives with, he wasn't saying	
	607	about his tummy but he was saying "I don't want to go", (laughs at	
	608	self?) and it didn't work at all, erm he you know he ended up crying, he	
	609	ended up angry with me, he ended up talking to his keyworker about it	
	610	and it was nothing personal form me to him but you know I definitely	INTRAPERSONAL TENSION
	611	realised at that point that you know, I knew anyway that they're all	
	612	different and they sort of react to different things but that was definitely	UNCERTAINTY
	613	not the way to approach that person.	
	614	Ben: How do you interpret that now?	REFLEXIVITY
	615	Mark: Erm, it comes a lot more naturally now that I know a lot of them	
	616	much better, erm how do you interpret that sorry? (speech much	
	617	slower)	
	618	Ben: When you think back to that, how do you interpret what motivated	
	619	you to erm to respond in that way to the client?	
	620	Mark: What, the first time from when I went wrong? or (laughs)	
	621	Ben: From what you're saying it felt like it wasn't the right way of	
	622	working with this person, with this individual, when you look back on	
	623	that now, what do you think was your reasoning in working with him in	
	624	that way?	

	625	Mark: He seemed to exhibit the same sort of signs as the previous
	626	person did, and I thought if that worked before perhaps it will work for
	627	him, because as I said I was still quite new, I didn't necessary know
	628	but I knew that within the service you know certain activities are
	629	deemed erm, quite important you know to most of the guys and so
	630	from the offices point of the view, from the shift leaders point of view
	631	and the registered home managers its important that they see that and
	632	they go to those activities so I was thinking he does not want to go, it
	634	may look bad on me, **** , he may miss out and I thought in the long
	635	term he may regret it so I thought I have to try something erm, I'll try
	636	this and it was the worse thing to do, he didn't go to the activity
	637	(laughs) and he didn't like me for a while so erm, I don't think I was
	638	rude, I don't think I was horrible about it, I was trying to be firm and it
	639	back fired on me.
	640	Ben: And whats your relationship like with him now?
	641	Mark: Very good, he's since realised, I explained to him that, you know
	642	I'm quite happy to admit when I've done something wrong but erm,
	643	yeah he erm understood. Fortunately his learning disability is not that
	644	profound and he can understand those sort of things and when I
	645	apologised to him I think he understood and I have since proven to him

COMPLEX PRESENTATIONS INFLUENCE ABILITY TO INTERPRET PERSON	646	that actually I'm a nice kind of guy and I would only do things that are	
	647	necessary for him and that er	
	648	Ben: Okay then, I think we've kind of covered quite a lot there erm so	
	649	its really if we start to close now, is there anything else that you would	
	650	like to talk about or anything you think might be relevant?	
	651	Mark: Yeah, we've had two people leave the service in the time in the	UNCERTAINTY
	652	time that I've been here with learning disabilities who have left our	
	653	house, erm, since I've been here, the first I mean the first one left	
	654	(speech slows down) when I was only been there for probably two	
EYES VACANT – SENSE OF HUMAN DISCONNECTION	655	months and I had worked with him quite a number of times and he was	
	656	very very challenging erm and as I understand it his needs, they	
	657	overlapped into a mental health needs and that sort of sort of	
	658	overshadowed the learning disability and the challenging behaviour	
	659	sort of thing. So I found it so difficult to connect with him and erm and	
	660	even with when working I was trying. I don't think he was unverbal but	
	661	I think he chose, he didn't speak, you know he never even uttered	
	662	anything close to words and so as far as I know he was able to speak	
	663	but chose not to and there was such a vacant look in his eyes, he	
	664	never really made any eye contact and I really struggled, I really	
	665	struggled to begin with and I thought maybe I can't do this job because	HOLDING IN MIND
INTERNALISE RELATIONSHIP – LEARNING FROM EXPERIENE	666	I can't connect with this person, I can't get any kind of a read off him at	
			TAKING RESPONSIBILITY

OBSERVATIONAL STRATEGIES - **READING**	667	all erm and I probably worked with him twelve times in the time he was
	668	there and whenever you worked with him, there was two of you, so
	669	perhaps that was, that made things a bit difficult as well, but I sort of
	670	got to know his behaviours a bit and so I knew when he was gonna do
	671	things erm, but never really understood him or what I said about
THINKING ABOUT THE PERSON, THEIR EXPERIENCES	672	reading him. The second person who left I found anytime that any
	673	person is working with him now that his left, you know he moved to
MINDFUL OF CLIENT'S WELLBEING	674	another house within the service and I found myself curious about how
	675	he is, what he's doing, how he's progressing and I was probably boring
	676	who ever I was asked because I was asking so many questions and
	677	asking the same people regularly, you know "hows he doing?", erm
METHODS USED TO INTERPRET CLIENT EXPERIENCE	678	and I think I connect quite a lot with that person even though he's also
	679	mostly non verbal, he only said a few words just a small amount and
EXPERIENCE OF CONNECTION HARD TO DESCRIBE – CONCEPTUALISED AS ABILITY TO MAKE LAUGH OR SHOW AFFECTION	680	again its sort of actions and his behaviour and the way he would sort
	681	of interact and sort of way of interacting with people and whenever I
	682	was working with him I sort of made it my goal to everytime sort of
	683	make him laugh at least once and erm you know just to make him
	684	happy because you got such concrete information back from him it
READING PEOPLE – ABSOLUTE & FINAL. OBSERVING CLIENT'S REACTIONS	685	was just either he's happy, or he's just calm or his anxious so you
	686	know it was so immediate the response erm, I don't know if I'm
	687	explaining myself very well, its erm (pause) there was no question, it

Right column annotations:
INTERPRETATION BASED ON KNOWLEDGE & OBSERVATION

HOLDING PERSON IN MIND

REFLEXIVITY

	688 was always absolute information that you got back from him and it's a	INTRAPERSONAL TENSION
	689 nice feeling that you could make him happy and he was clearly very	
	690 happy and he was you know became with that very affectionate and	
	691 you know it didn't always last very long but it was nice to feel that and	
INTELLECTUALISING	692 so when he left, you're not really supposed to have favourites, but he	MANAGEMENT OF DISTRESSING FEELINGS
	693 was one of, I liked working with him and so when he left it was	
EMOTIONAL LANGUAGE	694 actually quite difficult and I actually did he's moving in process to the	
	695 other house and all of a sudden he hated me, it was an immediate	
	696 switch and I sort of, I put that down to I was the person who brought	
	697 him here and he seemed to like it here, there's less people and he	
HUMOUR	698 doesn't cope with lots of stimulation, he can't process it quick enough it	
	699 makes him anxious and so I like to put it down to I was the person who	
CHANGES IN RELATIONSHIP ATTRIBUTED TO ASD & ID	700 brought him here and so because I am part of his past he thinks you	
	701 know (laughs) am I going to take him back which he may not want so,	
IMPACT OF ENVIRONMENT ON PERSON'S PRESENTATION	702 yeah so he tried to push me down the stairs (laughs) DEFENCE? and	
	703 then he tried to yeah get rid of me anyway he could when I was there,	
	704 when I was here sorry. So erm yeah working through that was very	
INTENSITY OF EMOTIONAL EXPERIENCE – "HATED"	705 erm difficult and even now he's not very sure about me, erm which	
	706 was quite hard because when he did live at the house that I'm at he	
RISKY BEHAVIOUR – IMPACT ON PARTICIPANT?	707 did, erm yeah we had a good relationship. USE OF PAST TENSE- MEANING?	

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SEPARATION & LOSS	708	Ben: You talked a bit about the way that maybe its to do with the
	709	previous place he lived and so its confusing because he lives here
	710	now, is any other way of making sense or interpreting whats gone on
	711	there?
	712	Mark: Erm, (long pause) well it could be the complete opposite I
	713	spose, he feels upset that I took him away from the place he liked erm,
	714	but I don't think so
	715	Ben: And by the sound of your voice there, it sounds erm I think you
CHALLENGES IN RELATIONSHIP	716	were saying that it was something you were working through and I was
	717	wondered before we end if you could tell me what it was like for you
NEGATIVE AFFECT	718	working through the relationship?
	719	Mark: I think that because it was so sudden it was quite difficult and as
SEPARATION & LOSS – STILL RAW	720	I said I found myself asking questions about him and I spose that I
	721	could just come here and find out, but he can't really tell me and so
LACK OF RECIPROCITY WITHIN RELATIONSHIP – SHARED EXPERIENCES? LIMITED MEETING OF MINDS	722	what it comes downs to is that I've got to ask other questions about
	723	him to find out how he is, I think I suppose I feel a bit sad that I can't
	724	come and be here because when I have he sort of tries to push me
	725	through the door and so I have to ask other people erm, yeah I spose
	726	it's a bit difficult really and a bit sad because its just been cut I spose,
	727	maybe from a selfish point of view I want him to interpret it the same

RATIONALISATION OF DISTRESS AS ATTRIBUTED TO SYMPTOMOLOGY OF CLIENT'S DIAGNOSIS	728	way I do (laughs) and be a bit upset about it but he's sort of not looked	
	729	back really erm but yeah maybe that's part of his condition	INTELLECTUALISING
	730	Ben: Maybe, I appreciate you telling me that it sounds like it is	
	731	something that has been something difficult to work through and erm	MANAGING DISTRESSING FEELINGS
	732	so thank you for that, for adding that in, I think it is very relevant and	
	733	very meaningful so I very much appreciate that and I thank you for the	
	734	input for today.	
	735	Mark: I think I talk too much (laughs).	
	736	Ben: I think there's some really interesting content there so erm thank	
	737	you very much	
	738	Mark: No problem	

Appendix 7: Tabulation of Converging Themes - Version 1

ORIGINAL THEMES	P1	P2	P3	P4	P5	P6	P7	P8
INTELLECTUALISING	X	X		X		X	X	
HIDING	X	X	X	X			X	X
CONSCIOUS VS UNCONSCIOUS ACTION	X	X	X	X		X	X	
INTERPRETATION	X	X	X		X	X	X	X
HUMOUR		X	X		X	X		
INTERPRETATION BASED ON KNOWLEDGE OR EXPERIENCE	X	X					X	
INTUITION/ATTUNEMENT	X		X	X	X	X	X	
THINKING ABOUT THE THOUGHTS OF OTHERS	X	X	X			X	X	
REFLECTING ON RELATIONSHIP	X		X	X	X	X	X	X
DIRECT EMPATHY	X		X				X	
HOLDING PEOPLE IN MIND	X	X	X	X		X	X	
REFLEXIVITY	X		X	X	X	X	X	
ACQUISITION OF KNOWLEDGE	X	X	X	X		X	X	X
ATTACHMENT	X		X		X	X	X	
TENSION/CONFUSION IN UNDERSTANDING	X		X	X		X	X	
PROFESSIONAL VS PERSONAL VALUES	X		X			X		
INTERPERSONAL CONFLICT	X			X			X	

Tabulation of Converging Themes - Version 2

THEMES	P1	P2	P3	P4	P5	P6	P7	P8
INTERPRETATION BASED ON KNOWLEDGE AND OBSERVATION	X	X	X			X	X	X
RELATING WITHOUT LANGUAGE	X		X	X	X	X	X	
DIRECT EMPATHY	X		X				X	
HOLDING PEOPLE IN MIND	X	X	X	X		X	X	
REFLEXIVITY	X		X	X	X	X	X	
INTRAPERSONAL TENSION	X		X	X		X	X	X
UNCERTAINTY		X	X			X		X
MANAGING REACTIONS	X	X	X	X	X	X	X	X
TAKING RESPONSIBILITY	X	X	X	X			X	X

Appendix 8: Participant analytical account

Table 1: Participant One – Jack

1. Tensions	2. Strategies to interpret the experience of clients	3. Responding to emotional experience
Attachment vs professionalism *Interpersonal exchanges/experience*	*Making sense of experience* • **Medical model** • **Metacognitive?** • **Utilising feedback** *Empathising* *Normalising*	*Reflecting* *Learning from experiences – changing values* *Detachment*

<u>Participant One: Jack</u>

Jack was a white British gentleman in his early thirties who had worked within various roles in learning disability services for a number of years. He had been in his current role for 3 years. His responsibilities included both support work and managerial duties. The organisation was a private residential service for adults with ID and challenging behaviour. Jack was very engaging throughout the interview and required little prompting to provide examples or elaborate on his experiences. Although the interview was the pilot Jack provided great depth and breadth in his narratives attempting to understand the needs and experiences of people with intellectual disabilities that it was possible to include his transcript as part of the study. There was a sense of vulnerability in Jack's discourse and emotional openness. On one occasion I was mindful of how Jack began to disclose sensitive personal information and gentle focussing was necessary to both protect Jack and direct narratives of relational experience with people with ID. There was a feeling of congruence during the interview which led to a sense of acceptance when listening to parts of Jack's discourse. Upon reflection more frequent clarification and exploration of themes may have resulted in a richer analysis. After the interview Jack reported that he had found the interview enjoyable and relaxing. He gave feedback on how some of my questions were a little complex and this led to revision of the interview schedule.

Theme One: Tensions

Throughout the interview Jack appeared to experience conflict when discussing his role and interpersonal exchanges and the impact that these had on his ability to interpret the experience of clients.

Attachment vs professionalism

Jack described a working culture in which it is expected that people acknowledge their role as paid employees and adhere to a professional code of conduct. However he communicated that he believed people with ID benefited from a degree of intimacy, "*If you're investing enough with that person you're gonna have an emotional attachment….we talk about professional boundaries…I don't think you can do your job properly unless you've got an emotional attachment*". He goes on to describe experiences of "*friendships*" and "*bonds*" and a need to carefully "*weigh it up*" for fear of being "*unable to move away*" from the person. He goes on to report that he feels "*that there sometimes needs to be that separation*" Jack appears to respond to this dilemma by ultimately adopting a professional position, "*I put my professional hat on sometimes, and that helps me rationalise what's happening*". He appears therefore to experience conflict in the degree to which he can attach to people with ID within his role.

Interpersonal exchanges/experience

Another tension that Jack talked about was the impact of his interpersonal exchanges and experiences with people with ID on his ability to interpret or understand their needs. In his early experiences working in care Jack informed me that, *"I would be verbally abused and I was quite young and it was hard to understand why"*. As Jack provided more recent narratives concerning his relationships with clients he told me that, *"You get very close to someone, you then you know touch each other's buttons"*. It appears that although Jack sought to create intimate bonds with people with ID he was acutely aware of not only his need to adhere to a professional code of conduct but also that he may experience aversive feelings in his interactions; when discussing a client he formed a secure bond with Jack stated that, *"he would know when I was stressed so he would be on my case"* and that *"we would just wind each other up"*. When recalling relational experiences of this nature Jack referred to a process whereupon, *"you get pulled in"* . This would suggest that at times Jack acknowledged lapses in his awareness of the impact that forming close bonds with clients could have on his ability to both make sense of and respond to affect experienced in his relationships.

Theme Two: Strategies to interpret the experience of clients

Jack described a range of different strategies that informed the way in which he attempted to interpret the experiences of people with ID. Often strategies were described in isolation to one another and Jack appeared to struggle to communicate the extent to which he thought various methods enabled him to understand and relate to the experience of the person he was supporting. Interestingly when Jack talked about how he tried to empathise or understand someone it was often described in the past tense and when reflecting on his experiences in contrast to understanding and connecting with a person's experience in the moment.

Making sense of experience

- **Medical model**

The accumulation of knowledge and experience appeared important to Jack and fundamental to the process in which he made sense of people's presentation or feelings. On a number of occasions diagnostic categories framed with a medical model informed Jack's thinking about the challenges people may experience, *"I just picked up books and read and read and kept reading and it gave me a lot of knowledge and that was very helpful at the time for, you know coz I used to work with people with mental health problems as well as on the autistic spectrum and being able to understand that the person is showing so much distress is actually because there's something going on internal for them"* . In discussion about a particular individual that appeared to struggle to form relationships with staff as a

result of his challenging behaviour, Jack stated, "*he's on the autistic spectrum and he struggles very much with all sensory input that's coming in*". Attributing challenging behaviour to a biological origin seemed to aid Jack's ability to empathise with the difficulties that the person experienced.

- **Metacognitive?**

Throughout the interview it was also apparent that Jack was mindful of the thoughts of the people he was supporting. When talking about the degree to which people with ID understood concepts of trust, dignity and respect and acknowledge their feelings Jack argued that, "*you can always assume they understand*".

- **Utilising feedback**

On several occasions' interpersonal responses and concepts of visual, audio or observational cues were described as a means to understand how people were feeling. In Jack's descriptions there was a sense that he felt affirmed in understanding the feelings of others when he was able to obtain a kind of "feedback", for example "*You get that feedback like when they're happy coz they're dancing*". It is possible that Jack also draws on this process to evaluate how he is experienced by others. This was framed within themes of gratitude or shared intimacy, "*you've got that feedback, like thanks for doing this*" and "*you have those moments where you knew they were talking to you about stuff that's quite important to them and personal*". The value of this process was apparent in not only Jack's narrative of seeking out feedback but also the language he used in which to describe them, "*looking for the signs…little nuggets of achievements*".

Empathising

Jack appeared to adopt a heartfelt and firm belief in the idea that to empathise with people with ID it was important to do this directly, reflecting on how a given situation or setting may impact on you. He stated, "*I think it's vital to put yourself in that person's position and actually figure out and try to understand where they're coming from*". In this instance Jack advocates that there is a requirement to "figure out" and "understand" the person's experience. This would suggest that Jack believes that effort is needed when trying to connect with someone's experience. He also goes on to talk about how this process is difficult by reporting, "*you know put yourself in that person's position and try to do that for a second*". The temporal element in Jack's phrasing suggests that empathising may be fleeting and challenging. Jack also adopted a comparative approach in which he thought about a person's life in general in comparison to his own, "*I get to de-stress at home and that person's still living in*

that care environment for the next maybe thirty years". Finally Jack talked about how his understanding of other's concerns may be aided by his own reflection on similar experiences, for example, *"I can imagine the feelings are, what's going to happen now for my child? so I understand that".*

Normalising

Throughout the interview Jack spoke at length about the importance of interpreting the lives and experiences of people with ID within a normative social framework. When recalling an account in which Jack had worked with staff who were struggling to support an individual as a result of his challenging behaviour he reported he told them, *"I said you know, he's not a monster, he's a person".* Jack also reflected on the way in which he attempts to see beyond the diagnosis of learning disability, *"I try not to look at them as a person with a learning disability".* This somewhat contradicts Jack's strategy of drawing on diagnostic information to inform his understanding of people's experiences. He also stated that *"every person's kind of going to be different"* suggesting that Jack viewed differences and dilemmas in interaction with people with ID as a normal social experience.

Theme Three: Responding to emotional experience

Jack talked about experiences of both positive and negative affect in his interactions with people with ID. Responses to his feelings were described as either immediate or as an on-going reflective process. Self-reflection appeared to be vital to Jack to both interpret his experiences and to use interpretations to inform his personal development. He also reported occasions in which he would try to detach himself from people, situations or feelings with an aim to more effectively manage them.

Reflecting

Jack presented as a reflective and thoughtful individual throughout the interview. He gave examples in which he appraised his feelings in the moment, *"I think ooh gorden bennet where does this come from?"* and his behaviour post event for example,*"I recognise it in myself that sometimes it's not worth fighting that fight coz actually it's not that important" and "I used to think, why are you doing that?".* Within Jack's narrative it is apparent that he values a reflective process and when asked how he responds to stress in his interactions with people with ID he replied, *"I manage it by one experiencing, two reflecting and three I spose building my knowledge up".*

Learning from experiences – changing values

Jack not only used his reflective capacity to interpret his thoughts, feelings and behaviour but also to inform how he responds to situations in the future, for example *"I used to say arr come on you're winding me up….it was only a toilet handle..don't worry about it actually, it's not that important…I suppose that's how I kind of manage it a little bit…it's not important to me".* He also talked about stress that he had previously experienced when balancing contact time with people and administration duties and stated, *"erm but I don't worry about it as much now, if I don't get my paper work done".* Jack appeared aware of fluctuations in affect and how this may influence his behaviour. When reflecting on occasions that Jack now believes was maladaptive or unhelpful in some way he describes those moments as *" always stuck with me".* He attributes deep personal meaning to these experiences which appear to connect both with a sense that it is important to maintain high personal and professional standards and also as opportunities for personal growth for example, *"just experiencing it and learning from my mistakes".* There is a sense that Jack is now more able to decentre himself from aversive emotional experiences and reflect on them to inform his personal development. This can be illustrated by his phrasing in the present tense of "just experiencing" alluding to less current motivation to self- judge.

Detachment

In contradiction to Jack's comments on "experiencing" emotional tensions he also described a process of detaching himself. This was within the context of both interpersonal conflict and general stresses associated with his role. In response to conflict Jack emphasised *"being able to talk about it and taking yourself away for five minutes".* He talked about striving towards clear boundaries to differentiate himself from his work environment for example, *"I make sure that when I'm not at work, I'm not at work. That's how I manage it now, if people phone me I don't answer it".* This would suggest that it is not only processes of decentring but also detachment that are employed in response to aversive or potentially aversive experiences. It is possible that Jack may not be fully aware of his tendency to engage in detachment as he talked about this process in both the past tense as a reflective comment, *"I used to put myself, pretend I was an actor"* and then on another occasions as a more descriptive statement in the present tense, *"I feel that right now I need to distance myself from him".*

Appendix 9: Tabulation of themes - Version 1

Superordinate	Subtheme	Quote/Keyword and participant number/line number
Responding to distress	1.emotional detachment/rationalisation 2.conscious vs unconscious awareness of distress 3.Humour 4.False self	**1.emotional detachment/rationalisation** P1 26.543-546 I put my professional hat on sometimes, and that helps me rationalise what's happening P3 14.446 "Samuel: I think I leave it, I try to leave it at the door" P7 11.219 -221 I have to talk myself around because I know sort of logically I don't think M is spiteful, I don't think M is a bad person erm but this is just a part of him **2.conscious vs unconscious awareness of distress** P2 17.356 It doesn't really affect me / 11.230 We feel uncomfortable P4 17.353-356 it can make you feel really awkward sometimes when you walk through the door and as I was saying he'll (inaudible) and then he'll just go and sit down because he's frightened of you and it does make you feel bad/ 23.464-466 Ben: Yeah, maybe upset, has there been an occasion when you've felt upset working here? (voice sounds uncertain) James: Not really no. P7 23.465-469 Mark: Yeah, well as I say I think I'm quite good at dealing with stress and perhaps not showing it, but you know countless times I've gone home with a headache and I've had to lay in a dark room, you know it's sort of, you know physically it builds up rather than me showing it so much erm. **3.Humour** P3 l13.444-448 I think I leave it, I try to leave it at the door. There's been times I haven't been able to obviously you know erm but, I think I joke it off. I can come in here and make people laugh that takes my mind off it. You know." P2 4.73 Grabbing is funny 29.591-596Derek: I tend to just (laugh) think fair enough and if I ponder on it enough I might go and try again in the field but then like when we're saying we've got this in place and this then it's okay, I suppose sometimes you just need to get you opinion across and say this is how I feel to get your point across and some people agree and some people don't I spose you've just gotta move on and get on with it **4.False self** 3.273-14 275 when you try to hard it feels like your relationship becomes false and you're not being yourself P1 15.313 I used to put myself, pretend I was an actor 13.423-427 Ben: When you're at work when you feel sad.. Samuel: I don't show it.

		Ben: You don't show it. Samuel: I don't show that I'm sad, because I feel that they can pick it up, the sadness I feel they can pick it up and you can't ask me why I know but I can feel it
Interpretative processes	1.Non verbal communication 2.Application of past knowledge 3.Existential? 4.Direct empathy 5.Utilising the medical model 6.Observation/Audio strategies	**1 Non-verbal communication** P1 28.587 They know, you know P5 20.417-421Your thinking changes and then you understand their thinking when they're displaying challenging behaviour then you can try to think about what is going on inside their head and when you are able to think about what is going on in their head that can help you to understand P8 26.530-556 Sometimes at handover it can be an anxious moment for them and if you are working with them and they see you before handover and you're in a bad mood then they're not gonna like that I think, even with any service user if they see you in a bad mood at handover and they know you're gonna be with them, they're gonna think what we ain't gonna nothing fun if you're in a bad mood that's what I mean kind of thing P6 22.442-452 Derek: Well, rare in the sense that, that banana took a long time I mean you know the eating for ages and he was like, look you've been feeding me for all this time, why should I bother now?, maybe he was thinking that or whatever he was thinking **2.Application of past knowledge** P5 13.264 sometimes you're just working with past knowledge really P727.557-562 I wonder what's going on in his head and why does he need to do that erm, yeah erm, and I've since learnt that sometimes because he feels out of control, sometimes because he feels unsafe, sometimes because he can't get something and that's the way that he has learnt to get the biggest response..erm but yeah, erm it's difficult to see it, it's difficult and it's hard to see that sometimes. P8 9.174-179 That's just knowing the individual yourself really, yeah I've been here a long enough time now to know when each service is feeling happy and when they're not really, and when they are happy, they are really happy and I try and keep them up there, up on their happy level P4 3.61 You get to know what that look means **3.Existential?** P1 35.715-716 Sometimes you just know and sometimes you're able to push that person P3 5.152-155 "He can have, it's like a treat to him and it makes him feel like he is on top of the world, you can see it in his eyes and you can see how happy he is, not because I'm giving it to him, but because he knows where it's come from before, he knows it comes from his mum and dad".

		P7 14.281-286 It felt like he knew, like he was aware that it might be the reason, you know that it could be the reason why a person might take up a keyworker role in its-self and that might have been quite worrying and it made me feel, no I'm gonna prove you wrong it's the reason why, and he knows, he definitely knows now that I have his best interests at heart P4 4.71 Naturally just connected with him P7 17.347-352 one of our guys is nonverbal, profound learning disability and sometimes you really feel that connect, maybe it's because he doesn't speak and can't talk erm and so you can feel the connection there when he sort of looks at you, you know each of his looks can be a bit more purposeful than his action **4.Direct empathy** P1 1.13-14 I think it's vital to put yourself in that person's position and actually figure out and try to understand where they're coming from P1 2.39-40 You know put yourself in that person's position and try to do that for a second P2 12.232 I'm not able to give myself a little slap because I know how I will feel P3 6.168,169 "its not gonna make him happy its gonna make problems for them surely, if I punch myself in the head everyday I'm sorry but I'm gonna have problems down the line" **5.Utilising the medical model** P7 7.141-143 Because of his Asperger's he lacks empathy massively to the point at which sometimes its extremely frustrating P 6 9.188-10.190 its difficult to know what people with learning disabilities are actually thinking, some people will never really know the situation, so you gotta assume and diffuse it the best you can P1 7.131-132 Hes on the autistic spectrum and he struggles very much with all sensory input that's coming in **6.Observation/Audio strategies** P2 3.57-58 As I study him, as I walk with him I speak with them, when his head is down, that means there's a problem P718.371-371 he gives you information back with his body language, with his actions and you know I don't, it's very difficult to lie when you don't speak so you know what you're getting is pure information as long as you are reading that properly so sort of erm.. P3 7.223-225 "Ben: Okay, and how do you know he's enjoying it? Samuel: Because he loves at ya, because he smiles and he shakes his body, you know he loves it." P5 7.127-129 express, how can I put this in a nice way, express the problems in their life, express their disappointment so express it in their challenging behaviour

Experiences of adopting empathic approaches	1.Reinforcing 2.Development of reflexivity 3.Distressing	**1.Reinforcing** P 5 14.275-277 when you are able to find out what that problem is then it is…..you feel good because then you are able to help out in whatever you can P1 7.138-139 You know we turned his life around. That gives you a lot of satisfaction P224.484 It brings joy to my heart P620.415-418 it felt fantastic, it felt really really good, its definitely something that if I became a rock start tomorrow and left this industry behind I would still think of that moment and still think that was great, **2.Development of reflexivity** P4 23.471-477 Ben: When somebodys distressed how do you make sense of it?James: Erm, its really hard to at the time but erm, afterwards I think you can see, obviously there was a reason why they become distressed and I think that is when, that is when you can actually see (voice stops and starts) that maybe someone who was with them at the time or something like that has not really understood that person you know more. P6 8.159-164 I still think about it, I still think about the situation what I could of done better, I told the people erm that were interviewing me about it I could of done better, but yeah I still feel disappointed about what I had done, but at the same time you've got to learn from your mistakes, you've got to be able to analyse what you do P6 16.328-332you know you do think of the worst sometimes, when you're working with challenging behaviour erm and people with challenging behaviour you know can be quite volatile at times say, you know I think about it all the time, if I go out its always in the back of my mind **3.Distressing** P835.723-729 I think I suppose I feel a bit sad that I can't come and be here because when I have he sort of tries to push me through the door and so I have to ask other people erm, yeah I spose it's a bit difficult really and a bit sad because it's just been cut I spose, maybe from a selfish point of view I want him to interpret it the same way I do (laughs) and be a bit upset about it but he's sort of not looked back really erm but yeah maybe that's part of his condition P33.53,54 "Erm I think that on the other side of seeing what they do in that negative way which is another part of it, it's the sad part of it", P15.5.99-100 You can feel like you are investing all the time and it is emotionally draining
Factors that may facilitate	1.Individual value base 2.Conceptualisation of role	**1.Individual value base**

empathic thinking and practice	3.Acquistion of knowledge 4.Acquistion of experience	P4 24.504James : (pause) well something like that it's not fair to be said and then just forgotten is it?, it's almost like you know, "well just get him away" do you know, just to get him of it.
		P73.63 – 4.66 it can be difficult to know that they are always being looked after, thought about enough and cared for enough and sometimes it does cross my mind that perhaps they do get neglected and that worries me a bit
		P3 2.43-48 " I've grown up with everything I am and they've grown up with everything they are, we're all human beings, but it's just things that click, it's the things that make them do weird things and I don't mean this in a nasty way I just think things like banging, hitting, grabbing, you know not basically getting what they want so..if we don't get what we want we except it, sometimes (laughs) if they don't get what they want I don't think they know how to except it, you know so.. I've lost the question."
		P317.558-539 "I see people and I'm like you know you're not actually good for this job because you've got no heart"
		## 2.Conceptualisation of role
		P316.502-503 "Samuel: Yeah, I don't every blame it on that person, I blame it on me because it's me that makes the decision that's got to be made unfortunately"
		P2 20.405 I just look, this is what I'm here for
		P4 32-33 It's a case you've got to try to understand
		## 3.Acquistion of knowledge P1 11.214-216 I manage it by one experiencing, two reflecting and three I spose building my knowledge up
		P2 1.18-19 I was given their books, I was able to read and learn about them
		P5 6116-120 I went to trainings and er there we are taught how to understand people's behaviour like challenging behaviour and one of the trainers say to you they, when somebody don't know you, they're not comfortable with you, they don't want you
		## 4.Acquistion of experience
		P3 4.98-100 "he can't talk to us, he can tell us in his own ways and that to me is how that person and how that person understands him its just about learning the person I spose"
		P510.206-11.211

		Frank: How do I understand how people feel? (Umm) Err (takes big breath) I know by their different communication like er when you know the client you work with, you know how they communicate. The other day I was sitting thinking not many of the clients here talk and we tend to understand what they're trying to say and how they are doing that it's about knowing the person and by knowing their likes and dislikes.
		P1 9.169-178 I used to say arr come on you're winding me up….it was only a toilet handle..don't worry about it actually, it's not that important…I suppose that's how I kind of manage it a little bit…it's not important to me P514.285-286 we tend to understand them with time, it's a time thing to be honest.
Tensions	1.Professional vs Personal 2.Attachement vs Separation 3.Knowledge vs Uncertainty 4.Lack of reciprocity within relationship	1.Professional vs Personal P122.447-451 If you're investing enough with that person you're gonna have an emotional attachment….we talk about professional boundaries…I don't think you can do your job properly unless you've got an emotional attachment P6 3.58-63I've always found it really really hard erm like to not use nicknames say erm because it's a professional environment, it's a professional job you're not their friend and that's tough for my own character, that's something I've had to work on a lot erm so yeah, its also interesting trying to find that line between being a professional and being a friend within banter P38.257-263 "Samuel: I would rather they would make their own decision (okay) I would rather….honestly I'm here to do my job and I'm here to get them out on activities, I'm here so that they can get their own clothes, I'm here so they can go and purchase their money so they can go and get a meal out, that's why I'm here, to give them the best life they can have (pause) and er.. I have to make that decision, I have to do as I am told to do, and you know er if, if #### said to me and he would, I want to go out for lunch but like I say there's only so much you can do with them." 2. (Attachment vs) Separation P73.46-53 I have definitely created a strong bond with some of the guys and erm it would be really difficult to, I've spoken to my wife funnily enough who occasionally has thoughts about moving to Australia and erm somewhere hot because she gets fed up with the weather here but you know found myself saying, you know I don't know if I could (laughs) erm which is erm opened my eyes massively because after only a year there that's, its frightening to find I am now tied down (laughs) and I won't be able to leave! P525.509-515 like I was saying to you earlier when, even when you are on annual leave and then you just remember things that have happened at work and you just remember and you just start laughing. I worked with a service user before and she just went home for a week and she didn't come back for a week and then I started missing here because she just come around and say all sorts of stuff to ya and they just make you laugh you know

		p3 12.364-366 When I go out Ben, I can go out and see something and think, man would he love that and my Mrs will go, "what you on about now?" And I'll go "oh I'm on about so and so at work, he would have loved this".
		3.(Knowledge vs) Uncertainty P2 10.206 There are times we cannot really say P37.199-201 "Samuel: No-one could tell me what it could be like, because I can't just go into his room and say "what's it like for you?" because one, it wouldn't be nice to say to them and two, maybe they don't know that themselves" P4 9.186-187 Ben: What do you think is the reason for that? James: I don't know, I don't know really/ **4.Lack of reciprocity within relationship** P76.119-121 it took me three attempts to get him to go, because he was in bed the first two times, he was in bed, he didn't want to get up, eventually he did and we went and he enjoyed it in the end but he just thought, its just Gatwick airport, I don't really want to do that and so you know when I spend some much time and effort for him when he doesn't want to do it, that's when it feels a bit personal and you sort of feel like, well I've really tired there M erm, yeah it is difficult P5 19.397-399 he spits as well so I was trying to defend myself from this client to find a way so that he doesn't spit on me and things like that is a bit depressing (laughs) P4 29.600-605James: Yes it is, with #### you feel like you're doing something to improve his life that if erm, ~~~~, \\\\ and {{{{ you know you are definitely improving their life but you don't actually get that feedback that sometimes want and need do you know what I mean? Coz you feel sometimes that no days different so to speak, did that make sense?

Choices for superordinate themes were made on the basis of prevalence across the group and relevance to the research aims. Themes which did not have strong enough links with quotations were removed. The following superordinate themes were omitted: 1. reflecting and describing relationships (due to breadth of data) 2. personal development/growth (as this deterred from research focus) and 3. client autonomy vs lack of agency (as this deterred from research focus). A number of convergences were present across all participants. Divergences included the degree to which people appeared able to reflect on their experiences, views on client autonomy, time spent discussing self or other and validation of personal negative affect.

Appendix 10: Tabulation of themes - Version 2

SUPERORDINATE THEME	SUBTHEME	QUOTATIONS
Experience and reaction to distressing feelings This theme enables exploration of the degree to which distress is noticed in oneself and acknowledged. It identifies the degree to which distress is validated and ways in which feelings are managed at either a conscious or unconscious level.	1. INTELLECTUALISING 2. HIDING 3. CONSCIOUS VS UNCONSCIOUS ACTION 4. HUMOUR	INTELLECTUALISING P7 "I have to talk myself around because I know sort of logically I don't think **** is spiteful, I don't think **** is a bad person erm but this is just a part of him" P1 "I just picked up books and read and read and kept reading and it gave me a lot of knowledge and that was very helpful at the time for, you know coz I used to work with people with mental health problems as well as on the autistic spectrum and being able to understand that the person is showing so much distress is actually because there's something going on internal for them" P7 "my first thought was why does this person need to do that? What are these people doing to him? (laughs) for him to be acting this way, erm and you know it's only after time that you realise that his anxieties are brought on by his learning disabilities"
		HIDING P3 "I don't show that I'm sad, because I feel that they can pick it up, the sadness I feel they can pick it up and you can't ask me why I know but I can feel it". P7 I will just take the time to deal with it and not make it anyone else's problem that's what I focus on, not making it anyone else's problem because it's me that's got to deal with it and I will deal with it." P8 "Not talking to people, not talking to people, that's my big one. If I don't talk to someone I'm either tired or in a really bad mood that's how I notice in myself I'm in a bad mood, erm yeah just not talking to people really" P1 I used to put myself, pretend I was an actor

		CONSCIOUS VS UNCONSCIOUS ACTION P2 17.356 It doesn't really affect me / 11.230 We feel uncomfortable P4 17.353-356 it can make you feel really awkward sometimes when you walk through the door and as I was saying he'll (inaudible) and then he'll just go and sit down because he's frightened of you and it does make you feel bad/ 23.464-466 Ben: Yeah, maybe upset, has there been an occasion when you've felt upset working here? (voice sounds uncertain) James: Not really no. P7 23.465-469 Mark: Yeah, well as I say I think I'm quite good at dealing with stress and perhaps not showing it, but you know countless times I've gone home with a headache and I've had to lay in a dark room, you know it's sort of, you know physically it builds up rather than me showing it so much erm.
		HUMOUR P3 I13.444-448 I think I leave it, I try to leave it at the door. There's been times I haven't been able to obviously you know erm but, I think I joke it off. I can come in here and make people laugh that takes my mind off it. You know." P2 4.73 Grabbing is funny P6 29.591-596Derek: I tend to just (laugh) think fair enough and if I ponder on it enough I might go and try again in the field but then like when we're saying we've got this in place and this then it's okay, I suppose sometimes you just need to get you opinion across and say this is how I feel to get your point across and some people agree and some people don't I spose you've just gotta move on and get on with it
The process of trying to understand another person's inner world of distress This theme provides data to illustrate processes of interpretation and	1. INTERPRETATION BASED ON KNOWLEDGE AND OBSERVATION 2. REFLECTING ON RELATIONSHIP 3. INTUITION/ATTUNEMENT 4. THINKING ABOUT THE THOUGHTS OF OTHERS 5. DIRECT EMPATHY (PUTTING ONESELF IN THE POSITION OF THE OTHER)	INTERPRETATION BASED ON KNOWLEDGE AND OBSERVATION P718.371-371 he gives you information back with his body language, with his actions and you know I don't, it's very difficult to lie when you don't speak so you know what you're getting is pure information as long as you are reading that properly so sort of erm.. P1 "I just picked up books and read and read and kept reading and it gave me a lot of knowledge and that was very helpful at the time for, you know coz I used to work with people with mental health problems as well as on the autistic spectrum and being able to understand that the person is showing so much distress is actually because there's something going on internal for them"

empathic connection. It raises questions about the extent to which empathy is understood and practiced in relation to "feeling into another's experience". It outlines the range of interpretative processes that people engage with in order to try to understand the inner world of people with ID.		P7 "he has Asperger's and he finds certain things difficult, you know empathy is near enough a completely foreign concept to him"
		REFLECTING ON RELATIONSHIP P5"the more you work with them the more you are able to identify those feelings and if it's just a particular thing they don't like" P727.557-562 I wonder what's going on in his head and why does he need to do that erm, yeah erm, and I've since learnt that sometimes because he feels out of control, sometimes because he feels unsafe, sometimes because he can't get something and that's the way that he has learnt to get the biggest response. Erm but yeah, erm its difficult to see it, it's difficult and it's hard to see that sometimes. P8 9.174-179 That's just knowing the individual yourself really, yeah I've been here a long enough time now to know when each service is feeling happy and when they're not really, and when they are happy, they are really happy and I try and keep them up there, up on their happy level P4 3.61 You get to know what that look means P6 "breaking those barriers to develop skills can take time for certain people so I guess that's why I've got a handful or small bag full of amazing moments erm, but then that's my own experience"

		INTUITION/ATTUNEMENT P7 "It felt like he knew, like he was aware that it might be the reason, you know that it could be the reason why a person might take up a keyworker role in its-self and that might have been quite worrying and it made me feel, no I'm gonna prove you wrong it's the reason why, and he knows, he definitely knows now that I have his best interests at heart." P1 35.715-716 Sometimes you just know and sometimes you're able to push that person P4 he sort of connected to the way that #### was just naturally, just connected with him and the way he was looking and the answers that #### was giving, he know whether to back off and give him his space or you know another person will keep just trying and trying you know and then it just becomes too much for #### to take and then you get his behaviour, shout. The guy that I'm on about er um who connected with him straight away, he was brilliant, he knows how #### works and you know when you know that, #### will trust you, you know erm. P3 5.152-155 "He can have, it's like a treat to him and it makes him feel like he is on top of the world, you can see it in his eyes and you can see how happy he is, not because I'm giving it to him, but because he knows where it's come from before, he knows it comes from his mum and dad". P7 17.347-352 one of our guys is nonverbal, profound learning disability and sometimes you really feel that connect, maybe it's because he doesn't speak and can't talk erm and so you can feel the connection there when he sort of looks at you, you know each of his looks can be a bit more purposeful than his action P5 "well you can see it by their confidence sometimes, you can feel it by the way they talk and who don't talk they make sounds and you can feel it "
		THINKING ABOUT THE THOUGHTS OF OTHERS P5 20.417-421Your thinking changes and then you understand their thinking when they're displaying challenging behaviour then you can try to think about what is going on inside their head and when you are able to think about what is going on in their head that can help you to understand P8 26.530-556 Sometimes at handover it can be an anxious moment for them and if you are working with them and they see you before handover and you're in a bad mood then they're not going to like that I think, even with any service user if they see you in a bad mood at handover and they know you're gonna be with them, they're gonna think what we ain't gonna nothing fun if you're in a bad mood that's what I mean kind of thing P6 22.442-452 Derek: Well, rare in the sense that, that banana took a long time I mean you know the eating for ages and he was like, look you've been feeding me for

		all this time, why should I bother now?, maybe he was thinking that or whatever he was thinking
		DIRECT EMPATHY P1 1.13-14 I think it's vital to put yourself in that person's position and actually figure out and try to understand where they're coming from P1 2.39-40 You know put yourself in that person's position and try to do that for a second P3 12.232 I'm not able to give myself a little slap because I know how I will feel P3 6.168,169 "it's not gonna make him happy its gonna make problems for them surely, if I punch myself in the head everyday I'm sorry but I'm gonna have problems down the line" P3Sad, yeah very sad because you see I do a lot of ghost tours and things like that that had people with special needs in and I go and do a lot of them and I can be walking around the buildings sometimes and you can see how the room was built and see there used to be a padded cell, and you think Jesus I wonder if he ever had that, one of the guys we support and then I feel sad and I can come to work and look at him when you know when he's not looking around and think I hope you wasn't, because standing in the middle of that cell and I can say that to whomever I want erm, (pause) you can feel that it's not right".
Values and conditions that may foster empathic practice This theme explores conditions that can enhance empathic practice and explores the role of attachment in ID settings as a process that may facilitate empathic understanding.	1. HOLDING PEOPLE IN MIND 2. REFLEXIVITY 3. ACQUISITION OF KNOWLEDGE 4. ATTACHMENT	HOLDING PEOPLE IN MIND p3 12.364-366 When I go out Ben, I can go out and see something and think, man would he love that and my Mrs will go, "what you on about now?" And I'll go "oh I'm on about so and so at work, he would have loved this". P7"I think that it creeps into your mind that are they always being sort of thought about enough and are people taking the time to do things like brushing their teeth, not always for them but you know encouraging them to do so, especially those who don't necessarily have the capacity to understand why they've got to do those things" P7 "I found myself curious about how he is, what he's doing, how he's progressing and I was probably boring who ever I asked because I was asking so many questions and asking the same people regularly, you know "how's he doing?", erm and I think I connect quite a lot with that person even though he's also mostly nonverbal, he only said a few words just a small amount and again it's sort of actions and his behaviour and the way he would sort of interact"

		P3 "A very lot of things go through my mind you know, how it works for them, what makes them wanna do this, what makes them wanna do what they've just done, what's made them sit there and be from that person to go to that person" P5"like I was saying to you earlier when, even when you are on annual leave and then you just remember things that have happened at work and you just remember and you just start laughing. I worked with a service user before and she just went home for a week and she didn't come back for a week and then I started missing her because she just come around and say all sorts of stuff to ya and they just make you laugh you know"
		REFLEXIVITY P1 9.169-178 I used to say arr come on your winding me up….it was only a toilet handle..don't worry about it actually, it's not that important…I suppose that's how I kind of manage it a little bit…it's not important to me P1 ,"I recognise it in myself that sometimes it's not worth fighting that fight coz actually it's not that important" and "I used to think, why are you doing that?". P4 "Ben: When somebody's distressed how do you make sense of it? James: Erm, it's really hard to at the time but erm, afterwards I think you can see, obviously there was a reason why they become distressed and I think that is when, that is when you can actually see (voice stops and starts) that maybe someone who was with them at the time or something like that has not really understood that person you know more."
		ACQUISITION OF KNOWLEDGE P2 1.18-19 I was given their books, I was able to read and learn about them P5 6116-120 I went to trainings and er there we are taught how to understand people's behaviour like challenging behaviour and one of the trainers say to you they, when somebody don't know you, they're not comfortable with you, they don't want you P1 11.214-216 I manage it by one experiencing, two reflecting and three I spose building my knowledge up
		ATTACHMENT

		P8 "you feel you've built that trust and they have kind of listened to you, which is good (emphasis on good) very good because you feel you can get somewhere and you know you can do it again then and build on that from there which is really good" P7 "Ben: Can you talk to me a bit about what you mean by the attachment, by the bonds? Mark: Erm (clears throat) yeah I think that when you spend time, a lot of time with anyone you end up getting to know that person" P1 Jack: The stress is more manageable for me now, but erm you know you sometimes have to manage er being upset you know because you're happy someone's done something or you know coz I've experienced teaching someone to do their shoe laces up once and they didn't want to ask their parents for those sort of things so I remember driving home and crying about it because you think oh, what a job I've got sometimes to actually, that young lad won't ask his mum or dad to do that but he's asking me, and sometimes that hits you when you don't think about it sometimes actually, it hits me anyway. P6 Derek: Erm, make sense of it (breaths out) er I don't know to speak on an equal level I haven't spoke to my friends for many years they still remember my name and they can, we can still speak to each other and know it's different because they're my friend, but then there's gotta be an element of that when you're supporting someone for them to trust you and it's the same on an equal level isn't it, you want them to treat people as much as the same so yeah I guess it's a similar kind of thing, once you know someone whether you work with that person or not, you know that person so you know that's quite a powerful thing I spose.
Tensions and Conflicts This theme explores the experience of tension and conflict with systems, interpersonal experience and personal values that can inhibit empathic practice and explores personal struggles with	1. CONFUSION/TENSION IN UNDERSTANDING 2. PROFESSIONAL VS PERSONAL VALUES 3. INTERPERSONAL CONFLICT	CONFUSION/TENSION IN UNDERSTANDING P3 "No-one could tell me what it could be like, because I can't just go into his room and say "what's it like for you?" because one, it wouldn't be nice to say to them and two, maybe they don't know that themselves". P6 it's difficult to know what people with learning disabilities are actually thinking, some people will never really know the situation, so you gotta assume and diffuse it the best you can" P3 "coz to me, learning from these people is hard, today he will eat porridge, tomorrow he may not, I can't tell you why he's not eating the porridge today, so I never ever learn that person, I just know how to be strong for them and support them in the way they need supporting".

tolerating intimate relationships		
		PROFESSIONAL VS PERSONAL VALUES P1 "If you're investing enough with that person you're gonna have an emotional attachment….we talk about professional boundaries…I don't think you can do your job properly unless you've got an emotional attachment". P6 "I've always found it really really hard erm like to not use nicknames say erm because it's a professional environment, it's a professional job you're not their friend and that's tough for my own character, that's something I've had to work on a lot erm so yeah, it's also interesting trying to find that line between being a professional and being a friend with banter" Ben: Hmm, hmm okay, are there any particular things you might draw on when you're establishing a rapport – a relationship with a person? P6 Derek: (draws breath) I think er its its about character of the person you're supporting, no matter how hard I try in this job, I can't be a robot, its human support with humans so there's gonna be human behaviour, you know the gentleman in there he loves his banter so can't help but dive into it and build a rapport because that's the way he is with you erm the same with other people and individuals that I've supported you warm to their character and that's how your relationship develops. that is a constant for me that I always think about, especially as a deputy manager because practice leadership is really important so erm, yeah I always think about that, I do try and have a balance between professionalism and you know friendly guy sort of thing. P38.257-263 "Samuel: I would rather they would make their own decision (okay) I would rather….honestly I'm here to do my job and I'm here to get them out on activities, I'm here so that they can get their own clothes, I'm here so they can go and purchase their money so they can go and get a meal out, that's why I'm here, to give them the best life they can have (pause) and er.. I have to make that decision, I have to do as I am told to do, and you know er if, if #### said to me and he would, I want to go out for lunch but like I say there's only so much you can do with them."
		INTERPERSONAL CONFLICT P1 "You get very close to someone, you then you know touch each other's buttons". P1 "he would know when I was stressed so he would be on my case"

		P7 "it took me three attempts to get him to go, because he was in bed the first two times, he was in bed, he didn't want to get up, eventually he did and we went and he enjoyed it in the end but he just thought, it's just Gatwick airport, I don't really want to do that and so you know when I spend some much time and effort for him when he doesn't want to do it, that's when it feels a bit personal and you sort of feel like, well I've really tired there **** erm, yeah it is difficult P7 "Even when we're playing football and he's captain. He will not choose me, even though, it sounds a bit big headed but I'm probably one of the better footballers there and he tends not to choose me, things like that make me think first of all you're not choosing me, that's fine if you sort of just haven't thought about it erm, but erm you know its regular, regularly it happens and I don't know, as I am his keyworker I make him question things that perhaps other people don't"

Appendix 11: Electronic Data File - Participant Transcriptions

See USB Data File