

The Emotional Landscape of Working in a Learning Disability Service

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CONTENTS

1.	<i>ABSTRACT</i>	5
2.	<i>INTRODUCTION</i>	6
2.1	Overview	6
2.2	How I came to this study	6
2.3	Current Learning Disability Services	8
2.4	Deconstructing the Problem: Policy, Power and Choice	10
2.5	Narrowing the focus	11
2.6	Nature of the Support Worker Experience	12
2.7	Cognitive Analytic Therapy and Reciprocal roles	16
2.8	Analytic Theories on Learning Disabilities	19
2.9	Altruism and Caring	20
2.10	Conclusions	20
2.11	Study Aims and Research Questions	21
3.	<i>METHODOLOGY</i>	22
3.1	Overview	22
3.2	A Qualitative Approach	22
3.3	Interpretative Phenomenological Analysis	22
3.4	Participants	24
3.5	Ethical Considerations	26
3.6	Data Collection	27
3.7	Data Analysis	28
3.8	Quality and Validity in Qualitative Research	29
4.	<i>RESULTS</i>	31
4.1	Overview	31
4.2	Emotional motivation	32
4.2.1	Personal fulfilment and motivation	32
4.2.1.1	Pleasure in the role	32
4.2.1.2	Tensions of 'ideal' versus 'insincere' care	36
4.2.2	The emotional struggle	40

4.2.2.1	Powerlessness and the emotional reaction to injustice	41
4.2.2.2	The relentless nature of struggles	45
4.3	Demands and coping	47
4.3.1	Safety and conflict within coping	47
4.3.1.1	Constricted and un-elaborative	47
4.3.1.2	The conflict of balancing multiple expectations	49
4.3.2	Persecution and protective positions	53
4.3.2.1	Protection	53
4.3.2.2	The circulation of blame	55
4.4	My relationship with the participants	57
5.	<i>DISCUSSION</i>	58
5.1	Overview	58
5.2	Reward, Motivation and Fulfilling Roles	58
5.3	Idealised Care and the Projection of 'unwanted parts'	61
5.4	Understanding Coping Processes	66
5.5	The Circulation of Blame	68
5.6	Contemptuous Blame	70
5.7	Study Significance	75
5.8	Methodological Considerations	77
5.9	A Final Word	78
6.	<i>REFERENCES</i>	80
7.	<i>APPENDICES</i>	96
7.1	Appendix 1 – Research Information sheet	96
7.2	Appendix 2 – Ethics Approval Documentation	98
7.3	Appendix 3 – Consent Form	108
7.4	Appendix 4 – Debriefing sheet	110
7.5	Appendix 5 – Interview schedule	112
7.6	Appendix 6 – Audit trail	113
7.7	Appendix 7 – Table of master themes for all participants	149
7.8	Appendix 8 – Table of recurrence of themes	174

1. ABSTRACT

Aims: The UK policy documents 'Valuing people' (DOH, 2001) and 'Valuing people now' (DOH, 2009) presaged a new direction in learning disability services: towards a human-rights model of care with the underlying principles of rights, choice, inclusion, freedom and independence. However, despite such legislative changes, a recent review (DOH, 2008a) candidly described that people with learning disabilities have greater need for healthcare than other people, yet have worse access to the care that they actually need and poorer health outcomes. Whilst some research has explored this from the perspective of people with learning disability (Jones & Donati, 2009; Jones & Parry, 2008) there is significantly less from the perspective of support workers. This research seeks to examine the emotional and psychological experience of support workers in learning disability services. Although research has explored the experience of support workers from the perspectives of 'stress' and 'burnout', there is a dearth of research in areas such as emotions, sense-making, their constructing of systems, relationships and their underlying motivations.

Method: Semi-structured interviews were carried out with seven support workers from three learning disability care homes. Verbatim transcripts of interviews were then analysed using Interpretative Phenomenological Analysis (IPA).

Results: The analysis produced two superordinate themes, both with two main themes. The superordinate theme 'Emotional Motivation' had the main themes 'Personal Fulfilment and motivation' and 'The Emotional Struggle'. The superordinate theme 'Demands and Coping' had the main themes 'Safety and Conflict within Coping' and 'Persecution and Protective Positions'.

Implications: This research suggests that the support worker role may evoke strong feelings of pleasure but also powerlessness, blame, deficit, injustice, responsibility and anger. Support workers seem to manage these emotions in various ways: such as compensating by striving to be the 'ideal' carer, protecting themselves by avoiding and not elaborating on difficulties, and also projecting their difficulties onto others. Problematically, this may reinforce a work culture in which no individual actually takes responsibility for the ongoing difficulties, conflict and struggles. Thus, political and legislative changes may be negated or ineffective unless addressed within the context of this dynamic; namely, the value, emotional and meaning systems within services, i.e. the nature of the relationship between the support worker and resident. Indeed, paid staff are often the *only* meaningful relationship that people with learning disability have in their lives. Such findings are discussed in light of existing theory, research and practice.

2. INTRODUCTION

2.1 OVERVIEW

The current study is an Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) of the emotional and psychological experience of being a support worker in a Learning Disability Service. This introduction will provide background information on current policy and service contexts; the psychological experience of being a support worker; and explore how Cognitive Analytic Therapy (CAT), psychoanalytic and altruism ideas may facilitate understanding of the emotional, relational and interactional dynamics in this role. I will elaborate on the rationale and aims of the current study, including the decision to adopt a qualitative approach.

2.2 HOW I CAME TO THIS STUDY

My personal experiences

I came to this research with my own experiences, values, ethics, attitudes and assumptions, which has led me to write in the first person rather than 'the researcher' (Webb, 1992). During my childhood, I lived in various different countries, frequently moving between the cultures of English (paternal) and Chinese (maternal). I have since reflected on the fluid nature of these (literal and emotional) movements, through both wider narratives and idiosyncrasies of language, ethnicity, race, customs and moral values. Whilst I hope that these experiences have engendered a security in experiencing and coping with ideas of 'difference' and diversity', I have come to understand myself as situating 'the space between'; i.e. between cultures, between languages, between interests, between people and, perhaps, between myself. I have noticed the chronic resilience of this narrative, or identity, emerging as a feeling of 'disconnection' and 'detachment' in numerous group activities. It is this relationship with myself and others which, I believe, has led me to identify strongly with, the historically marginalised, i.e. people with learning disabilities, and thus pursue this research.

My interest for this field is also informed by my experiences of being an assistant and trainee clinical psychologist working in various residential care homes for people with learning disabilities. During these experiences I began to notice the intense, poignant and powerful impact of working closely with support workers. I felt drawn to their narratives of working lengthy double shifts earning relatively little, whilst being dogged by bureaucratic documenting demands and the emotional sphere of working so intimately with people with complex difficulties. There also seemed to be a sense of moral gratification and deeper personal fulfilment that came with the role. I noticed myself becoming repeatedly, and with much concern and unease, drawn to their high levels of tension, distress, anxiety and frenzy. I wondered how support workers could tolerate such intense feelings, whilst also being

perplexed by regular, and indeed, routine acts of going into their own time (unpaid) and even using their own money to provide the best support and quality of life for the residents.

As I paused to reflect on these experiences and my own personal reactions, it raised numerous questions regarding professional identity, boundaries, and the nature of emotional gratification and moral fulfilment. I experienced an intense pull and fascination with support workers' endeavours towards supporting residents lead 'happier' and 'fulfilling' lives. Concurrently, I noticed an acute uneasiness and discomfort at what it was costing them (in their personal lives) to deliver such a quality of care. Whilst, I am not stating that I experienced a universal sense of all support workers like this, there was a strong penchant towards this observation.

I have since become conscious of my (perhaps) over identification with their (and others') narratives of moral and ethical obligation towards supporting people maximise their quality of life. They seem to carry an obligation which seemed to surpass the aspiration to see people with learning disabilities lead fulfilling lives, to answering a deeper internal system of morality or 'moral compass', which if left unchecked has the potential to fracture the integrity of personal and professional identities. I have been alarmingly and disconcertingly forced to recognise my own frenetic penchant towards such 'perfectionist' caring roles. Indeed, this can be evidenced by my commitment to becoming a clinical psychologist. Within my musings I realised this would be a valuable focus for my major research project; understanding the emotional and psychological experience of support workers in learning disabilities services.

My Social Constructionist Stance

Clinical Psychologists are fortunate to have access to over a century of theory, practice, research and empirical evidence. Over this period there have been numerous epistemological, ideological and theoretical transformations and paradigm shifts, whereby ways of working, understanding and thinking have been deconstructed and reconstructed (Lock & Strong, 2010). The past 30 years has seen the gradual emergence of a new array of rubrics, such as 'critical psychology', 'discursive psychology', 'deconstruction' and 'poststructuralism' (Burr, 2003). These reflect a move away from empiricism, positivism and the belief that knowledge is obtainable through an observable and external reality. Social Constructionism is the term that has come to underpin these newer and more qualitative approaches towards knowledge.

Social Constructionism urges us to take a critical stance towards taken for granted knowledge (empiricism), to appreciate that all understanding is culturally and historically specific, that knowledge and understanding is constructed *between* people, and thus the primacy of language as the vehicle by which we understand and make sense of life (Burr, 2003). Personally, I have become increasingly cognisant of the authority of language, from

its ability to shackle and disempower individuals and groups, to reshaping understandings and liberating people. Constructionist approaches urge us to challenge and develop some of the existing research grounded in empiricism (Locke & Strong, 2010); a philosophy which fits comfortably with my personal values, ideals and interests. It is through this lens that this research has been undertaken.

2.3 CURRENT LEARNING DISABILITY SERVICES

Policy change and Learning Disability Services

The recent UK policy documents ‘Valuing people’ (DOH, 2001) and ‘Valuing people now’ (DOH, 2009) presaged a new direction in learning disability services; towards a human-rights model that people with learning disabilities are ‘people first’. These policies explicitly proclaim the importance of person-centred approaches with the underpinning principles of rights, choice, inclusion and independence. This ethos aims to empower people with learning disabilities to take control, have employment, educational and leisure opportunities, have choice over their daily lives and foremost have a better quality of life. The vision underpinning ‘Valuing people now’ (DOH, 2009) is one which sees people with learning disabilities leading autonomous lives, exercising control over their own finances, preferably in paid employment, and living as fully integrated members of the community in independent accommodation (Fisher & Byrne, 2012). The reiterated use of terms such as ‘valuing’ and ‘people’ highlights the agenda of embedding a service culture of choice, empowerment, freedom and humanity; working with ‘the person’ not ‘the problem’ or diagnosis.

The organisational, ideological and legislative shift in these policies can be understood from differing motivational and contextual backgrounds. Firstly, the underlying dogma (person-centred approaches, rights, choice, inclusion and independence) is consistent with promoting economic autonomy, which may be understood as a prerequisite for National UK Strategies of inclusive citizenship¹ (Department for Work and Pensions, 2008; DOH, 2006).

Alternatively, the pledge to reposition people with learning disabilities as active citizens in their own right and promoting social inclusion can be seen as ostensibly linked to the values and advocacies of numerous disability activists (Finkelstein, 1980; Goodley, 2000; Priestley, 1999). Fisher and Byrne (2012) interestingly, although perhaps cynically, propose that ‘Valuing People’ (2001) is Janus-faced, with the understanding that progressive critiques of the welfare state have been adopted to further essentially neo-liberal reforms (Burton & Kagan, 2006; Cowden & Singh, 2007). They postulate that empowered citizenship is conflated with consumer choice without taking account of the challenges many people face

¹ This is also consistent with the Department of Health’s (2003) ethos of providing a National Health Service that is accessible, fair and equitable to all patients’ needs.

in making such choices (Dowse, 2009). Within this policy context the role for learning disability professionals has changed from 'care' to 'enabling', as measured by criteria such as living independently and exercising financial autonomy, particularly through managing personal budgets, and preferably by entering paid employment (Fisher & Byrne, 2012).

However, an incongruence appears to have emerged between government models of promoting personalised care, and a contemporary welfare state characterised by the imperatives of performativity (Lyotard, 1984). This performativity emphasises a prescriptive framework, adherence to procedures, goals, targets and scrupulous documentation, so that performance at work can be scrutinised according to an instrumental rationality, emphasising measurable outcomes (Clarke, Gewirtz & McLaughlin, 2000). However, with measureable outcomes comes a reduced sense of individualised and personalised care, which is conflictingly, the foundations of recent 'Valuing People' (DOH, 2009) policies.

Finally, the policy reforms can also be seen as catalysed by various media related exposes of the 'abuse' and 'injustice' apparent in learning disability services (Kenyon & Chapman, 2011). Such documentaries have increased the public and political pressure on national policy change.

Within this milieu, the specialist needs of people with learning disabilities have been increasingly discussed (Mencap, 2007; Sowney & Barr, 2004). Indeed, the past 20 years has seen significant research and political endeavour into meaningfully involving people with learning disabilities in decisions regarding numerous aspects of their lives (Finlay, Antaki & Walton, 2008a; Young & Chesson, 2006). Much endeavour has focused on developing ways to support people with learning disabilities to gain control, become more actively involved in decision making and through changing service structures and philosophies (Jingree, Finlay & Antaki, 2006). There has also been significant financial investment, namely the 'Choice and Control' goal of 'Valuing People' (DOH, 2001) to fund advocacy and person-centred care projects. Finally, policy has also illustrated efforts to create comprehensive networks of providers, by moving from the statutory sector to an evolving independent sector (Fisher & Byrne, 2012).

A need for change

Despite the dominant policy context and various legislative, ideological, organisational and macro-level changes, research continues to indicate the need for change. Sir Jonathon Michael's Independent inquiry 'Healthcare for All' (DOH, 2008a) carried a salutary, candid and grave message that people with learning disabilities have greater need for healthcare than other people, yet have worse access to the care that they actually need and poorer health outcomes. Other research purports that people with profound learning disabilities and more complex needs have significantly lower levels of daily choice availability (Burton-Smith, Morgan & Davidson, 2005), consistent with 'Valuing People' (DOH, 2001) that this

group of people are the most excluded, least independent and most likely to lack control in everyday life.

Further, authors allege that the quality of support remains generally low and inadequate (Carnaby, Roberts, Lang & Nielsen, 2011). Examples of this entail over-reliance on the use of anti-psychotic medication (Ahmed et al., 2000), low levels of engagement, high levels of inactivity (Mansell, Beadle-Brown, Macdonald & Ashman, 2003), poor understanding by frontline staff of the need for individualised communication strategies and an associated over-estimation of service users' communicative abilities (Bradshaw, 2001). Indeed, as Mansell states:

‘The dominant model of support in services for people with learning disabilities is relatively unskilled caring and ‘minding’. The evidence is that staff do not generally interact with the people they support in a way that enables them to achieve greater levels of independence, participation or integration’ (DOH, 2007a, pp. 8).

He also remarks on the significant disparity between services, in their level of quality, with the ways in which staff provide support being seen as a major factor (Bradshaw et al., 2004; Jones et al., 2001; Mansell, Bennet, Northway, Mead & Moseley, 2004). Ultimately, the evidence suggests that much is to be done before it can be said that people with learning disabilities are socially included in a meaningful way as a result of the ‘capable environments’ supporting them.

2.4 DECONSTRUCTING THE PROBLEM: POLICY, POWER AND CHOICE

The question emerges: to what degree are top-down national strategies actually impacting on the lives of people with learning disabilities? To explore this question, attention must be focused and attuned to the idiosyncratic processes of enabling ‘choice’ and ‘control’.

A Social Constructionist perspective argues that choice and control arise in the manner with which people talk to each other (Burr, 2003). These emerge within which utterances are taken up and which are ignored, in how and what options become offered, in how preferences are expressed, how information is presented, how spaces are opened up for people to express preferences, and how spaces are closed off (Hibberd, 2005). Expression and recognition of preferences in everyday interactions are acutely important for people with communication difficulties, who may have restricted access to other sites in which they might exercise control over their lives (Jingree, Finlay & Antaki, 2006). Indeed, this process is further complicated and convoluted by the interplay with the emotional reactions and feelings of staff, working in learning disability services. Whittington and Burns (2005) found that the role entails a variety of complex and powerful emotions, such as happiness, anger, guilt, sympathy, resentment and frustration. Thus, any government policy must not just

promote ‘choice’, ‘autonomy’ and ‘independence’ as solitary aspirations, but within the context and understanding of difficulties of learning and communication, and staff’s emotional spheres.

The problems of translating policy goals of choice and autonomy into practice for people with learning difficulties have been discussed by commentators (Beamer & Brookes, 2001; Edge, 2001; Harris, 2003). The obstacles include poor communication, discriminatory attitudes and a lack of understanding in relation to this vulnerable group (DOH, 2008a; DOH, 2009; Mencap, 2004). The UK government report ‘Improving the Life Chances of Disabled People’ (Prime Minister’s Strategy Unit, 2005) discussed two main barriers: supports are often not matched to the individual, rather disabled people are expected to fit into existing services and services tend to focus on incapacity, inability and risk, with the result that dependency is created. This article frankly and forthrightly exposed a culture of care and dependency in health and social care services in the UK, in which those with significant cognitive and/or communication impairments are particularly at risk of being denied choice and control in their lives.

2.5 NARROWING THE FOCUS

It is the challenge facing the staff of learning disability services, namely the support workers who provide 24-hour care, where the focus of this research begins to emerge. To achieve ‘personalised’ services which promote enablement as presented within ‘Our care, our health, our say’ (DOH, 2006), the Department of Health states there is a need to develop the skills of staff at all levels (2008a)². Previous surveys of nurses’ attitudes, though minimal, suggest that without education and training, their attitudes remain similar those of the general public (Shanley & Guest, 1995). Policy-makers also recognise that even with service structural changes and the types of services available, without a sensitive workforce these broader values will not be achieved (DOH, 2005).

It thus follows, in my opinion, that any policy change must address experiences of ‘choice’ and ‘power’ at a one-on-one level, namely the relationship and interactions between people with learning disabilities and the support workers, spending long and extended periods in their role. If real, meaningful and profound change is to be accomplished this dynamic is crucial. If ‘people first’ is to be a meaningful aphorism, as opposed to a superfluous promotional slogan, then the spotlight must be switched to the value, emotional and meaning systems within services, i.e. the nature of the relationship between the support

² The idea of developing staff skills was originally set out in ‘Valuing people’ (DOH, 2001), which outlined the role of community learning disability teams (CLDTs) to provide the training and support needed, whilst the updated strategy within ‘Valuing people now’ (DOH, 2008b) addressed how the recruitment, training and support of paid carers of people with learning/intellectual disabilities should be approached. This illustrates that drives to promote staff skills and development have been present for some time.

worker and person. Paid staff are often the *only* meaningful relationship that people with learning disability have in their lives.

This research takes place in the political climate of policy, ideological and organisational focusing on the moralistic values of choice, freedom and equitable care. Whilst some research has explored this from the perspective of people with learning disability (Jones & Parry, 2008; Smyt & Bell, 2006) there is significantly less from the perception of support workers. This thesis seeks to examine, in detail, one aspect of the support worker experience, namely the emotional experience of support workers in their role within learning disability services. Although research has explored the experience of support workers from the perspective of 'stress' and 'burnout', there is a relative dearth on areas such as emotions, sense-making, their constructing of systems, relationships and motivations.

2.6 NATURE OF THE SUPPORT WORKER EXPERIENCE

This section will present an overview of the different aspects of the support worker's role and the relevant literature. A particular focus will be the emotional experience and how support workers make sense of their role.

Continuity and boundaries

The principal responsibility of support workers in a learning disability service is to provide continuous care for people with learning disabilities, day and night, all year round (Menzies Lyth, 1959). The staff therefore bear the full, immediate and concentrated impact of stresses and gratifications arising from care, and account for the largest expenditure (Jenkins, Rose & Lovell, 1997). The conceptual nature of the work setting is one of permanence and continuity; the care home does not 'shut down' or 'close' and as such there is a reduced sense of boundaries. The support worker leaves work knowing that the people with learning disabilities continue to live and be supported. Furthermore, a 'duty of care' means that support workers, whilst off shift, must contact work if something arises which requires immediate attention. Menzies Lyth (1959) describes that, from the outset, this setting is intrinsically uncontainable, physically and emotionally for the staff member.

Support working entails carrying out tasks which, by 'ordinary' standards, may be distasteful, disgusting and boring, such as being in close proximity to bodily fluids, intimate physical contact and household chores (Thomas & Woods, 2003). Bromley and Emerson (1995) reported that the repeated and recurrent nature, 'the daily grind', of chores was one of the significant sources of stress associated with caring. These roles may also arouse a variety of emotions and impulses, due to the physical intimacy and closeness of the relationship.

Psychoanalytically, they may be understood as evoking strong libidinal³ and erotic wishes, in the support worker, that may be difficult to control (Menzies Lyth, 1959).

Support workers undertake a diverse range of tasks including: direct interaction with the people they support, food preparation and service, domestic tasks, administration, training and attending meetings. Thus, their relationship to the person with learning disabilities takes on different dynamics and roles, including teacher, facilitator and/or advocate (Windley & Chapman, 2010). Support workers must thus balance different requirements and demands from varied sources. For instance, a focus on documentation and adhering to procedures from management, adhering to a busy scheduled from shift organisers, spending quality one-on-one time as to the person's wishes, whilst also managing their own desires and beliefs of effective working⁴.

'Cure' and 'expertise'

Support workers are in regular contact with people who may present in physical, emotional, cognitive and behavioural ways that are 'uncommon' and difficult to make sense of. Bromley & Emerson (1995) found that a significant source of concern, stress and confusion for staff was the apparent absence of an effective way forward. The notions of 'recovery' and 'cure' have challenging implications as it is not certain whether people are actually 'ill', how much 'progress' can be made, how thus to conceptualise the 'problem', and there is the real threat and reality of death. This confusing and ambivalent makeup of ideas creates a backdrop to the support worker role which may be undefined, blurred and ambiguous.

A component of the support worker's 'task' may be understood as to care for people who 'cannot be cared for in their own homes'. Thus, the support worker is implicitly given a status of 'expert'; to cope with what other people and/or services cannot. Most notably, relatives have vastly contrasting feelings towards support staff, showing appreciation, gratitude, affection, respect, a touching relief that the hospital copes, helpfulness, concern for nurses in their task, anger, blame, frustration and resentment (Menzies Lyth, 1959).

³ Libido, a Latin term meaning desire, want, amorous desire, is defined as the instinctual sexual energy underlying all mental activity. Psychoanalysis saw libidinal development as spanning the whole psychosexual evolution of the individual from birth to adulthood. Libido is the psychic structure that results from the individual's Oedipus complex and the modes of its resolution, the adolescent phase and the resulting genital organisation of the adult and choice of object (Freud, 1893). Some confuse the term libidinal wishes with the idea of specifically genital feelings. Sexual gratification is the broad concept of bodily pleasure, the states of excitement and pleasure experienced since infancy. When individuals discuss happiness, excitement, pleasure, anticipation, love or longing, this is describing libidinal wishes (Ursano, Sonnenberg & Lazar, 2004).

⁴ This is consistent with Windley & Chapman (2010) who found that support workers often described experiencing 'role conflict', the sense of being in pulled in different directions; professionally and emotionally.

Disability and support

The role involves working closely with people who require high levels of support and facilitation in numerous areas of work, and who struggle at tasks that many others find easy. King (2005) described that people with learning disabilities have powerful feelings of 'woundedness', weakness, limitation, difference and vulnerability, alongside the need for independence and autonomy. This may arouse very strong and mixed feelings in the support worker: pity, compassion, love, guilt, anxiety, hatred and resentment of the people with learning disability who arouse these emotions (Jahoda & Wanless, 2005), but also envy of the care and attention given to them (Menzies Lyth, 1959). Buckhalt, Marchetti and Bearden (1990) reported that resident characteristics of low levels of ability and limited capacity for social interaction, negatively affect staff satisfaction and stress⁵.

'Challenging behaviours'

Harris (1993) reviewed 168 incidents of 'challenging behaviour'⁶ in one month finding that 51% showed punching, slapping, pushing or pulling, 24% kicked, 21% pinched, and 20% scratched, amongst other behaviours. Lloyd & Williams (2003) felt these cold figures do not capture the stress and struggle of this role. Numerous studies have illustrated that aggressiveness, resistance, self-destructive behaviour, and screaming are common among people with learning disabilities (Jahoda & Wanless, 2005). Such behaviours often result in the use of physical restraint (Lovell, 2004; Menckel, Carter & Viitasara, 2000). Lundström, Graneheim, Eisemann, Richter and Astrom (2005) found that 40% of carers in group homes for people with learning disabilities reported incidents involving violence from residents, and the carers seemed to accept violence as a natural part of daily care.

Research suggests that challenging behaviours produce a range of emotional reactions in support workers, such as fear, irritation, anger, sadness and disgust (Bromley & Emerson 1995; Hastings & Remington 1994a). Jenkins, Rose and Lovell (1997) demonstrated that challenging behaviour is a factor in predicting staff anxiety and lower job satisfaction; thus having implications for staff well-being. However, much less clear is an understanding of the association between challenging behaviour, staff attributions of challenging behaviour and emotional reactions of staff. Some research has reported associations (Wanless & Jahoda 2002), others have not (Bailey, Hare, Hatton & Limb, 2006; Rose & Rose, 2005).

⁵ This is consistent with Lloyd and Williams (2003) who explored the reaction of support staff to unresolved incidents and painful episodes. They found that staff described numerous emotions, such as feeling hopeless, shocked, hurt and 'hyped up frustration' about how to reach and teach people with severe learning disabilities.

⁶ Emerson (1995) defines a challenging behaviour as a 'behaviour of such intensity, frequency or duration that the physical safety of the person is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities'.

The impact on staff of challenging behaviour has been explored in terms of emotions, stress levels and behavioural responses (Lloyd & Williams, 2003). Emerson & Hatton (2002) reported that in response to aggressive behaviour from clients, half or more of the staff usually report such emotions as annoyance (in 57% of cases), despair (41%), sadness (40%), anger (39%), fear (27%) and disgust (16%). Emerson (1995) described the clinical responses of staff stresses as hopelessness, anxiety and PTSD, with the connected behavioural responses as avoidance to imitating the residents' behaviour. Hastings, Reed & Watts (1997) reported that staff have difficulty managing their own feelings of aggression, with further reactions of lack of warmth, lack of attention, exclusion from community services and a hardening of attitudes. Lloyd & Williams (2003) found that staff admitted that they often pretended that nothing had happened after being attacked by residents, feeling that residents would be unaware of the hurt incurred and they did not want other staff to know they were upset or perceive them as unable to cope.

Conclusions

This section aimed to convey the profound and complex emotionality of the support worker role; this backdrop entails experiencing, coping with and resolving an array of emotions. As illustrated from the different sections, these emotions emerge, actualise and become intensified through the multi-directional and multi-faceted nature of the role. Namely, interacting with different individuals (residents, family members, staff, the organisation and the public) each occupying their own position, emotional sphere and most likely unconscious relationship with difference, damage and normality.

The predominant focus of research into the support worker role has been on identifying what behaviours, client characteristics, activities or service models impact on their levels of stress and emotions⁷ (Storey, Collis and Clegg, 2011; Whittington & Burns, 2005). However, there is a significant dearth on *how* these emotions are elicited. Namely, what interactional processes, or relational activities and role 'dynamics' give rise to the complex array of emotions that support worker's may experience.

The following section aims to elaborate on the support worker experience from two theories: Cognitive Analytic Therapy (CAT) and psychoanalysis. CAT has relevance due to its focus on interactional processes, relational processes and role dynamics, which is salient given the importance of the support worker-resident relationship⁸. Psychoanalysis has importance due to encompassing both a model of therapeutic intervention and an

⁷ With regard to emotions the focus of research has been on what emotions are elicited (Hastings and Brown, 2002; Dilworth et al., 2011).

⁸ King (2000) states these processes have direct relevance to the roles that teams may become stuck in and the attached emotional experiences. This is consistent with Bancroft et al. (2008) who report that CAT's relational model is suited to the systemic nature of learning disability work, as the immediate working context involves negotiating and collaborating with multiple agencies.

underlying theoretical model of human personality and its development⁹ (Royal College of Psychiatrists, 2006).

2.7 COGNITIVE ANALYTIC THERAPY AND RECIPROCAL ROLES

CAT¹⁰ is a time-limited therapy, evolved as an integration of cognitive, psychoanalytic and Vygotskian ideas (Llewelyn, 2003). Bancroft et al. (2008) emphasise the inherent elegance of CAT in respecting all therapeutic models, thus allowing for fluid movement between lexicons whilst retaining the same meanings¹¹, i.e. the dialogic¹² nature of CAT. Accordingly, I contend that this model can offer something unique to understanding the emotional experiences, roles, sense of identity and motivations of support workers working in learning disability services¹³.

Reciprocal roles

Ryle (1999) described how our early learning about the social world is stored in the form of internalised templates or reciprocal roles (RRs)¹⁴. These consist of a role for self, a role for other and a paradigm for their relationship. Common examples are 'bully' to 'victim', 'controlling' to 'controlled' or 'admiring' to 'admired'. Ryle postulates that when an individual adopts one pole of the RR pairing, the other person feels pressured to adopt the

⁹ It thus has implications for both therapeutic interactions and the psychological aetiology of learning disabilities.

¹⁰ CAT was developed in the early 1980's by Anthony Ryle, who felt it was important to develop a therapy that integrated the best of different approaches to people's problems and that could be researched and refined with the growing experience of clients and therapists (King, 2000). CAT was originally designed as a model of individual therapy but now offers a general theory of psychotherapy with applicability to a wide range of conditions in many different settings (Ryle & Kerr, 2002; Llewelyn, 2003). The literature has expanded to indirect work, such as ideas about psychologically harmful environments (Walsh, 1996) and contextual reformulation (Ryle & Kerr, 2002).

¹¹ Bancroft et al. (2008) argue that this engenders a more flexible and integrated approach, a way of formulating *within* and *with* the multitude of theories, as opposed to separating out commonalities and discrepancies.

¹² Dialogic or dialogism refers to the concept used by the Russian philosopher Mikhail Bakhtin, who contrasted the dialogic and the 'monologic'. Dialogic work carries on a continual dialogue with other works and authors, it does not merely answer, correct, silence or extend previous ideas but informs and is continually informed by previous work (Markova, 2003). For Bakhtin, all language, indeed all thought, appeared dialogic. In this sense everything anybody ever says always exists in response to things that have been said before and in anticipation of things that will be said in response. Accordingly, all language (and the ideas which language contains and communicates) is dynamic, relational and engaged in a process of endless redescriptions of the world.

¹³ This is consistent with King (2000) who states that there is an expanding volume of evidence on the effectiveness of CAT, with modifications, for people with learning disabilities, support teams and their carers.

¹⁴ CAT ideas on how people internalise and fully adopt patterns of relating, named RRs, has largely been informed by Kleinian Object Relations and Vygotskian activity theory (Moss, 2007). Ryle (1993) integrated these theories to illustrate how multiple roles arise initially from the primary carers' relationship with the infant.

congruent pole¹⁵. CAT suggests that our sense of self is actually constituted by these early socially meaningful experiences (Moss, 2007). Ryle & Kerr (2002) purports that the child learns to predict the responses of the care-giver as a consequence of their actions, thus engendering a number of reciprocal responses to their caregiver. For example, a compliant child develops in response to a controlling mother, or neglected child to a neglectful mother. Therefore, the child learns, and internalises, both the child and parental derived poles of the reciprocal relationship¹⁶. Ryle & Kerr (2002) outline some of the common childhood derived reciprocal role patterns, as detailed in the table below.

Parent derived roles	Child derived roles
Ideal care-giver	Ideally cared for / fused dependency
Over-involved	Over-dependent, suffocated
'Good enough'	Appropriate autonomy and trust
Incomplete, unreliable	Premature autonomy, fragile, needy
Conditional accepting or loving	Striving, performing
Dependent / uncaring	'Parental child'
Dependent / controlling	'Parental child'
Rejecting / controlling	Deprived / guilty or rebellious
Abusive / explorative	Crushed or angry

Table 1: Common childhood-derived reciprocal role patterns (Ryle, 2002)¹⁷

Reciprocal roles and people with learning disabilities

¹⁵ Ryle (1999) argued that although consistent with the psychoanalytic concepts of transference and countertransference, the explanations of these concepts are unduly mystifying. He felt that RRs offer a less complicated and more transparent explanation of the pressure involved.

¹⁶ This can be paralleled to Vygotskian theory in which the relationship is internalised by the infant in the form of 'voices'.

¹⁷ In particular, Ryle & Kerr (2002) emphasise the power of parents who may impose rather than negotiate their reciprocal role patterns and who have the power to define the agenda of these. The parents' personal restrictions and distortions may create idiosyncratic and confusing patterns and they may be unable to supply mediating concepts with which to make sense of some aspects of reality. Thus, observed and experienced role enactment with parents become powerfully, fundamentally and pervasively internalised and re-enacted by children, impacting on the development of their internal world and how they will be often unconsciously re-enacted (Ryle & Kerr, 2002).

People with learning disabilities have a historical legacy characterised by marginalisation through fear and ignorance (Wright & Digby, 1996). The pejorative names, such as ‘spastic’, ‘idiot’ or ‘imbecile’, used to refer to people with learning with learning disabilities, coupled with their segmentation in institutions, is symbolic of how they are regarded by society (Gray & Jackson, 2002). Moss (2007) states that their vulnerability has led them into RRs of being abused¹⁸ by those with greater power (‘abusing’ to ‘abused’).

Lloyd and Williams (2003) report that the relative isolation of people with learning disability results in them being exposed to a narrower assortment of relationships compared with others, thus being more likely to develop a more restricted array of RRs with a more concentrated force to reciprocate. Psaila and Crowley (2005), discussing the RRs of people with learning disability, found four recurrent RRs of contemptuous to contemptible, neglecting to deprived, rejecting to rejected, abandoning to abandoned¹⁹. King (2005) explained these findings by the limited and punitive nature of interactions impeding the development of mutually beneficial reciprocation. Lloyd and Williams (2004) found five common reciprocal role procedures that staff found themselves in, namely:

Persecuting	to	persecuted
Ideally caring	to	ideally cared for
Rejecting	to	rejected
Punishing	to	punished
Controlling	to	compliant

Moss (2007) explains that staff do not permanently occupy single roles, but indeed they may enact polarised positions²⁰, such as the staff member who is the ‘ideal carer’ to the those more allied to ‘punishment’.

Reciprocal roles and support workers

Bancroft et al. (2008) described that in LD services, one of the most familiar staff roles is the ‘rescuing’ RR. These RR procedures centre upon striving for perfection, common for staff who may wish to ‘heal others’. Collins (2006) also described that support workers may be attracted to the role to meet a need to be the ‘perfect carer’, which he hypothesised as a

¹⁸ Moss (2007) states that whilst such abuse has been increasingly challenged there remains frequent interactions of being ignored, infantilised and overprotected, all illustrative of a chronic inhibition of healthy relating.

¹⁹ Ryle & Kerr’s (2002) research confirms these RRs except that ‘damaging to damaged’ was replaced by ‘not hearing or understanding’ to ‘not heard or understood’.

²⁰ This links to Ryle and Kerr’s (2002) postulation that the staffing system can itself become a part of the reciprocation and therefore re-enact and reinforce patterns. Thus, by understanding the common RRs of people with learning disabilities one can begin to conceptualise the types of relationships and dynamics that support workers may enter, or be forced, into.

compensation for being unable or failing to adopt this position in a previous relationship. Lloyd and Williams (2003) found that ideologically and motivationally, staff were striving to 'create a better world' but also seeking personal acceptance through accepting others. Collins (2006) reported that this rescuer role may promote power and control, thus adopting a position of parental authority, ultimately belittling and disempowering the resident. Concurrently, others in their veneration of a marginalised and disempowered client group, may take the appeasing, acquiescing and supporting role too far, thus excusing any intolerable behaviour ('worshipful' to 'enobled') (Bancroft et al. 2008).

Researchers have observed the tendency of support workers to be reluctant to display or express pain, fear or disgust, for concern peers may see them as incompetent and unable to cope (Lloyd & Williams, 2003). Within RR procedures, these perceived vulnerabilities are incongruent with the pole of 'ideal carer', thus support workers may rapidly shift to the opposite pole, which may be characterised by previous experiences of being punished, powerless and unable (disabled) to care. This may explain Lloyd and Williams' (2003) observation that support workers and residents frequently oscillated between common RRs, which causes staff splitting; arousing anger, dismay, frustration and rejection.

2.8 ANALYTIC THEORIES ON LEARNING DISABILITIES

Hollins and Sinason (2000) propose that support staff must work with and resolve various psychic organisations (or unconscious internal conflicts), due to the inherent existence of the disability from birth, particularly the conscious and unconscious fantasies that accompany it. These entail the existence of the disability itself, loss (of the normal self who would have been born), sexuality (internally distorted by the impact of the disability), dependency, fear of death and murder (existing as part of a group that society marginalises). This can be linked to Linington's (2002) ideas that disabled individuals may come to symbolise damaged aspects of the self that people want to be rid of, evidenced by the movement to veil people with disabilities away from the community. Issues of loss, of the perceived normal self who would have been born, may be associated with the support worker's projections of loss, regret and unfulfilled desires. De Groef & Heinemann (1999) said that those who care for people with disability must face their own disability, weakness and wounds, a disposition that many would habitually ignore, conceal, deny or thrust on others. Symington (1992) elaborated that in the face of such challenge, they may experience contempt and guilt, pushing unwanted parts of themselves into those who are different, resulting in denigration, contempt, rejection, abuse and exclusion.

Mannoni (1972) elaborates on these ideas to a more global level of culture and society. She describes that the marginalisation, rejection and objectification of people with learning disabilities results from the 'normal' person's failure to recognise the fears, myths and superstitions that clouded their childhood, and unknown to themselves, live on within. She describes that as the 'normal' adult meets someone who is socially different and not of the

expected mould, they waver between positions of rejection and charity. She explains that what hinders movement beyond such a dynamic is the dominance of developmental theories which take the human's past history into account only to the extent that it favours or hinders maturation, or the social norm of maturation.

2.9 ALTRUISM AND CARING

Although it is difficult to reach a precise definition of altruism, broadly speaking it refers to motivation that is 'other-directed' or that aims to increase or benefit another individual's well-being (Batson, Ahmad & Lishner, 2009). There is a longstanding tradition that health care careers are expected to involve the provision of compassionate care and helping behaviour; the view that medical professionals are or should be altruistic (Coulter, Wilkes & Der-Martirosian, 2007). This has led to an increasing demand for altruistic, humanistic and patient-centred qualities among health care professionals, both at work and during recruitment. Furthermore, the promotion of relevant guidelines and policies has become increasingly salient among health care ethics boards, training programmes and medical organisations (Burks & Kobus, 2012).

In the context of caring for people with learning disabilities, altruistic behaviour may manifest in behaviours that supersede typical professional duties, such as a carer may go out of their way to write a letter to help a patient obtain an expensive piece of equipment or by making home visits. Such behaviours may be construed as entailing a degree of sacrifice or loss, such as financially or in time. Concurrently, such behaviours may inherently be understood as facilitating gains, such as a positive feelings about oneself for helping another or the avoidance of guilt and distress at not helping (Burks & Kobus, 2012).

Socio-cultural factors of the caring role may also exert a pressure and expectation on the support worker to be altruistic. The professional culture of 'providing care' includes customs, beliefs, communication styles, actions and thought processes that are transmitted via informal norms, role modelling, observational learning and implicit social conditioning (Coulehan & Williams, 2001). Perhaps most strongly, in a field such as caring for people with severe, profound and lifelong difficulties, there is a stereotype of the 'good support worker' to be altruistic, unconditionally caring and humanistic.

2.10 CONCLUSIONS

The literature explored in this review has illustrated that the processes of enabling choice and inclusion are complex and challenging, with innate psychic challenges of working with 'disability' impacting on the interactions, emotions and roles dynamics with support workers. I contend that the spotlight must be switched to the value, emotional and meaning systems within services, the emotional nature of the relationship between the support

worker and person. Although research has explored this from the perspective of the person with learning disabilities there is a relative dearth of literature regarding support workers.

This research thus seeks to provide a voice for a marginalised and under-researched group, namely support workers in learning disability services. The sparse research available on these individuals has focused on delineating the specific characteristics that impact on their level of stress, such as the client behaviours, client characteristics, activities or service models (Storey, Collis & Clegg, 2011). However, the current research seeks to put the support workers' perspective, view and experience at the centre, thus allowing for a new understanding of this caring role to emerge based on their experiences, as opposed to imposed ideas and characteristics. Furthermore, as described above, there will be a particular focus on interactional and relational processes, which is paramount given that policies of promoting choice, freedom and autonomy in people with learning disabilities are embedded within relationships. For this reason, I have decided to draw upon CAT ideas (particularly reciprocal roles) as this theory promotes thinking in interactional, relational and process ways. This theory has also rarely been applied to support workers in learning disability services and thus it is providing a novel area of research enquiry.

In conclusion, the available literature reveals some important and interesting findings, although I contend that there are significant gaps in the available knowledge and understanding around emotions, sense-making, construct systems, relationships and motivations of support workers, which this research aims to address.

2.11 STUDY AIMS AND RESEARCH QUESTIONS

In line with the aims of this study the primary research question was framed as:

What is the emotional and psychological experience of support workers in a learning disability service?

This question was explored via further subsidiary questions:

- What emotions does the role evoke?
- How do support workers make sense of their emotions and experiences?
- What motivations and values do support workers hold about their role?
- What roles and positions do support workers adopt in their work?

3. METHODOLOGY

3.1 OVERVIEW

This study aims to explore the emotional and psychological experience of support workers in learning disabilities services. I have employed the qualitative methodology of Interpretative Phenomenological Analysis (IPA), developed by Smith & Osborn (2008), to meet these research aims. This section explains the rationale behind the employed methodology, detailing participant recruitment, data collection and analysis and summarising the steps I have taken to adhere to ethical and quality guidelines.

3.2 A QUALITATIVE APPROACH

Research exploring the experiences of support workers in learning disability services have, to date, primarily focused upon staff experiences of challenging behaviour (Storey, Collis & Clegg, 2011). This work has predominantly utilised a quantitative research methodology. It has attempted to isolate measurable variables such as the topography of the residents' behaviour, or the emotions, beliefs or actions of staff (Dilworth, Phillips & Rose, 2011). However, research illustrates that training on challenging behaviour, particularly cognitive behavioural theories, does not always increase staff morale nor change practice (Rose et al., 1998). There is a relative dearth of qualitative research into the experience of support workers in learning disabilities services, particularly in comparison to the wealth of quantitative studies.

As the aim of this study is to capture in-depth the experiential nature of the support worker's role, I have adopted a qualitative methodology. This has the benefit of allowing a detailed study of phenomena that are not easily quantifiable by quantitative methods, but more by explorative research, that also promote the emergence of unanticipated findings (Barker, Pistrang & Elliot, 2002). To best facilitate exploration of experience I will use a semi-structured interview (Appendix 1), which Smith, Flowers and Larkin (2009) argue encourages flexibility, yields rich data and allows exploration of interesting, important and salient ideas that are brought up by the participant in the interview.

3.3 INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

Rationale for choosing Interpretative Phenomenological Analysis

IPA, developed and articulated by Jonathan Smith, is embedded within three philosophies of knowledge: phenomenology, hermeneutics and idiography (Smith & Osborn, 2008). In this section I will illustrate how these underpinning ideas are both relevant to this research's

experiential focus of the support workers role and also the broader field of learning disabilities.

Phenomenology is concerned with how knowledge of the world is grasped by human beings (Ricoeur & Embree, 1967). It is interested in 'lived experience', what the experience of being human is like, in the numerous aspects that are significant to us, and which constitute our lived world (Smith et al., 2009). The founding principle is that experience should be examined in the way that it occurs and in its own terms. Husserl & Welton (1999), argued the importance of 'going back to the things themselves', the experiential content of consciousness, alluding that this approach allows us to circumvent people's tendency to 'fit things' within our pre-existing categorisation systems. This issue is particularly relevant and significant to the experience of support workers, who work in a field dominated by pre-existing classifications and labels, such as 'learning disability' or 'challenging behaviours'.

Hermeneutics is the theory of interpretation (Schleiermacher & Kimmerle, 1977), focusing the researcher on the methods and purposes of interpretation itself, to uncover the intentions or original meanings of the author, or at least as 'closely' as possible. Schleiermacher (1998) raises the notions of grammatical and psychological interpretation: the former being concerned with exact and objective textual meaning; the latter to the individuality of the author or speaker. Idiography is concerned with the particular and the individual, this entails a commitment to detail, depth and that analysis must be systematic. It also refers to understanding how particular experiential phenomena (a process, relationship or event) are understood from the perspective of particular people, in a particular context, thus not eschewing global generalisations. This has increased relevance to this study, which exists in a field dominated by generalisations across people (diagnostically) and services (with diverse service models and staff bases).

Finally, at its simplest level, the support workers role is a subjective process. Who the support worker is, how they perceive their role, whether they make sense of it as a 'carer', 'teacher', 'guide' or 'parent', how they relate to the residents, how this relationship is experienced, and where their sense of identity lies, will make the experience unique and multi-faceted. All this suggests that external observation of any kind will not provide the lived feeling, the embodiment of such an experience which IPA can bring. Further, the qualitative framework, described above, connects strongly with the social constructionist nature of this research, in that it conducts a detailed examination of the individuals' personal experiences and perceptions, whilst considering the social context of these experiences from a 'critical psychology' perspective.

Other possible qualitative methods

In this section a rationale is presented for choosing IPA over other qualitative methodologies, namely Grounded Theory, Discourse Analysis and Narrative Analysis.

IPA was preferred over Grounded Theory as this may be considered more of a sociological approach (Willig, 1999), with an underlying positivist philosophy, which attempts to draw wider conceptual or theoretical explanations of psychological phenomena as opposed to capturing personal experience (Smith et al., 2009); the latter being in keeping with this study's aims.

IPA was preferred over Discourse Analysis as this is incredulous towards the accessibility of cognitions and focuses on language more in terms of its function in constructing social reality. Whilst the importance of language fits well with my social constructionist stance, this particular study is focused on the experience of support workers, in a field dominated by terminology and distinction. IPA undertakes the analytic process as a way to conceptualise sense-making and meaning-making in experiences (Smith, Flowers & Osborn, 1997), which feels more aligned to the present studies aims.

Narrative analysis was considered, given its focus on how people construct their own accounts (Burck, 2005), with sense, order or chaos created through their stories (Riessman, 2008). However, because of the strong focus on the temporal dimension and that narrative is only one way of meaning making (others entail metaphor or discourse), IPA can take into consideration narrative as part of a wider process system of sense-making, without being inhibited by its centrality (Smith et al., 2009).

3.4 PARTICIPANTS

Recruitment

Purposive criterion procedures (Patton, 1990) were employed to identify a sample of support workers, working in learning disability services. Due to my geographical location, I approached eight Learning disabilities services, covering Hertfordshire and Essex, which satisfied my service inclusion criteria (see section 3.3.2). Recruitment was undertaken by contacting these services by telephone, informing the manager of my research and providing the 'Research Information Sheet' (appendix 1) to be circulated to staff. The 'Research Information sheet' provided a summary of the research, what participating entailed, and participant inclusion criteria (see section 3.3.2). Six out of the eight Learning Disability services consented to circulating the Research Information Sheet to their support workers and two refused. Both of these stated that due to 'practical' and 'logistical' pressures they did not feel their staff could participate and they were not interested. Of the six services where information was circulated, on a follow-up phone call, three services responded by saying they had staff interested in participating. From this, seven interviews were organised, in a location that felt comfortable to participants, which for all of them was their care home in a quiet room.

Inclusion and Exclusion criteria

Service criteria

The inclusion criteria for services were that they had to be a nationally registered care home with Care Quality Commission (CQC) certification, providing 24-hour care, which is specifically designated to care for people with learning disabilities, between the ages of 18 and 65. The care home was to have no specialist designation, for instance being a dedicated service for people with 'challenging behaviour', physical problems, adolescents, autism, 'profound and complex disabilities' etc. The care home had to belong as part of a charity or private organisation, not NHS, to keep the sample homogenous, and due to the far higher prevalence of these types of services. The service had to provide space for seven residents or more. My previous experience had shown that care homes providing six or less residents, often had small staff numbers, working more intensively, thus providing difficulties logistically organising interviewing times. Further, smaller care homes were often specialist homes for people with 'milder' difficulties, with residents being more independent and spending longer periods in day centres or colleges. Having worked in these areas as a Trainee Clinical Psychologist I excluded any services that I had had previous contact with in the past.

Participant criteria

Participants had to hold a position of 'support worker', or an equivalent title. Participants had to have worked a minimum of six months in the role, thus excluding experiences that are related to being new to the role. I did not include any further criteria specifying years of work experience because Lernihan and Sweeney (2010) report that there was no association between years of experience of working with people with learning disability and feelings of stress and burnout. Thus, I included support workers with both short and longer years of work experience in this field. Participants had to have no formal qualifications, such as Nursing, Occupational Therapy, Speech and Language Therapy, Clinical Psychology or be in a position of management, as this would have decreased the homogeneity of the sample. Participants had to be English speaking, as due to qualitative research relying heavily on language there was a concern that the richness and meaning of language may have been lost if using a translator. However, as all of the participants worked at English speaking care homes this was generally a redundant criterion. There was no disability, gender, religion or sexual orientation restrictions on participants.

Sample

The three care homes provided total space for 8, 10 and 18 residents. Participants were seven support workers (five female and two male). Their ages ranged from 24 to 48. See table 1 below for further details of all participants.

Participant Alias*	Gender	Age	Length of time working in care home	Qualifications	Number of residents in care home	Ethnic Origin**
<u>Emeka</u>	Male	35	13 months	APLEX, NVQ2	8	Black African
Caroline	Female	24	11 months	None	8	White British
<u>Nnamdi</u>	Male	31	10 months	NVQ2	8	Black African
Anne	Female	42	8 years	NVQ3, LDQ3	18	White British
Francesca	Female	35	11 years	NVQ, LDQ3	18	White British / Mixed
<u>Habika</u>	Female	48	14 years	NVQ2	10	Black British
<u>Zarina</u>	Female	26	18 months	None	10	Black African

Table 2: Participant characteristics

* All participant names have been replaced with aliases to protect identity

** Ethnicity was self-identified by the participant

3.5 ETHICAL CONSIDERATIONS

Ethical approval was granted by the University of Hertfordshire Research Ethics Committee. Relevant documentation is provided in Appendices 2. The research complies with BPS Code of conduct, Ethical principles and Guidelines (1993).

Informed Consent

Prior to and during the meeting, all participants were provided with a detailed Research Information Sheet (appendix 1), which clearly set out the purpose of the study, the interview process, who would have access to the data and how it was stored. I also verbally detailed

this information upon meeting and stressed that participation was voluntary and they could withdraw at any time. Before interviewing, all participants provided verbal and written consent (see appendix 3).

Confidentiality

All participants were informed, written and verbally, of the limits of confidentiality prior to partaking. In particular, I explained that if anything were to arise during discussions that would put themselves or another at significant risk I was obligated to tell the relevant professional, namely their manager and/or a relevant outside body. I also explained that a professional transcription service with signed confidentiality agreements would be used²¹. They were aware that formal supervisors and representatives from academic bodies would look at the anonymised transcripts. Participants were informed that any quotes selected for thesis documents or journal articles would be fully anonymised.

Potential distress

There was the potential that partaking in this research may be distressing for participants, for example in describing the range of emotions that this role may evoke. This was addressed by providing information regarding the types of questions asked and areas of exploration prior to interviewing, thus allowing potential participants to make informed choices regarding decisions to take part. It was reiterated to participants that they could break at any time, terminate the interview and refuse to answer any questions that they did not desire to. Informed by my clinical experiences in this field I endeavoured to conduct the interviews sensitively to minimise the distress levels of participants. A debrief followed each of the interviews, in which I reviewed how participants had found the process, and provided a debrief sheet (appendix 4) detailing sources of support should they be interested.

3.6 DATA COLLECTION

A semi-structured interview schedule (see Appendix 5) was developed and re-developed through a process of assessing relevant literature and discussions with my supervisors. This was further informed by Smith et al.'s (2009) guidance on semi-structured interview development. The schedule was designed to be adaptable, with the ordering of sections being flexible based on what the participants brought. This aimed to facilitate the probing of unanticipated areas and a selection of brief questions was placed alongside the more structured questions to engender this. The interviews lasted between 54 and 72 minutes.

²¹ Participants were informed that the audio data would be destroyed on completion of my doctorate and anonymised data would be kept for five years post thesis submission (June 2017), in accordance with The University of Hertfordshire's 'Good practice in research' guidelines, after which it would be destroyed.

Five of the interviews were transcribed by myself and two by a professional and confidential transcription service, verbatim and with all identifying information removed.

3.7 DATA ANALYSIS

Data was analysed using IPA (Smith, Flowers & Larkin, 2009). This process was informed and adhered to guidelines for ensuring quality in qualitative research (Spencer, Ritchie, Lewis and Dillon, 2003; Yardley, 2000). Further, my supervisors were consulted throughout the process to ensure quality, as well as my attendance at peer IPA workshops where thematic material was reviewed for credibility.

Individual case interviews

The analysis was approached idiographically, with each interview analysed separately, facilitating the exploration and detection of repeating patterns whilst remaining receptive to new themes developing (Smith & Osborn, 2008). All recordings were listened to twice and transcriptions read numerous times. Initial exploratory comments were made in the middle column, reflecting preliminary thoughts regarding the content, language used and the structure of the text. As the transcript was read and re-read, I elaborated on these ideas with more conceptual, interrogative and interpretative comments (Smith et al., 2009). Gradually, I used the right-hand column to generate emergent themes from the exploratory comments section.

Generating emergent themes entailed moving to a level of abstraction general enough to allow theoretical connections to be made across themes and ideas. This process was embedded with a system of constant scrutinising and linking between text and abstractions, to ensure emergent themes remained grounded in the text.

Emergent themes

Once a list of emergent themes was generated, the next stage entailed making sense of connections and associations between these, and the subsequent organisation to form sub-themes. Smith et al. (2009) detailed how sub-themes can be identified through abstraction (putting like with like and developing a new name for the cluster); subsumption (where an emergent theme itself becomes a super-ordinate theme as it draws other related themes towards it); polarization (examining transcripts for oppositional relationships); contextualization (identifying the contextual or narrative elements within an analysis); numeration (the frequency with which a theme is supported) and function (themes are examined for their function). During this analytic process key quotations from the text were

chosen to symbolise and represent the emergent themes. An example of the analytic process for one interview is provided in appendix 6.

Cross Case Analysis

The next phase entailed exploring and identifying connections across cases. This was achieved by drawing up a table incorporating the sub-themes and emergent themes from all interviews. A similar process to the individual analysis was conducted again, whereby I examined and subsequently clustered the sub-themes into main and superordinate themes, representing shared higher-order qualities. Transcripts were re-reviewed to ensure accuracy of the themes, and thus a framework to represent the participants' experiences of the support worker role was developed. The master table of themes is illustrated in Table 7 in the results section.

3.8 QUALITY AND VALIDITY IN QUALITATIVE RESEARCH

To demonstrate the quality, validity and reliability of my study, I have referred to Spencer et al.'s (2003) published criteria on best practice in qualitative research. Particularly, their four central principles: Research as contributory, Defensible in design, Rigorous in conduct and Credible in claim.

Research as contributory

A fundamental tenet of all research is that it should contribute and advance existing theory and knowledge (Spencer et al., 2003). This was addressed by demonstrating sensitivity to context, namely existing literature, theory and socio-cultural setting of the study (Yardley, 2000). I endeavoured to demonstrate these aspects by situating the research in the context of current policy agenda and existing learning disability services; and exploring the relevant literature on the experience of support workers. I was also keen to attend to issues of power in the interactions between myself and participants, namely being aware of the limits of confidentiality and possible perceived differences in roles. Finally, I aimed to embed sensitivity into the data analysis process through supporting all argument with verbatim text extracts.

Defensible in design

A defensible design relates to how the overall research strategy appropriately meets the aims of the study (Spencer et al., 2003). This is particularly through the relevance and aptness of the preferred methodology. I have explored this section 3.2 of this methodology.

Rigorous in conduct

Spencer et al. (2003) describe the commitment to qualitative data collection, analysis and interpretation being systematic and transparent; applied to the complete research process. Yardley (2000) expands on this to iterate the importance of an in-depth engagement with the material, which facilitates a competence and skill in the employed method. I have endeavoured towards such 'rigour' through being reflective and reflexive regarding my underlying research motivations, formulations, interpretations and reporting of data. This entails acknowledging and being aware of the impact of my personal position on the research process (Spencer et al. 2003; Yardley, 2000), which I have striven to elaborate on in the first section 2.2 'How I came to this research'²².

I also used the IPA peer support group, which was facilitated and supported by a member of the academic staff team with extensive IPA experience, to support the process of data analysis. My supervisors agreed with the themes produced and could see how they had emerged from the transcripts. Finally, I have aimed to carry out all aspects of the research in a thorough, reflective and careful way drawing on available training and supervision.

Credible in claim

Spencer et al. (2003) argue that the credibility of evidence generated from the study needs to be supported by well-founded and plausible arguments. In the analysis section I have endeavoured to provide a robust supporting trail between themes and transcript texts, namely by providing verbatim a wealth of extracts. Smith and Osborn (2008) described triangulation as vital to establishing credibility, transferability and meaningfulness in IPA research. Triangulation refers to the convergence of data from multiple perspectives as an indicator of validity; these can be across different data sources, methods, raters or perspectives. In this research, Investigator triangulation occurred through the use of multiple supervisors and peer supervision, who confirmed my themes and analysis were an acceptable reflection of the interviews. Furthermore, reflective and interpretative analysis from other individuals was aligned with my Social Constructionist perspective. Namely, that meanings and understandings are co-created and thus the multiple perspectives that may emerge through triangulation promote a richer understanding (Smith, 1996).

²² I have endeavoured to illustrate and link in this reflexive thinking through reflections in the text and particularly in the footnotes.

4. RESULTS

4.1 OVERVIEW

This section presents the results of an IPA of the experience of support workers in learning disability services. Seven interviews resulted in the emergence of two superordinate themes, both with two main themes, and each with two sub-themes. This is represented in Table 3 below. Detailed exploration and deconstruction of these superordinate, main and sub-themes will form the focus of this chapter. Each theme will be illustrated and supported by verbatim extracts from the interviews. I will aim to provide the reader with a rich and vivid account of the lived experience of the participants, both to increase engagement in the text, but also to do justice to the meaningful contributions that all participants have made.

I recognise that these themes are one possible construction of the experience of working in a learning disability service. Nor is the intent to encompass a complete exploration of the participants' experience. The intent, as my research question states, is an in-depth exploration of the emotional and psychological experience of support workers in learning disability services. Quotes, comments, emergent themes, sub-themes and master themes were selected due to their relevance and proximity to the research questions. Moreover, the selection process was impacted by my own constructions, interests and reflexive responses, thus adding to the subjective and double hermeneutic (Elliot, Fischer & Rennie, 1999) nature of this research. However, I have striven to present a systematic and rigorous account of the analysis by illustrating my deductions and reasoning.

EMOTIONAL MOTIVATION	PERSONAL FULFILMENT AND MOTIVATION	Pleasure in the role
		Tensions of 'ideal' versus 'insincere' care
	THE EMOTIONAL STRUGGLE	Powerlessness and the emotional reaction to injustice
		The relentless nature of struggles
DEMANDS AND COPING	SAFETY AND CONFLICT WITHIN COPING	Constricted and un-elaborative
		The conflict of balancing multiple expectations
	PERSECUTION AND PROTECTIVE POSITIONS	Protection
		The circulation of blame

Table 3: Superordinate themes, main themes and sub-themes

4.2 EMOTIONAL MOTIVATION

This superordinate theme aimed to capture the participants' variety of emotional experiences and explore the underlying factors, such as motivations, role dynamics and their sense of fulfilment in the role.

4.2.1 PERSONAL FUFILMENT AND MOTIVATION

This main theme aimed to capture the participants' experiences of happiness, gratification, pleasure and joy in their role and understanding the underlying motivations. For many of the participants, the role entailed a profoundly deep and meaningful sense of personal satisfaction, a gratification that accompanied working dually for the residents (happiness) and an ideal (goodness, fairness and equality). Notably, participants aspired, endeavoured and strived towards this morality level, and within this journey their sense of fulfilment and 'goodness' was actualised or introjected. Failure to ascertain this level of 'goodness' resulted in participants experiencing a range of feelings; namely anger, guilt, distress, failure and even catastrophic identity collapse²³.

4.2.1.1 PLEASURE IN THE ROLE

This sub-theme aimed to capture the participants' vivid descriptions of pleasure, joy, happiness, reward and gratification in their role. This pleasure seemed to derive from different levels of interaction and meaning; such as from partaking in activities, developing relationships, adopted certain roles, and engaging in moral ideals of intrinsically 'worthy' and 'good' practice. For instance, Anne repeatedly stated '*I just do love coming to work*' and described the joys of participating in activities:

*'Because you are working so closely with somebody. Some of the clients are really good fun to work with and they enjoy so many activities that I enjoy, like swimming, walking, shopping, and they love that, and going to the pictures and dinner, I like doing all that, I like socialising'*²⁴

This extract expresses the pleasure Anne experiences in working closely with the residents. She continues on to describe her happiness at developing '*a connection*' with the residents, and the associated '*fun*' and '*joy*' of participating in activities. There is a sense of warmth in the connection of having similar interests with the residents and the pleasure of working in

²³ 'catastrophic identity collapse' refers to unforgettable pain and distress that some participants described when they could not reach the level of care they desired.

²⁴ I have made some minor amendment to verbatim extracts to improve readability, such as minor hesitations, word repetitions and utterances. For instance I have removed three 'umms' from this extract and omitted the double use of '*really*' before '*good fun*'.

an environment where her joy of ‘socialising’ fits so well. Francesca similarly described the feeling of enjoyment:

‘...and to see that look in their faces when they think Santa has been [laugh]. There are 18 huge Santa sacks under the tree and it’s just chaos. Its mad [laugh]. It’s lovely and I much rather, maybe not so much now I have my own child, but before I loved to be here on Christmas morning. It’s really good you know.’

I recall experiencing the affectionate, warming and tender nature of Francesca’s humour at this festive activity, and the repeated use of words such as ‘lovely’ and ‘love’ indicating her emotional and intimate connection with these occasions²⁵. Various participants also described the fulfilment of the supporting role, feeling they are adding value to residents’ lives. For instance, Zarina explained:

‘with people who have learning disabilities it’s more enabling and it gives you that excitement, that joy, that fulfilment, that satisfaction that you can actually add value to someone’s life’

Terms such as ‘enabling’ and ‘add value’ give the sense of her experiencing pleasure not just through witnessing the residents’ happiness, but through her role of enabling and facilitating this²⁶.

Similarly Habika described the role of being a helper:

‘Well, it makes me feel like you’re helping²⁷ someone who can’t do something, yes? Yeah I get a lot of comfort from that, yes’

Interestingly, Caroline, Anne, Francesca and Zarina all compared their experiences of working with people with learning disabilities to elderly care²⁸. Habika compared the

²⁵ This is consistent with Fisher and Byrne (2012) who found that despite support workers expressing an ambivalence regarding the appropriateness of emotional engagement, it was evident that, for most, their motivation and professional commitment was significantly emotionally based.

²⁶ In CAT terms, Francesca may be understood as adopting the RR of ‘enabling’ with the alternative pole of ‘enabled’ being held by the resident. RRs consist of a role for self, a role for other and a paradigm for their relationship. Thus, when an individual adopts one pole of an RR pairing, the person with whom they are relating feels pressured to adopt the congruent pole (Denman, 2001).

²⁷ Consistent with footnote⁶, Habika may be adopting the RR of ‘helper’ with the resident in the position of ‘helped’.

²⁸ They all associating working in elderly care with deterioration, worsening and descent. This is exemplified in Anne’s account: ‘Elderly I did do for a little while. And that was heartbreaking. Knowing that some of those people were.... lawyers, policeman, professional people and yet they were reduced to sitting in a chair. Didn’t know what day of the week it was, or no family visiting them at all’. Caroline described, more graphically the

experience to working with children. Unanimously, they described preferring learning disability work because of there was a sense of *'adding quality'* (Anne) to the lives as opposed to *'basically, sitting around and waiting for them to die'* (Francesca). This supports the hypothesis that participants' gained pleasure and fulfilment through the roles of *'supporting', 'facilitating'* and *'helping'*.

Caroline explained the joy of physical affection:

'I always used to get a kiss and cuddle from her [past resident], every time I came on shift...²⁹ she would give it to me, she was always sweet.'

This extract raises the idea and relationship that support workers may seek mutually beneficial interactions, or even personally fulfilling interactions. Anne described the fulfilment of being *'missed'* by the residents and thus feeling noticed, important and recognised:

'I will be off two weeks on holiday, come back with a really nice tan and... a couple of them go 'ah your back' and that really does make you smile. Because it makes you think, well at least somebody missed me.'

Anne's account evokes a sense of appreciation and gratitude, most emphatically in the phrase *'at least somebody missed me'*, which emits a sense of fulfilment in being noticed and appreciated. Zarina also expressed a profound happiness at being appreciated and acknowledged by the residents:

'When they come back [from the community] they are very very good and they tell you 'thank you' and it's just that thank you and love and you go and you feel so, I've helped somebody that in a way is, 'thank you for taking me out', 'thank you' [sounds happy].'

'oh I've got my support worker to help me' out and you prove to that person that you could help them out.'

In contrast to the other residents, Nnamdi explained his fulfilment as derived from knowing that he is contributing his *'quota to humanity'*³⁰, reciprocating his grandmother's care of him:

feeling of working with elderly: *'the feeling of dread, you know that sinking feeling in the pit of your stomach, and that rising feeling in your throat, and I just can't stand that feeling. It terrifies me to some degree'.*

²⁹ I have employed dotted lines within brackets (...) to symbolise omitted material, and square brackets to elucidate any confusions in what participants may be referring to.

³⁰ Nnamdi described his ethnicity as 'Black African' and I wonder if this *'quota to humanity'* may relate to his ethnic, cultural, religious and spiritual upbringing.

'And I thought of it, and I said, to whom much has given, much is expected, and one good turn deserves another. And to be those things, because she [grandmother] did that for me when I was very young and I did it... all along I have been trying to think about how to help people, how to help people. I think the idea of helping people came into mind. And I was looking for something to contribute my quota to humanity.'

He continues on to explain *'there is nothing you do in good, that it will not come back to you in good'*, indicating a cycle to his understanding of care, that his grandmother cared for him, he cares for others and then someone will care for him and his children. His prose emanates a sense of balanced karma, providence and cyclical goodness returned. Similarly to the other participants' account, his sense of this role is strongly allocated in a dynamic of being a *'helper'*.

Caroline described the most pleasurable relationship as:

'when you see someone will give the affection back to you, that's when it becomes the most rewarding, but it's not only getting that affection back, it's when you know you are the only one getting that affection back from them. I think that's what's really like the gold star for me.'

This extract gives a sense of the fulfilment at being singled out, special and extraordinary in the eyes of the residents. The use of terms such as *'gold star'* hold a certain childlike and school imagery, thus suggesting a new type of role dynamics, in which the support workers may seek or desire special approval from the residents.

There was also a sense of pleasure, reward and joy in feeling part of a family or community; happiness embedded in belonging to something. Zarina described the beautifulness of working in this family:

'It feels really like a family. It feels like a family and I think the other senior staff they're really really supportive... they are willing to listen, they are willing to show you stuff you know and it's-it's-it's really beautiful, really beautiful.'

'That's just how it is and I could honestly say [care home name] where we are, we really work as a team so it is amazing'

The use of phrases such as *'beautiful'*, *'really supportive'* and *'amazing'* illustrate the positive and fulfilling connection that Zarina experiences to her colleagues.

4.2.1.2 TENSIONS OF 'IDEAL' VERSUS 'INSINCERE' CARE³¹

This sub-theme describes the endeavour of participants to provide the best possible care, to offer the ideal care, to be the ideal carer, and ultimately maximise the residents' quality of life³². The accounts emphasised the importance of striving towards this ultimate overarching care, with everything and anything demoted below this ideal. Concurrently, linked with this endeavour was the alternate pole, which emerged as feelings of anger, negativity and confusion towards other staff working for anything but genuine and sincere care. Notably, there was particular disdain of staff working for money. Within this sub-theme emerged a dual support worker-resident dynamic, namely to experience themselves as the ideal carer and be perceived by the residents as providing the ideal care.

Anne described the importance of clients' happiness:

'...the client being happy really. As long as they are happy and their needs are being met. Then that's all I can say. The minute they are upset that's when you know you have sort of failing in some area and... make sure it's not happening any more'

The use of terms such as *'the minute they are upset'* and *'failing'* here, indicate the extremity of how she perceives her role; success or failure. The question thus arises, what and whom is she failing; the resident, the other staff, herself and/or the field? Similarly, Francesca explains:

'Their needs are what is important to me, and their enjoyment. It's about them having fun, you know, you don't know how long they have got to live, you don't know how their disabilities are going to increase or decrease. You don't know how long they are going to enjoy their lives, so my role here is to give them a happy day.'

This extract emanated a sense of obligation, duty and responsibility to make the residents' lives happy. Caroline similarly described the need to do everything possible: *'But you should try and do everything you can when you are out there, to make the present better'*. However, there was also a sense of the negative consequence of not being able to offer this care, as

³¹ I initially considered having these two positions ('ideal' care and 'insincere' care) as two separate sub-themes. However, I came to realise their connection, being heavily linked and associated in the participants' descriptions and constructs systems. They seemed to exist as part of a dichotomy or RR relationship, with aspirations to be ideal carer at complete odds with any ideas of insincere or selfish acts. This is most exemplified in Anne's extract where she described the conflict and rejection of assimilating any notion of self-gratification and self-fulfilment (in her role) into her internal model of being a carer.

³² This sub-theme is consistent with Lloyd and Williams (2004) who found five common reciprocal role procedures that staff found themselves in, one of them being 'ideally caring' to 'ideally cared for'.

indicated in Zarina's account, *'if I do not come to take her out, I'm going to be letting her down and that really makes me, really unhappy'*. This extract illustrates that the consequence of not being there for the residents is failure (*'letting her down'*) and the attached emotional response of being *'unhappy'* at this.

Zarina also provides an image of her ideal carer in her descriptions:

'It's just like that kind of joy I've explained to you when you know that there is somebody somewhere that really that's looking up to you like Jesus Christ'

Whilst this extract also supports the previous theme (4.2.1.1 – Pleasure in the role), the description of being looked up to *'like Jesus Christ'*³³, has connotations of being a saviour, the ultimate goodness, sacrificial and revered. These words provide a sense of how Zarina understands her role as a support worker, and the depth of benevolence that she perceives herself as giving. If Zarina positions herself, perhaps more implicitly, as *'Jesus Christ'* to what role does she position the residents; followers or worshippers?

Namdi described the aspiration to be always looking to improve and help more: *'I still look for room to help people more. That's it'*. There is a sense of a continual striving to be more caring and a better carer. Anne further illustrates the sense of responsibility and obligation:

'When somebody has nobody, and you know you have got a rapport with somebody. And you get on well with them. And they look to you for reassurance. You know that you have got to step up to the mark and do a little bit more.'

The use of terms such as *'you know'*, suggests the idea that support workers must implicitly or intrinsically know and understand their responsibility to care and support, above all else. This phrase suggests the presence of an overarching morality that support must or aspire towards. Indeed this idea extends to the realm of staffing teams, as Habika describes being asked to come in for an ill colleague:

'Hmm yes if any person needs it I will do it for that person. It doesn't matter what I am doing at home, I will have to come and not that I would have to, I will do it.'

³³ This is consistent with Psaila and Crowley (2005) who identified the support worker idealised role of *'Special/perfect'*, namely Jesus, to *'Learning disabled'*.

This latter aspect of this extract *'I will have to come and not that I would have to, I will do it'* suggests a definitiveness to her actions, a sense of moral obligation³⁴. Furthermore, there may be the implicit understanding that the ideal carer must do *everything* for the resident; even not caring for themselves. The desire to provide the ideal care also extends to staff and staffing teams, as Francesca states: *'We cannot have a staff Christmas do. Because it's a twenty-four hour home so somebody has to miss out.'* Thus there is a sense of inhibiting any activity or action that does not correspond to an ultimate level of fairness and equality. I wonder why they could not rotate staff being allotted to Christmas and holidays each year so different members may be able to attend the party?³⁵

The desire to match an internal model of caring also extends to when they are out of the professional role, which suggests this morality originates from a deeply personal and fundamental element; namely part of the identity. For instance, Francesca explained:

'If someone is ill I worry, I worry all the time. I phone up every day and make sure they are alright. I have been with a couple of chaps in ambulances, one having a heart attack, with a defibrillator and out. I have sat in there, holding their hand all night [laugh]. The staff here told me to go home, and I was sat up in hospital all night because it just didn't want to leave them on their own up there. And you know you are not getting paid for it but that's just, you know. That to me is part of my job.'

This extract suggest that support workers motivation cannot be relegated to interactions, but that support worker belief systems were regarded as intrinsic to the role. The feelings and roles that support workers aspire and strive towards, namely the drive to provide the best care possible and make the residents as happy as possible extend beyond the realms of a professional commitment to a deeper ethical and moral dedication.

This idea is supported by Francesca's description of visiting an ex-resident after he left:

'No, no I knew that I had to do it for my own peace of mind and his. To just be able to carry on with my work.'

The term *'for my own peace of mind'* suggests a sense of having to act virtuously as the consequences may be negative, uncomfortable and punishing. This idea is also represented in Zarina's account:

³⁴ This finding is also consistent with Storey and Collis (2011) who found that staff often worked overtime to cover shifts, staff absences, keep the service safe and supplement their wage.

³⁵ Although I did not ask the question so there may be other justifiable reasons.

*'Because I was like, well why didn't I put it on my rota, ooh I've let I've let [resident name] down I've really let her down I have, oh and it's not like just letting her down, it's letting everybody down'*³⁶

This extract suggests that failure to be the ideal carer results in feelings of shame, guilt and responsibility; so intense that she experiences *'failing'* one resident as failing all residents. This suggests that in construct framework of caring, than any mistake is globalised as a failing to all. Although more intense than the other residents, this sense of anguish indicates that for Zarina, any act in opposition to her model of the ideal carer results in a cataclysmic fracture to her identity³⁷.

Several participants described a feeling of anger, negativity, confusion and resentment towards people being a support worker for anything but genuine and sincere care. Francesca, articulately expressed this stance:

'No one in care can say they're in care for the money. No one, because the money, it does not pay for what you do. You know the amount of hours through the night I have been up the hospital where I have had to go to the mental health departments and have people sectioned in the night, you know, all unpaid till 3 or 4 o'clock in the morning. You wouldn't do that if you were here for the money. You do that because you care.'

Francesca's extract emanates the importance of the word *'care'* and meaning that it created for her identity as a worker. Caroline goes further to describe feeling disturbed that people could work for money:

'But you do just get the odd member of staff you can just tell really deep down inside it's just a job to them, it's just money, and that what's kind of disturbing'

Caroline's language emits a feeling of disdain, disbelief and anger that support workers work for anything other than care³⁸. Her words *'really deep down inside'* suggest the profound integration of *caring* into her understanding of the support worker role. Similarly Anne states:

³⁶ This links to my previous description of a 'catastrophic identity collapse' that failing one resident is failing all residents.

³⁷ Note, the term *'letting everybody down'* can be understood on numerous levels; letting the other residents down, letting the staff team down, letting the care home down, letting all of herself and her moral ideals down.

³⁸ Caroline's extract delineates her belief that the ideal carer does not work for money. Further, the use of the term *'disturbing'* suggests the importance of her ideals and her difficulty to consider any other model of caring.

'...it's a job to them and its money. And that always amazes me why they stay in the role because I just think... this is people's lives. And you are making a difference to their lives.'

Anne's feelings also illustrate her belief that the ideal carer must have 'heart':

'We did have a manager many years ago, and I had to stand up arguing with her because she said, you haven't got to have a heart to do this job. It's just a job... but if you have no heart how can you put your soul into it and do it properly. And I had an argument with her over that.'

The repeated use of intimate and poignant language such as 'heart' and 'soul' indicate the connection Anne has for this role, a sense of needing to give something very deep and meaningful to this role. Further, the words 'I had to stand up' to the manager suggest that the ideal carer has an obligation to stand up and speak out. Caroline, described struggling with any personal actions that she felt stemmed from 'selfish' desires:

'I suppose it's selfish to some degree to jump around and act like an idiot to try and distract yourself [from her problems]. My only distraction to me would be a very selfish act, especially since I would be trying to do it for someone else, but yet it would be mainly for me, to me that would be a very selfish kind of feeling.'

This extract indicates Caroline's struggle, tension and conflict to integrate mutual benefits of her role into her professional identity. This conflict is also revealed in Anne's conflict with the notion of 'gratification':

'People seem to think you do it because you like helping people. That annoys me a little bit because it's almost like you are doing it for your own satisfaction and gratification, and it's not that at all.'

For Anne, there exists a conflict of integrating self-gratification and personal-satisfaction into her role identity as the ideal carer. Her construct system or understanding of the carer role cannot integrate any notion of self-gratification.

4.2.2 THE EMOTIONAL STRUGGLE

This main theme described the emotional struggle that participants experienced in their role, namely the resonance of powerlessness, helplessness, anger, sympathy at the injustice the residents' life and disability. Further this struggle appears relentless and unyielding.

These emotions emerged from their experiences of the residents' plight and their own experiences³⁹.

4.2.2.1 POWERLESSNESS AND THE EMOTIONAL REACTION TO INJUSTICE⁴⁰

This sub-theme represented the participants' sense of powerlessness⁴¹, anger and sympathy at the injustice of the residents' experiences. In particular, powerlessness emerged as a dominant factor, being multifaceted, transpiring through their descriptions and linguistic tones. The nature of these feelings varied significantly, echoing within their own experiences, those of the residents, the staff team and the field. Emeka described the powerlessness of the residents' experience:

'Because this people they can't say anything, they can't talk, they can't challenge, they can't stand up for themselves'

Caroline described the powerless inevitability of becoming attached to the residents:

'You know you can't help when you are working with people day in day out, seven days a week, you know entire years, you do get attached, you can't help it.'

Zarina recalled the feeling of powerlessness to residents' behaviour, connecting this to herself:

'they get really violent... and there's just nothing you can really do about that... it's really sad where we know there's just a limit to what we can do'

Francesca described the sense of 'horrible' powerlessness towards family members who did not come to visit their relatives in the care home:

³⁹ The similarity between their own emotional experiences and the residents may be understood as a transference reaction; internalising the sense of powerlessness and injustice that the residents feel, and experiencing this within their work. Furthermore, the residents' communication and language difficulties meant that their distress may not be expressed, thus intensifying the transference reaction; the support workers may be the only voice for the residents' pain. This will be explored more fully in the discussion.

⁴⁰ I initially considered separating these ideas ('powerless' and the emotional reaction to injustice') but I came to realise that they were intimately linked. Participants described the numerous reactions to the injustice of residents' struggles and life, such as anger, fear, sympathy, pity, to name but a few. However, in being unable to do anything about this injustice they felt powerless. As such, their varying emotional reactions to the injustices were heavily laden with powerlessness, helplessness and hopelessness.

⁴¹ This factor is consistent with Storey and Collis' (2011) qualitative research that identified powerlessness as a recurring theme in influencing the way participants constructed their accounts.

'You can't do anything with it. You just got to accept that's who they are and that's their choice.'

These extracts are examples of a litter of references to powerlessness in the support worker role. Francesca introduces the idea of society and politics, indicative of the numerous directions that participants' experience of powerlessness is directed at:

'It's society isn't it. It's politics. We are fighting red tape all the time anyway, everything is about what's right and what's wrong so you just, you can't fight that. You can't.'

The repeated use of terms such as *'fighting'* and *'fight'* illustrate the sense of her conceptualising this role as a battle. Caroline, similarly, describes her feelings of helplessness towards the organisation she is working in:

'It's just trying to get people to understand, like head office with extra staff members, that could actually help us. But it's just the way the rules work, way the system works unfortunately. It's... nothing can really be changed about it, you just have to grit your teeth and bear it.'

Similar to the other participants, Caroline's interview emanated a sense of having to forcibly *'bear'* the system and your powerlessness within it⁴². Zarina described the powerlessness of being at the mercy of government changes:

'It's just like you know, this is what is happening now [laughs] it's, it's beyond me to do anything else or I just can't, this is what this is what it is, the government has done.'

Zarina is describing a recent policy change in her care home that has resulted in residents now having to pay for the staff member if they want to go on holiday. However, interestingly she attributed this organisational change to the government and not her actual charity where the policy change occurred.

The global sense of these descriptions of powerlessness, with its roots in numerous areas, gives rise to a sense of the support worker role as fused and integrated with a sense of helplessness and hopelessness. This hopelessness appeared in reaction to the numerous participants' descriptions of a strong feeling of sympathy and injustice towards the residents. Interestingly, these statements were often brief, succinct and/or repeated. I wonder if this is indicative of the support workers' challenge of sitting with painful feelings

⁴² I noted the stark absence of any narratives in Caroline's or any participants' interviews of ways that the system may be supported or advocated for change. This further indicates the powerlessness that the participants experience.

of sympathy and injustice, with anger being one of the only outlooks of release. For instance, Emeka repeated several times throughout his interview, *'Sometimes it's not fair, sometimes it's not fair to them'*, regarding the residents being unable to choose their own clothes. He elaborates on this sense of injustice by saying:

'I feel sorry for them. It's not their choice. They were just born like this so it's not their choice... There is nothing we can do. Other than just help them.'

The immediacy with which Emeka returns from stating feeling *'sorry'* to *'there is nothing we can do. Other than just help them'* may indicate a need to reassure himself, to ward off the experiences of powerlessness and pain at the injustice⁴³. It may be that, due to the residents' communication difficulties, the staff are unaware of how they may be feeling (powerless or otherwise) and thus they project their feeling of powerlessness into the residents⁴⁴. Caroline's description of the residents' monotonous lifestyles emitted a sense of frustration, unfairness and anguish:

'They will sit down in front of the TV, they will be watching TV most of the day. They might have the opportunity to go outside, over to Asda for a quick 10min, with the staff. Other than that they are at home. And I just don't think it's fair because they don't get to do the things they want to do.'

She reiterates this sense of inequality, towards family's behaviour:

'It's really gutting. When you know that they have family literally 10min up the road, but umm... it won't take long for them to come and visit and see their son, and they just choose not to... I think the main feeling is just disappointment'

The use of terms such as *'gutting'*, *'really really difficult'*, *'disappointment'* and *'horrible'* emanate the magnitude of the anguish that she experiences in response to the residents' plight. Anne reacts to the residents' struggle in the form of externalised anger, for instance:

'they are people that are different from us. So... why are they treated so differently? [said loudly] Why are they not given the same choices and

⁴³ One hypothesis may be that Emeka has internalised the residents' experience of (perceived) powerlessness, and copes with this introjection by reassuring himself, 'there is nothing we [I] can do', thus dissolving himself of blame and responsibility.

⁴⁴ This is consistent with Symington (1992) who described that through the feelings of hopelessness that accompany working with people with complex, severe and irreversible disabilities, staff may experience contempt and guilt, pushing unwanted parts of themselves into those who are different, as a way to cope with such painful emotions.

independence as the rest of us? And that's what I feel about the role, that's how they should [emphasis] be treated.'

Francesca's feelings of anger and perhaps fury are more explicitly stated:

'It annoys me. It really angers me because I just think there is some... there are residents that could then have two holidays if they didn't have to pay for the staff member.'

Anne provides a visual depiction of how she perceives the residents world to be:

'some of them can only go out with the support of us. And that's really, really like it is a form of imprisonment, they are trapped inside their own shell really. And that's really sad for them... But I would love to be in their brain for just one day to know how it must really feel. Because it's sad I think.'

The use of phrases such as *'imprisonment'*⁴⁵, *'trapped'* and *'shell'* indicate the sense of captivity and caging that Anne perceives of the residents world; whilst also giving a vivid image of their powerlessness. The words of *'I would love to be in their brain'* also suggests her struggle to empathise and understand residents' experiences. Thus, she experiences empathy but may not fully understand what her empathy is for. The depth of Anne's conceptualisation of the resident's quality of life is acutely demonstrated in her reference to the choice of food:

'The dietician says, oh no she shouldn't be having this that and the other one. But it is hard, what much else have they got in their life? So, I you just get on with it. Yeah, so what else have they got in their life?'

The repeated statement *'what else have they got in their life'* regarding food, suggests the sense of minimalistic deprivation that she perceives of the residents' lives.

Emeka explains the unfairness of reduced choice in daily choices, such as clothing, food and day activities:

'I meant to them, it's not. I just put them some trousers and trainers maybe. Doesn't wear them she doesn't want to wear them then nothing is fair to them. Nothing is fair. You can't do anything, you have to do it.'

Francesca describes the feeling of heart-break regarding knowing residents' past lives:

⁴⁵ This imagery may also indicate how she perceives her own struggle to support the residents, namely that she is trapped and restricted from being able to provide the care and support that she hopes to give.

I would say 80% of our chaps have either come from institutions settings or umm [pause] or have been abused in whatever way shape or form, whether it's financially, sexually or physically... They have had such tough lives... It breaks my heart'

I recall the emotional tone of Francesca's description and the sincerity of her repeat of the words *'breaks my heart'* several times within her interview. This sense of sadness at injustice was also echoed in her description of residents' relationships:

'Yeah, especially those of our chaps that don't have any family or even friends. You know some of our people here don't have anyone that isn't paid to be in their life... you know everybody in someone's life is paid to be in their life that is quite a sad thought.'

Caroline described, vividly and with potent imagery, the impact of residents' past experiences of abuse on herself, namely the rising and uncontrollable feeling of anger and violence:

'It's like when I get reminded of it, the feeling engulfs me, it's the best way to describe it, it's literally like a suit that you slip on. It like rises in your stomach, and it just sets off everywhere'

4.2.2.2 THE RELENTLESS NATURE OF STRUGGLES

During generation of sub-themes, this particular one, 'The relentless nature to struggles' emerged somewhat surreptitiously but persistently. This was due to the various other sub-themes, such as 'Tensions of 'ideal' versus 'insincere' care' (4.2.1.2), 'Powerlessness and the emotional reaction to injustice' (4.2.2.1) and 'The conflict of balancing multiple expectations' (4.3.1.2) all emanating a strong sense of struggle in themselves. However, what I came to recognise as emitting strongly from the dialogue and perhaps more acutely within the interviews⁴⁶ was a sense of the struggle being relentless, continuous and ruthlessly obstinate⁴⁷. This sub-theme was most apparent in Caroline, Anne and Francesca's accounts, and, to a degree, in Zarina's accounts. For instance, Anne described the feeling of constantly having to talk staff members through some of the residents' behaviours:

⁴⁶ By this I mean the feel in the room with the participants, the non-verbal experience.

⁴⁷ Further, I came to reflect on the sense of a detached and suffocating struggle which, due to its permanency, drains the support workers and leaves them feeling stressed and sapped. There was also a sense of rawness to the descriptions, unprocessed and unrefined, the struggle to simply be, work and stay with the work.

'Umm...can be frustrating because, you have to constantly say to them, why do you think they live here?'

Zarina described the feeling of stress at some resident's behaviours:

'she's been very very unsettled, opening doors going out, pushing chairs, punching other residents and so and so is three-to-one today, and you come back home feeling really tired and stressed. Really stressed. It all builds up continuously. It's really tiring.'

Francesca recalled the strain of taking residents on holiday:

'And we are working 24 hours round the clock on holiday. We come home absolutely shattered. We end up spending more money of our own than what we earn out there. And then when you come back you know, you have to come back and fall straight back into your shift pattern. You can't have a couple of days off to recover... you come home and you are shattered.'

This extract in particular, and the rapid, in-one-breath, speed of the description illustrated Francesca's perception of the unyielding nature of the support worker role. Zarina described the challenge of communicating ideas to family members:

'Mums could be like eighty and above so it's really, it's as if you are dealing with two residents. It's really hard, you sit them down you explain things to them, you see their family and everyone is just not understand, you go around and it's tiring, it is.'

Francesca also uses some poignant imagery to describe the role:

'You know, what we do here, you know, we are dealing with people's bodily fluid, we are dealing with their emotional needs. We are dealing, you know, it is blood and guts and sweat and tears every day'

The imagery of blood, guts, sweat and tears, echoes a sense of having to give everything into the role, and it taking everything from you. I recall being particularly struck by Caroline's use of imagery to describe the struggle to work with staff teams and not let this impact on the residents:

'It's really hard, I don't think it's the best things they should have to deal with. You know they have a lot of their own problems, so I don't really think having staff having issues with each other should really be pushed on them. So it's really kind of hard when you are working with someone, who in all

honesty, you really just don't want to have to work with, you know you grin and bear it, you swallow it up, and then you get on with it.'

Caroline captured the sense of a relentless challenge by explaining:

'Really shitty. Really really shitty is the only way to describe it... I can argue as much as I want [about getting money for resident holidays] but I will just be blue in the face, won't get any further with it. I keep and keep trying but you know.'

The latter part of this extract, *'argue as much as I want but I will just be blue in the face'* further illustrates the relentless, unyielding and constant nature of the support workers' struggle.

4.3 DEMANDS AND COPING

This superordinate theme encapsulates the participants' construction of coping with the emotional demands of the role. A particular theme that emerged was the deviation towards becoming constricted and unexplorative; which perhaps allowed participants to avoid speaking about potentially painful experiences or allowed them to make sense of the plurality of complex emotions and expectations. Concurrently, this lent itself towards contradictions and conflict in managing diverging expectations.

4.3.1 SAFETY AND CONFLICT WITHIN COPING

This main theme explored the participants' experiences of coping and how this resulted in feelings of safety, comfort and protection, but also contradictions.

4.3.1.1 CONSTRICTED AND UNELABORATIVE⁴⁸

A number of participants' language, descriptions and views emanated a sense of constriction and reluctance to elaborate⁴⁹. The way in which emotions and views are talked about have

⁴⁸ Of all the sub-themes, the titling and indeed evidencing of this section was most difficult. I was deeply concerned with using possibly pejorative terminology (such as concrete, succinct, rigid or structured). Indeed, what I hoped to describe was my experience of the participants as constricted; constricted within their descriptions, constricted by a need to protect themselves or others from revealing potentially persecutory information, constricted to deal with the powerlessness and overwhelming array of emotions and constricted as a safety mechanism.

⁴⁹ This sub-theme emerged in Nnamdi, Emeka, Anne and Habika's accounts.

significant implications for how they are experienced and managed. Emeka expressed his views in a succinct, un-explorative and un-elaborative manner:

- Int:** *What parts of the role do you most like?*
Emeka: *In the morning, everything... [pause]. Everything.*
Int: *Is there a particular thing you like the most?*
Emeka: *Not really. I guess I am enjoying everything at the moment.*

This sense of an unelaborated way of describing emanated throughout his interview.

- Int:** *What do you feel are the things you are good at as a support worker?*
Emeka: *I think I am good at helping people with their personal care.*
Int: *What are the things you are good at, what kind of abilities, strengths or skills do you have, that make you good at working with personal care?*
Emeka: *I have done this quite a long-time so I think I can do anything.*

This sense of constriction, un-elaboration and unambiguousness may be understood from different perspectives. Emeka parallels the environment to a 'family' or 'community'. Within this metaphorical paradigm the group, unity and team behold paramount importance, thus individual differences and preferences, namely strengths, may be unimportant, or indeed in contradiction to his mental blueprint of the role⁵⁰. It is also important to consider language here and I wonder if the word 'strengths', taken literally, may have been understood differently to Emeka. Further, it may be that he does not feel safe with me to express things elaborately.

Nnamdi's description of the clear distinction between wrong and right suggested a definite and structured way of thinking:

'There is no one that doesn't know the wrong thing and the right thing... So I think everybody should know the right thing and everybody should know the wrong thing... every human being'

Nnamdi further indicates this concreteness as he describes other staff's decisions to work or not work:

'You know, if you're not satisfied with what you do, then you quit it, so simple. So simple.'

⁵⁰ Thus when I ask him what his individual strengths are, it may feel immaterial within the context of his family metaphor; as he explains 'One day you are doing the cooking, the other day you are doing the washing, the other day you are doing the ironing, hovering. So you have to know everything'.

In recalling her experiences of assessing for capacity, Habika describes the simplicity and ease of this process:

Habika: *Well, we just you have to assess that person to know that they know, that person is not capable of doing that, hmm.*
Int: *Is it kind of easy to find the balance or?*
Habika *Oh it's easy! [emphasis]*

Anne's interview had a different feel to Habika, Nnamdi and Emeka's, in that she was considerably more talkative, giving longer answers in comparison⁵¹. However, what emitted from her account was a sense of surety, definitiveness and concrete style of thinking⁵². For instance, she described the confusion of why people would be negative:

'I just find them quite negative people. I don't know, I'm just not like. I think if you are negative your miserable, simple as that, and I can't stand being miserable for long, so I'm just not negative you know'.

This sense of concrete, succinct and direct reasoning emanates in her comparison to a friend who works with animals:

'But she couldn't do my job because she is not very good with people. She loves animals. I like animals, but I like them, I don't love them like she does... I can do the job and that's what I am good at, that's why I do it.'

4.3.1.2 THE CONFLICT OF BALANCING MULTIPLE EXPECTATIONS

Many of the participants⁵³ described the conflict of managing multiple, contrasting and unmanageable expectations from numerous sources, such as from the residents, staff, managers, the organisation, government policies and indeed within themselves. This conflict of balancing multiple expectations, emerged explicitly (through participants' descriptions), but also more subtly and unconsciously through incongruities⁵⁴ in their narratives. Zarina explained the struggle of trying to facilitate residents with their chores:

⁵¹ This resulted in me having to ask significantly less questions in comparison to the other participants in this sub-theme.

⁵² Namely a way of thinking that things were either this or that, black or white, negative or positive, caring or uncaring.

⁵³ This sub-theme was present in Caroline, Anne, Francesca, Habika and Zarina's accounts.

⁵⁴ These incongruities might show up in the description of promoting and facilitating a government ideal (such as independence, choice and empowerment) whilst describing doing something different. This is evidenced later.

'I think most of them don't really like doing it. I think they'd be really really happy if they could just sit down and people do things for them.'

This extract raises the conflict of managing resident's wishes, the organisations desire for independence and her own belief in promoting autonomy. Habika described balancing the demands of family members with the care home:

'Well the only difficulty is [pauses] they [family] think it should just revolve around just hers or his here but there are so many people here. They expect that whenever you are here you are just his or hers... taking just that one person out, but what about the rest?'

Similarly, Zarina described the challenges of balancing family member's wishes with the realities of procedures and rights around choice:

'Parents like you know, like they are kids, we need to babysit them whereas it's difficult for them to understand that they've got what we call choice and rights and you know, we could just prompt and say things but if they say, I'm not doing it I'm not doing it and there's just nothing we can do.'

Similarly, Francesca described the challenge of managing policies with the realities of working with pain and physical affection:

'And you can walk through the door and get a big cuddle and a kiss. And it's so hard to sort of push them away, and say no you can't do that, you are not allowed to do that. You can, you know, say good morning, or shake my hand, but it's very hard because when they are upset and they are crying the first thing they do is put their arms out and cuddle you, its comfort.'

Francesca explained the conflict of funerals, having to balance the demands of the residents, the care home and the family members:

'Umm, but you have to give the residents the opportunity to decide whether they wish to go to the funeral or not. And most of the home went. When another resident dies, do the residents go to their funeral? Or is it just family? Some families don't want them there.'

Her description of the challenge of managing routine, boundaries and political drives for choice was exemplified in her description of breaking down institutional barriers:

'there are so many institutional things here as well, that we try our hardest as well to break the institutional setting, but then you also need routine and boundaries. Especially with the autistic chaps here.'

Francesca's interview was saturated with explicit and implicit references to the challenges of balancing multiple demands. What echoed strongly from her words, and the other participants, was a feeling of being powerless to meet the demands of all parties; ultimately, being unable to satisfy everyone. For instance, she described the struggle to retain professional boundaries in an informal setting:

'They [family] will come in and if you are on they will come and talk to you rather than go and see their [pause] and they, you know obviously having a baby as well, oh have you got a photo of your baby? Oh let's have a look, so you know, they encroach on your personal life as well. It's hard to say actually it's none of your business that's my personal life and I am paid to look after your family member, you can't do that.'

Her words *'it's hard to say it's none of your business'* illustrate her conflict and struggle to maintain and operate within the multiple expectation and demands of the role. Thus, support workers do not just struggle to uphold expectations and demands they agree with, they face an internal conflict to know which ideas may actually be appropriate, correct or most beneficial to the resident. Caroline explained the challenge of balancing organisational demands for chores against promoting activities for the residents:

'It is a constant battle to do housework & chores, which if we don't do we get in trouble for. But we get in equal as much trouble if we ignore the activities for the service users... its quite literal a case of one or the other, there is no room for both.'

Anne also reiterates the challenge of balancing organisational demands with trying to promote choice and independence:

'They [government] promote independence, rights of choices, when the bottom line is, if it comes down to money... the choices go out the window. Sorry we can't do that because we don't have money... how can we promote their independence, rights and choices, if the funding isn't put in place to make that happen?'

Anne emphasises this dilemma more specifically with regards to meal times:

'So, you order in your food and because it's from umm, like a big company, it comes in bulk. But how can you promote their choices at meal times if they are not actually going out there in the community doing their shopping.'

Finally, Zarina describes the challenge of implementing strategies and an ethos of choice whilst appreciating the individuality of staffing differences:

'We work towards the same goal so that's what we try to do here, we don't work in the same way but work towards the same goal because they tend to relate to us differently, they tend to relate just differently and it just can't be the same. I am more of my own way and other staffs are more of their own way.'

What emanated strongly from many of the descriptions of this conflict of managing multiple expectations was a sense of feeling unsure, hesitant and undecided about how to proceed in the circumstances. For instance, understanding the rationale behind policies or family expectations but being 'stuck' with the demands of the actual situation.

In the process of constructing their accounts, participants often described promoting particular ideals (such as empowerment, choice and independence) whilst describing with their language something different. For instance, Habika described working with anger, violence and aggression:

'Well you know what's going on with him or her so you don't let it get to you. It gets to you, you're human being, but you just let it go [pause] because you know she's got that problem, hmm.'

Caroline expressed this contradiction more implicitly within her interview, by her contrasting statements of treating the residents as adults:⁵⁵

'You know they are adults so you treat them like adults. That's how I would want to be treated myself if I was in that situation... I pull the toys out the box, the hand puppets, and the stupid stuff like that and I will just start acting like an idiot. I'll start singing, I'll start dancing, I'll basically try and do anything'.

This theme of promoting the residents independence, choice and adulthood but using childlike imagery⁵⁶ and references reverberated throughout Caroline's interview. She described:

'I try and get them to be as independent as humanly possible. I really hate when I see an old member of staff babying a resident... you know, one of

⁵⁵ I locate this extract here because I feel this contradiction emerges due to the conflict of balancing multiple views, namely the view of advocating for treating residents as adults and her own view of doing what she believes will make the residents happy.

⁵⁶ This is consistent with Lloyd and Williams (2003) who described the tendency of support workers to play out the RR of 'infantilising' to 'infantlised', which they believe fosters dependency.

the girl's here, she is my baby girl, I call her that all the time. 'Alright gorgeous', 'alright beautiful', 'how you doing baby girl?'... My little [baby name]'.

4.3.2 PERSECUTION AND PROTECTIVE POSITIONS

This main theme aimed to illustrate the strong sense of protection and persecution within the workplace (from the organisation, public or government). The protective positions ranged from relying on procedure and documentation, supportive team members to blaming and attacking others, as a way to cope with the challenge of the role.

4.3.2.1 PROTECTION

This sub-theme addresses participants' accounts of experiencing a need to protect either the residents or themselves from danger or persecution. The sub-theme was strong and elaborated, represented in all but Anne's transcript. Emeka's account entailed a wealth of references to protection, privacy and the importance of being trustworthy. For instance he described the importance of maintaining confidentiality:

'if I say, private and confidential you don't have to like, for example what you see here you have to take it out and tell your friends. This person is not suffering from this, this and this... You have to be trustworthy, for example you can go out with someone, they might give you money to buy some stuff, some people they misuse the money, you know. You have to be trustworthy. You have to be careful.'

This extract raises the notion of protecting the residents and himself. He elaborates on this theme in his description of the media:

'I read it in the newspaper, in the news. Some people they misuse. For instance, money, which is not good... I think it makes you aware that something happened out there. Of which it was not supposed to be done... you have to be careful yourself as well.'

Emeka concluded by describing the dire consequences of not being careful and protecting yourself, *'because maybe, if you are someone who does entirely things... you can end up in a serious situation... You have to try to control yourself'*. Similarly, Nnamdi described the importance of being careful:

'Because we wouldn't want any lapses. You know, outside our job. And we got a lot to think of. We got, you know, we got video, we got health and

safety people.⁵⁷ We got, we got inspectors, we got everybody, around us. It's like err, people looking at us. So we wouldn't want to let anybody down. So, that it's self you know, gives us a kind of impression that you can't just do otherwise. And it helps us.'

Nnamdi perceives the external inspectors and checks as being protective for his work environment (*'it helps us'*), feeling that without them there may be problems⁵⁸. As he explains:

'Maybe... I wouldn't know, maybe there might be negligence. That's why it is so important that people are checks.'

Habika's account entails less explicit and serious references to protection and prosecution, however there remained an undertone of needing to be careful and vigilant for the residents' sake:

'You have to make sure that the whole place is clean, yeah. Just everything is in place just not to have any accident so you make sure it's, that is done but [short pause] we don't obstruct ways and corridors, no. It' no no no no [emphasis]'

Zarina's account focused on the importance of documentation to prove and protect her actions against others:

'so they think it's our fault but you know we've got the books to show them, we have said this and we have reminded and it's up to them if they want to do it or they don't want to do it so they fail to understand.'

Francesca's account was fused with numerous references to abuse that occurred within care homes, thus the importance of protecting the residents and herself from persecution:

'Umm, the safety is the most important part. Umm, to protect them [residents] from abuse and harm. Umm, protect myself at the same time.'

'You hear and you see on the telly so much abuse still happening in homes and it's unbelievable that it is still goes on.'

⁵⁷ I wonder if this is an unconscious or implicit reference to me (the researcher), namely that *'...we got health and safety people'* and *'we have you [me]'*. Does this suggest he perceives me as a threat or someone who is checking up on them?

⁵⁸ This idea provides a sense of the depth of his concerns of abuse, that external inspectors are experienced as positive and supportive to his workplace.

4.3.2.2 THE CIRCULATION OF BLAME

This sub-theme represents the tendency for participants to blame others, other staff members, other professionals, the organisation or the public. I use the term 'circulation of blame', to describe the sense of blame being targeted at seemingly everyone within the system. Within numerous descriptions there was also a sense of needing to not just blame another, but with anger and contempt⁵⁹.

Caroline's account entailed the most powerful and pervasive theme of anger and blame towards others. Whilst she expressed frustration towards doctors, she depicts a workplace potent with fault, irresponsibility and ignorance:

'Yeah all the top doctors, when you speak to people who are higher up in the professions, they try and come across with best intentions, but sometimes it's best of intentions but worst of outcomes.'

'But it's just very irritating when you are working with someone you have to tell four or five times over and over again the same thing, you know it should be done like this... I feel that strongly that it should be done in the correct way or it should be done in a different way as opposed to it is being done at the moment... Because he is just too pig-headed ignorant to actually listen to what someone else is trying to tell him.'

Francesca also positions herself as above many healthcare professionals:

'You tend to tell the GP what's wrong with your client, rather than the other way around [laugh]. Just to get the medication that you think that they need and to be honest 99% of the time you are right because you know their traits or it's an obvious thing. The consultants it's very hard because a lot of them, like you⁶⁰, have just come out of university with all the new ideas, and all the new plans, and let's try this, but it doesn't work.'

The phrase 'it's an obvious thing' emanates a sense of the attacking on the other professionals who do not understand the needs of the residents. I recall the feel of belittling, blame and derogatoriness at hearing Francesca find fault in all professionals:

⁵⁹ This is consistent with Psaila and Crowley (2005) who found one of the common RR in learning disability services as 'contemptuous' to 'contemptible'.

⁶⁰ The phrase 'like you' suggests that Francesca also may perceive and position myself (the researcher) as someone with 'ideas' and 'plans' that do not work; just as she describes the GP, dietician and consultants. I wondered at the time if she was being implicitly contemptuous towards me? I wonder how she makes sense of this research and indeed why she became involved in it?

'A GP is a GP, and they are what they are, they are general practitioners they are not advances in learning disabilities, Umm the dietician is a dietician, again is not advanced in learning disabilities. Umm, the consultants... the learning disability consultants they are, but then they are not qualified in general medicine.'

Many of Anne's remarks also emitted a sense of contempt and belittling:

'They [staff members] go well, they live here because they have a learning disability. And I say, yeah [condescending tone], then they go yeah but bla bla bla, but do they have to do so and so? And I say 'yeah its part of their daily routine that's what they do'... and some staff you have to keep reminding them that. And you sometimes wonder who has got the LD, the staff or the client? [laugh]'

This extract emits a sense of Anne positioning herself as above both the residents and other staff. This sense of hierarchy of views and position is illustrated in Francesca's description of differing standards, *'I have fallen out with several members of staff because my standards were slightly higher than theirs and I believed that they were quite lazy.'* Francesca goes on to highlight the superiority of her family:

'My family are all medical. Umm... and whenever someone was ill the whole family sort of chip in and help whereas a lot of people haven't got, live a busy lifestyle nowadays they have carer's come in. My family would not ever have carers come into to look after the members.'

Finally, these accounts emit a sense of blame being targeted externally but without a particular focus. For instance, Anne began by blaming the 'world' and government for placing financial restraints on the residents:

'Everything comes down to money. And they [government] promote independence, rights of choices, when the bottom line is, if it comes down to money, all umm... the choices go out the window.'

However, after further questioning on the actual link of government funding and how this impacts on the residents, Anne seemingly backtracks to allocate blame on the charity organisation she works in. Subsequently, she backtracks further to detract blame from the charity before, doing a complete conversion and stating the positives of the charity:

'You have umm... in house policies and procedures that fit your actual home, and then you have the company ones. That are across, go across all the homes. And if I am honest, they are a really good company to work for.'

This sequence of questioning⁶¹, left me with the feeling of a nameless or faceless target of blame, perhaps suggesting Anne's need was the actual act of blaming as opposed to having a specific identifiable person or organisation.

4.4 MY RELATIONSHIP WITH THE PARTICIPANTS

There was one particular observation that I noted during several of the interviews; namely my tendency to doubt myself, wondering whether I was asking the right questions, getting at the right information and connecting with the participants. I often left feeling incompetent, doubting my skills as a researcher and even blaming myself. This felt at extreme odds with my clinical work, in which I feel confident to be myself, make mistakes, situate problems within the frame of me being a trainee, and indeed I enjoy modelling this approach within therapy, to illustrate my fallible nature, thus addressing possible power imbalances. I have since reflected on what may have caused such a reaction.

One hypothesis is that I was experiencing a transference reaction, or responding to a reciprocal role dynamic, similar to that of the support worker-resident. For instance, it is interesting that during these interviews I located the blame as centrally in myself, questioning my own abilities, struggling to situate this reaction within the context of this research. May this be what the residents are experiencing? In CAT terms this may be understood as the RR pairing 'blaming' (participants) to 'blamed' (myself). This is not to say the participants were consciously or explicitly blaming me, but that I may have been experiencing a subtle relationship dynamic; a reciprocal force to adopt the role of 'blamed' and locate the blame as in me⁶². Similarly, may the residents be experiencing such as a subtle reaction to the participants, locating the blame as within themselves or their 'disability'? Thus emerges the question, what role might this dynamic play for the participants, such as protecting themselves from the painful feelings of blame and responsibility⁶³. Might this blame carry the multitude of painful emotions that participants described during the interviews, such as anger, sympathy, 'heart break', powerlessness and helplessness? I will explore this further in the discussion.

⁶¹ An alternate hypothesis may be that Anne ends the sentence with '*and if I am honest, they are a really good company to work for*' because she may be worried that this information will get back to her employer. This may be consistent with the previous sub-theme 'protection'.

⁶² Concurrently, just as I describe experiencing self-blame and adopting the 'blamed' position, am now switching poles and blaming the participants for my insecurities? Just as the participants may be blaming others to cope with the challenges and pain in their role am I now doing the same, blaming the participants for my struggles? Thus raises the question, what is occurring in this system that it promotes the reciprocal relationship of 'blaming' to 'blamed'. This RR was also stated as one of the five common RRs in learning disability services by Lloyd and Williams (2004).

⁶³ This is consistent with Storey, Collis and Clegg (2011) who described the interviewer as feeling she was experiencing unconscious projections from the participants concerning their fear of being blamed and held responsible for such incidents. The interviewer also felt that the participants were indirectly expressing a wish not to discuss such events and feelings any further, so did not probe further.

5. DISCUSSION

5.1 OVERVIEW

The primary research question in this study was:

What is the emotional and psychological experience of support workers in a learning disability service?

This question was explored via further subsidiary questions:

- What emotions does the role evoke?
- How do support workers make sense of their emotions and experiences?
- What motivations and values do support workers hold about their role?
- What roles and positions do support workers adopt in their work?

The following section explores the key findings in respect of the above questions and in relation to existing theory and evidence base. The significance of the study, clinical implications, methodological issues, suggestions for future research and reflections on the study will subsequently be explored.

5.2 REWARD, MOTIVATION AND FULFILING ROLES

Reward, reciprocation and 'Valuing Now'

Whilst numerous authors have associated working in learning disability services with high levels of burnout and stress (Buckhalt et al., 1990; Hatton, Brown, Caine & Emerson, 1995), the discourses of the participants in this study suggest that the relationships and interactions in the workplace have potentially joyful, pleasurable and motivating dimensions (sub-theme 4.2.1.1 – Pleasure in the role). This pleasure derives from different levels of interaction and meaning; such as from co-engagement in enjoyable activities, rewarding relationships, gratifying roles, and on a moral level, the engagement and enactment of intrinsic 'goodness'. Indeed, although there were descriptions of struggle and conflicts, several of the support workers had been employed for extensive periods (Anne - 8 years; Francesca - 11 years; Habika - 14 years). Zarina also described her colleagues as being employed for many years⁶⁴. These results suggests that many support workers find ways to cope with the stress, find a work-life balance and gain sustainable meaning and fulfilment from the role.

⁶⁴ *'...she's been here for like ten odd years. [Staff name] fifteen years, even some of the casuals they've been here for like seven or eight years'*

Thus an important question emerges, what is the nature of the participants' joy, fulfilment and reward? Whilst participants described the pleasure of being involved in particular activities such as Christmas meals or recreational activities, what emerged strongly was the fulfilment of adopting the specific roles of 'supporter', 'facilitator', 'enabler' and/or 'helper'. This is exemplified in Zarina's account:

'with people who have learning disabilities it's more enabling and it gives you that excitement, that joy, that fulfilment, that satisfaction that you can actually add value to someone's life'

This repeated theme (observed with all participants) delineates the existence and importance of a reciprocated pleasure in the support worker role. This could be understood via CAT theory, wherein the support workers are adopting the roles of 'supporting', 'facilitating' and/or 'helping', whilst the residents occupy the alternate pole of 'supported', 'facilitated' and 'helped'. As discussed in the introduction, RRs consist of a role for self, a role for other and a paradigm for their relationship. Thus, when an individual adopts one pole of an RR pairing, the person with whom they are relating feels pressured to adopt the congruent pole (Denman, 2001).

Furthermore, this expectation upon the resident to adopt the congruent role is increased by two particular factors, namely the nature of the care home and the parental-like relationship. Alison & Denman (2001) explain that in more intimate and closed environments (such as a care home or the therapeutic situation), where fewer environmental cues guide role choices, the compulsion to reciprocate is intensified. Walsh, Hammerman, Josephson & Krupka (2000) highlight the similitude of the staff-resident bond to a parental relationship, namely due to the differential levels of dependency, power and/or emotional vulnerability. They argue that this power disparity intensifies the RR dynamic. Furthermore, De Groef and Heinemann (1999) state that the handicapped⁶⁵ individual runs the risk of putting themselves in the position of a satisfying object for another, particularly within a parent-child dynamic. They argue that the resident not only becomes an object of care, but also an indispensable object for the other (parent or support

⁶⁵ The 'handicapped individual' or 'handicapped child' is a term most notably employed by Valerie Sinason (1992) to describe people with learning disabilities. I would like to declare that the term 'handicapped' holds certain negative and presumptuous connotations which I dislike, namely that disabilities or difficulties always results in a handicap, limitation and/or deficit to an individual's quality of life. I would contend that there are many individuals with a diagnosis of 'learning disability' who, perhaps through various creative coping strategies, learn to lead lives as rewarding, meaningful and enjoyable as any 'normal' person. However, to stay consistent and respect Sinason and other authors' work, I will employ this term in their theorising. Furthermore, the dichotomy between 'disability' and 'normality' has been challenged by many authors, irrespective of the labels. Dudley-Marling (2004) critiqued the view of individualism that situates individual success and failure as *within* individuals. He argued a social constructivist perspective that locates learning and learning problems in the context of human relations and activity. He proposed that the performative aspects of learning disabilities emerge in the context of human relationships, thus ultimately one cannot be learning disabled on their own.

worker) in order to efface their hurt; namely the hurt of being handicapped. These studies indicate the propensity and compulsion of residents to adopt and indeed surrender to the RR of being ‘helped’ and ‘supported’.

‘Valuing Now’

Problematically, these RR poles (supported, facilitated and helped) do not situate the resident in a position of empowerment, control or autonomy, but actually one of dependency and reliance on the support worker. Thus, as the support worker gains fulfilment and gratification from their RR, they inadvertently compel (and perhaps implicitly coerce) residents into the disempowered roles of ‘supported’, ‘facilitated’ and ‘helped’. These RRs are consistent with Bancroft et al. (2008) who described one of the over-arching RRs in learning disability services as the ‘rescuing’ (support worker) to ‘rescued’ (resident) RR. Accordingly, I contend that the basic drives for pleasure, joy and reward in support workers may be in contradiction with ‘Valuing Now’ (DOH, 2001; DOH, 2009); which highlights policies of choice, independence and autonomy. Thus, to what degree can ‘Valuing Now’ principles and ethos prevail and be meaningful, if in conflict with the support workers’⁶⁶ impulses towards parental and gratifying positions⁶⁷. It stands that for ‘Valuing Now’ to move forward, support workers may have to reflect and reinterpret, to a degree, a part of their role from which they gain satisfaction and motivation. Ultimately, it may be that the basic staff-resident relationship dynamic is embedded within a power dynamic that negates recent political endeavours of ‘Valuing People’ (DOH, 2009).

An alternative hypothesis would be that support workers aim to *‘facilitate’* the residents’ independence, autonomy and choice. However, this did not appear to emerge within the accounts. For instance, Caroline described the *‘most reward’* as *‘when you know you are the only one getting that affection back from then. I think that’s what’s really like the gold star for me’* or Zarina described the joy of being looked up to *‘like Jesus Christ’*. Notably, there was an absence of narratives of pleasure and fulfilment in seeing residents’ develop independence, learn new skills, act autonomously or express choice. Ultimately, the participants’ sense of personal gratification and reward seems intimately interwoven within the emotional sphere of such *‘facilitating’*, *‘supporting’*, *‘helping’* or parental roles. This may explain the contradictions in sub-theme 4.3.1.2 (The conflict of balancing multiple expectations), as participants are balancing government policies of ‘Valuing Now’ (DOH, 2009) with their own emotional desire for fulfilment.

Finally, it is also important to balance out this perspective with an understanding of *‘supporting’* and *‘facilitating’* roles within the context of support workers’ altruism and a

⁶⁶ Who are arguably the primary agents of carrying out such policies.

⁶⁷ I am not arguing that this is an inevitable and global conflict which permeates all levels of interaction between support worker and resident. However, I am contending that a strong element of the support worker *‘facilitating’* motivation may be at odds with empowerment initiatives. I would hypothesise that this element may become increasingly salient during times of anxiety and difficulty.

medicalised caring system. Support workers act in ways that represent their devotion to or living for the welfare of others; the principle of altruism. These altruistic behaviours were evident throughout the participants' interviews in their descriptions of working extended hours and supporting the residents with their own personal money. Another understanding for the contradictions in sub-theme 4.3.1.2 (The conflict of balancing multiple expectations) may thus be the paradox of balancing altruistic and humanistic views with the customs of a medicalised care system. For instance, there is a tendency to view and discuss patients in objective, technical, detached and non-humanistic ways in the culture of medical care. This does not imply unkindness but rather has developed for beneficial purposes, such as the provision of scientific expertise and efficient communication (Burks & Kobus, 2012). A potential negative side-effect of this tendency is detachment or de-individualisation (objectifying patients) which may differ from and contradict the other-directedness of altruism. This may explain the descriptions of feeling powerless (sub-theme 4.2.2.1) and indeed conflict within their role as support workers strive to provide altruistic care within a medicalised caring system which may work against this in some ways.

5.3 IDEALISED CARE AND THE PROJECTION OF 'UNWANTED PARTS'

Being unable to offer the ideal care

Sub-theme 4.2.1.2 (Tensions of 'ideal' versus 'insincere' care) explored the participants' relentless endeavours to be the best support worker they could be, work the hardest and ensure the maximum quality of life for the residents⁶⁸. Whilst this drive and ambition can be seen as positive, in the sense that it means the support workers are motivated to offer the best quality of care possible, I wonder what underlies this. For instance, acts of being unable to offer this ideal care were associated with negative reactions, experienced as acute failure, anger, guilt or even catastrophic self-blame. Zarina described the pain of forgetting a trip with a resident and feeling *'ooh I've let [resident name] down I've really let her down I have, oh and it's not like just letting her down, it's letting everybody down'*; or Francesca explains the need to check (unpaid) on ex-resident's after they have moved on to make sure they are okay, *'I knew that I had to do it for my own peace of mind and his, to just be able to carry on with my work'*⁶⁹. These extracts illustrate the negative or paralysing reactions to being unable to offer their model of ideal care. In this sense, the endeavour towards offering 'ideal care' can be seen as a coping mechanism to ward off or avoid experiencing the painful feeling of failure, guilt and blame.

⁶⁸ This is consistent with Lloyd and Williams (2004) who found one of the common RR of support workers to be 'ideally caring' to 'ideally cared for'.

⁶⁹ Francesca reiterated this several times that she would be unable to work without checking to make sure ex-residents are okay.

I thus came to wonder what underlies this extreme compulsion to offer such ideal care; that support workers would drop anything to cover a colleague's shift (Habika), be constantly looking to build on their experience for the better of the residents (Emeka) or come in to check on residents during their maternity leave (Francesca). The extent of the support workers' endeavour to offer such idealised care often impacted upon their personal time, suggesting that the gratification and fulfilment surpassed professional boundaries to being integrated within their personal identities. The following section explores diverging hypotheses on what may underlie this unyielding drive.

The projection of 'unwanted parts'

The anguish that participants described at being incapable or failing to make the residents happy (thus fulfilling their ideal role) seemed to be particularly acute, painful and distressing. Thus emerges the question, what was internally occurring that the failure was perceived as so painful? Or alternatively, what was the nature of this failure? One hypothesis may be the unconscious transference of a conflictual psychic experience. De Groef & Heinemann (1999) described that those who care for people with disability must face their own disability, weakness and wounds, a disposition that many would habitually ignore, conceal, deny or thrust on others. De Groef and Heinemann (1999) coined the term 'lack' to describe what the handicapped individual awakens in others, leading the other to adopt an attitude of extreme solicitude in an attempt to make sense of the life which, they perceive, as being deeply hurt.

Let me elucidate this idea of residents awakening the 'lack' in support workers. Sinason (1992) described that the unspoken question for a person with learning disabilities is 'Why was I born like this?' and the adult carer 'Why were you born like this?'; although hidden and unspoken, these questions frequently come to the fore during anxiety. De Groef and Heinemann (1999) similarly, propose that working with learning disabilities confronts us with a selection of questions: 'What is a human being without defects?' or more acutely 'Is a human being with a defect still a human being?'. Freud (1893) argued that it is in human nature that every defect, lack or shortcoming calls for rectification. Further, in my perspective, the support workers must work through a selection of role dilemmas. Firstly, supporting residents who they will be unable to fully cure (in the sense they cannot take away the disability), the irreversibility of difficulties, and thus they will always be in a state of failing to rectify the defect⁷⁰ (Freud, 1893). The inevitability of this failure may account for the extensive feelings of powerlessness (section 4.2.2.1). These questions or dilemmas, be they conscious or unconscious, illustrate that learning disability poses a threat to support

⁷⁰ Furthermore, Menzies Lyth (1988) also described that although the caring/supporting service has considerable successes with the residents, the carer misses the reassurance of seeing a patient get better in a way she can easily connect with her own efforts.

workers' sense of identity, order and psychic integrity. How do support workers cope with this 'lack' and the threat it constitutes?

Symington (1992) explained that in the face of learning disability, support workers may experience sympathy, guilt and resentment. This is consistent with many of the accounts in this research (section 4.2.2.1 - Powerlessness and the emotional reaction to injustice); sympathy and guilt for the individual's plight and struggles of having a learning disability, anger at the injustice, whilst also anger and resentment at the 'lack' that it arises in them. Symington (1992) argued that support worker copes by pushing unwanted parts of themselves into those who are different; projecting the 'lack'. Similarly, Sinason (2002) argued that the learning disabilities individual can become the receptacle of all handicapped, unwanted and stupid parts of every person. The support workers thus split and project the deeply agonising, painful unmanageable 'lack', which is aroused in the presence of a learning disability, into the residents. Thus, the act of '*supporting*', '*facilitating*' and '*rescuing*' the residents (by striving to offer the ideal care), is simultaneously caring for the unwanted parts of themselves⁷¹.

Within this model of understanding various realisations are made. Firstly, the zealous solicitude of support workers may also be understood as a denial to accept the impossible by sparing the individual from confronting the presence of a learning disability. For instance, fervent care prevents the residents from facing the existence and impact of the learning disability, or indeed the unbearable pain of this. This is consistent with Sinason (1992) whose observation of the frequency of carer comments such as 'I want to give him everything', 'I don't want him to be in need of anything', 'I don't want him to suffer'⁷². Simultaneously, the support workers may be, unconsciously and implicitly, preventing themselves from confronting the existence of their own 'lack' and 'unwanted' parts in this care⁷³.

This projected 'lack' can be paralleled to attachment theory. Research on attachment, infant observation and development (Ainsworth & Eichberg, 1991; Bowlby, 1980; Main & Hesse, 1990) state that learning disability can become the space into which unresolved intergenerational trauma is projected. People with learning disabilities can suffer a void of subjectivity; namely the space in which they might have existed can become the container for the parents' own overwhelming emotional experience (Linington, 2002). Thus, just as the parents project their overwhelming emotional experience into the 'container' of the residents; support workers may project their overwhelming emotional experiences.

⁷¹ This is consistent with Collins (2006) who postulated that support workers may be attracted to the role to meet a need to be the 'perfect carer', which he hypothesised as a compensation for being unable or failing to adopt this position in a previous relationship.

⁷² These comments are consistent with the accounts in this study.

⁷³ This is consistent with King (2005) who described that 'ideal care' is often sought out and reciprocated, which he understood as the desire to magically compensate for internalised feelings of limitation, vulnerability and 'woundedness', which the person with learning disability has experienced throughout their lives.

Thus emerges the question, what unwanted parts of themselves, or what 'lack', may the support workers be projecting into the residents? Interestingly, although all participants described reward in the roles of facilitator, teacher or provider, many also subtly described a sense of desiring recognition, acknowledgement and acceptance from the residents (Nnamdi⁷⁴, Anne⁷⁵, Caroline⁷⁶, Zarina⁷⁷). Their accounts emitted a sense of reward in being acknowledged and appreciated, which may underlie a sense of striving for acceptance, comfort and love. Thus I wonder if in deconstructing this relationship and exploring the 'lack' that at an unconscious level there exists a desire to be accepted, comforted and loved, with an underlying fear of rejection.

It is beyond the scope of this research, nor was it the intent, to explore elaborately and in-depth the idea of 'unwanted parts'. What I have ventured to elucidate is that the processes of '*facilitating*' and '*supporting*' positions, adopted by support workers, are embedded within a multi-faceted motivation and emotional internal system. The roles of '*supporting*' the residents (by striving to offer the idealised care), may also entail splitting and projecting the painful, unmanageable and 'unwanted' parts of themselves into the residents; thus avoiding the deep agony of their 'lack'.

The consequences of projected 'lack'

Firstly, the 'lack' allows support workers to compensate for their narcissistic lesions (unwanted parts) through the effect of overinvested ideals; enacted through their excessive altruistic care (De Groef & Heinemann, 1999). Supporting residents can thus be conceptualised as vicariously supporting the unwanted and painful parts of the support workers themselves. In this sense, zealous care, whilst tiring and time-consuming, may be a way of coping with the pain of being in contact with someone with learning disabilities; which arouses their 'lack'. This may account for the intensity of pain and catastrophic blame that the participants feel when experiencing failure; because experiencing the residents' struggles to be independent and indeed accepted by society, is concurrently arousing their failure to liberate themselves; a two-fold failure. This is consistent with Lloyd and Williams' (2003) findings that staff reacted with hopeless, shocked, hurt and 'hyped up frustration' about how to reach and teach people with severe learning disabilities; in essence how to support the unwanted part of themselves that they have projected.

⁷⁴ Nnamdi described the '*gift*' of appreciation '*When they appreciate it. I will be so happy I tell you. I am always very very happy when I do something and they appreciate it. It makes me feel happy. I feel home and dry*'.

⁷⁵ Anne described the pleasure of being noticed for being away on holiday '*that really does make you smile. Because it makes you think, well at least somebody missed me*'.

⁷⁶ Caroline described needing hugs '*I pretty much demanded it [hugs] from her [laugh], she would give it to me*'

⁷⁷ Zarina described the pleasure at being appreciated '*and they tell you 'thank you' and it's just that thank you and love and you go and you feel so, I've helped somebody that in a way is, 'thank you for taking me out', 'thank you' [sounds happy]*'

This may also explain the separation pain and anxiety that participants described. Many participants⁷⁸ described struggling when residents moved onto another home, many visiting to check up on the residents. This is because separation would mean re-owning the projected aspects of each individual. This separation can also be taken more broadly, to equate to any act of parting. For instance Sinason (1992) described the frequent saying of mothers 'we can't come out, you know we have to look after Tommy, he can't manage on his own'. This is consistent with some of the accounts in this study, namely Francesca who re-organised her childcare so she could take a resident to the GP and save him the cost of a taxi. Thus the question emerges, what fears, conflict or challenges (such as maintaining relationships) had been hidden under the excuse of 'caring for Tommy'; or in this case, hidden under the guise of supporting the residents? I would hypothesise that the nature of these hidden conflicts differs significantly from support worker to support worker, and from their interactions with different residents, as the individual nature of different residents' struggles and disabilities may evoke significantly different aspects of 'lacks'. I contend that one of these 'lack', based on this research, may be rejection, or a desire to be accepted by others. More in-depth investigation may reveal a selection of different 'lacks' or unwanted parts for support workers, based on their past experiences

To conclude this section, I would assert that the caring relationship in learning disability homes is more complex than the mirror-like division between carer and the one being cared for. Disability, handicap and defect provides a useful space for support workers to locate 'unwanted parts', such as incompetence, damage, depression and pain, to name but a few. The process of this projection, accompanied by poignant feelings of guilt, shame and sympathy, may lead to a zealous solicitude (or over-caring) which negates participants' development of control, choice and autonomy; the quintessence of 'Valuing Now' (DOH, 2001; DOH, 2009).

Negativity towards insincere care

The preceding ideas on the 'unwanted parts' of support workers being projected into the residents may also explain the rejection of caring for anything but sincere care (sub-theme 4.2.1.2 – Tensions of 'ideal' versus 'insincere' care). This sub-theme discussed the idea of support workers struggling fervently, to accept other staff members who did not work for anything but 'care', 'heart' and 'soul'⁷⁹; with a particular aversion towards working for money. The use of such internal and intimate references indicated the depth of emotional and personal investment that support workers devoted to their work. Their poignant detest of staff who would work for money, may be understood as the unconscious aspects of themselves (the 'unwanted parts') reacting painfully to another's unconscious realm; a realm that does not need to project unmanageable pain onto the residents and does not

⁷⁸ Namely, Anne, Francesca, Caroline, Habika and Zarina.

⁷⁹ This is from Anne's account.

experience such a psychic conflict, or to not such a degree. The participants often interpreted this position as *'not caring'*, a recurring phrase from numerous interviews. Thus, this repeated phrase *'not caring'* may actually not just be communicating, you do not care about the residents, but actually you do not care about me; because support workers have located their own *'unwanted parts'* in the residents.

Within this denunciation of insincere care, the support worker keeps hold of their identity of the ideal carer, an affective coping mechanism to manage their underlying pain. To accept that a support worker can work without *'care'*, *'heart'* and *'soul'* is to effectively castrate themselves of a position (caring, supporting, enabling) that they are deeply invested in. Furthermore, in the incidence of this acceptance they may be forced to confront the personal fulfilling and self-gratifying aspect of their roles; which is starkly incongruent with their model of being a support worker. This is most exemplified in Anne's account:

'People seem to think you do it because you like helping people....That annoys me a little bit because it's almost like you are doing it for your own satisfaction and it's not that at all, it's just.... they seem to think you are doing it for your own gratification, it's not that, I just like this line of work.'

Anne's brusque refusal to accept that she works for any personal *'satisfaction'* symbolises the degree of role idealisation; that she understands herself as the altruistic, giving and unconditionally caring support worker. Indeed, she is able to locate herself as the all-giving ideal carer because she has projected all the unwanted and un-ideal parts of herself into the residents, who she now cares for.

5.4 UNDERSTANDING COPING PROCESSES

The main theme *'Safety and Conflict within Coping'* (section 4.3.1) suggested one particular tendency of participants', that of being *'Constricted and un-elaborative'*⁸⁰ (section 4.3.1.1). Thus emerges the question, why would support workers need to hold such a processing structure, or more aptly, what would cause support workers to hold this position?

One premise is that this constricted and un-explorative style of thinking provides protection and a way of coping with the demands of the role. For instance, the main theme *'The emotional struggle'* (4.2.2) described vividly the range of challenging and painful emotions that support workers are forced to experience, contain, cope with, and indeed sustainably

⁸⁰ This theme was also identified in other research (Storey, Collis & Clegg, 2011) which found support workers struggled to access and elaborate on their work feelings and experiences. They found participants responded, consistent with this study, with succinct and repetitive responses of things just being *'part and parcel'* of the role.

manage⁸¹. I contend that these emotional experiences would be unmanageable on the support worker, without a system of coping. Thus, the support workers *need* a coping structure to prevent all these experiences from being overwhelming and debilitating.

Thus, it could be understood that the sense of being constricted and unexplorative provides a protection for the residents against painful emotions; such as against powerlessness and hopelessness, which they nevertheless experience, but in a more manageable capacity⁸². This was echoed in the brief, succinct and unelaborated answers of numerous participants, *'that's just the way it is'* (Nnamdi), *'You can't do anything about it'* (Emeka) and *'there's just a limit to what we can do'* (Zarina). This is most exemplified in Francesca's account where she describes the importance of learning to become *'hard'*⁸³ to cope with working in the field. The *'hard'* or hardening may not just be a metaphor she employs but literally symbolise her experience of internal solidification, making herself impenetrable to pain. However, it appears that this solidification is semi-permeable or only partially effective, as all participants still describe experiencing a range of painful emotions.

Another hypothesis is that this constriction exists to prevent the re-integration or re-introjection of unwanted parts. Participants' develop a hardness which is sustained by the fear and pain of having to re-internalise the unwanted or damaged parts of themselves. I feel that a major facet of this pain was the powerlessness (section 4.2.2.1), which was extensive, powerful and permeated expansively within the participants' descriptions. Thus, I would argue that the constricted and unelaborated answers are both a form of avoidance (of exploring painful material and emotions) but also figurative of the participants' powerless position, namely that it is pointless discussing things that cannot be changed.

A further hypothesis may be the influence of cultural, language and ethnic differences on the understanding and expression of language. For instance, Emeka, Nnamdi and Zarina described their ethnicity as 'Black African'. Kim-prieto and Eid (2004) described that people from collectivist African nations generally found negative emotions less desirable, such as anger, resentment, pride and frustration, with a concomitant reluctance to discuss them. They found that people from collectivist African nations rely more on nonverbal communication to express their feelings, such as through eye contact, physical touch and local forms of gesticulations. Thus it may be that the cultural, language and ethnic differences impacted on the way we communicated and experienced each other.

⁸¹ These painful experiences are evident in the sub-themes of 'powerlessness and the emotional reaction to injustice' (section 4.2.2.1), and 'The relentless nature of struggles' (4.2.2.2).

⁸² One hypothesis may be that the concrete style of coping inadvertently prevents participants from fully experiencing, understanding and learning to cope with such painful emotions, which may paradoxically sustain and maintain the problem.

⁸³ This is consistent with Storey, Collis and Clegg (2011) who reported that support workers described needing to develop a 'harsh exterior' to cope with the client work.

Finally, a consequence of this coping style is that it may lead to conflict (section 4.3.1.2), particularly due to the immensely complex interplay of emotions in this working environment. For instance, participants described advocating for treating the residents as adults (empowerment) but described childlike interactions (Caroline), promoting choice whilst describing control (Nnamdi), preaching acceptance whilst describing conformity (Anne) or advocating for detachment whilst describing attachment (Francesca). It may be that fears of external persecution (sub-theme 4.3.2.1 – Protection) cause them to zealously advocate for such principles, experiencing me as someone who may criticise or even blame them. Further, it may be that my experiences of this constricted style of thinking is related to participants not appearing to be comfortable discussing their emotional reactions with someone perceived as an outsider. It is possible, and indeed likely, this was because they did not know me well enough to feel safe, particularly as I described of the limits of confidentiality in the introduction. However, I would argue, that I experienced the participants as reluctant to engage in more in-depth and detailed narratives of painful experiences, particularly those they felt they could not change⁸⁴.

5.5 THE CIRCULATION OF BLAME

Global and extensive blame

Throughout the interviews, my attention was repeatedly drawn to the high levels of blame from participants (section 4.3.2.2). The target of this blame seemed both global and extensive, such as blaming other staff for not understanding the resident's difficulties, the organisation for being unappreciative, other healthcare professionals for being inexperienced in learning disabilities, the government for not supplying the money to back up policies, and indeed the public for their ill-treatment of the residents. The magnitude and wide-ranging inclusivity of the blame emitted a sense that support workers required a target for their blame. Hence the important question, what motivates this circulation of blame?

Blame releases responsibility

Firstly, it was notable that the blame was rarely targeted at the resident; at least not explicitly. Indeed, the resident was never seen as blamed because it was the *'problem'*, *'difficulty'* or learning disability and not them. In this sense, the resident was excusable for anything; such as the negative impact of *'challenging behaviours'* on the staff. One hypothesis may be that the circulation of blame involved a release, discharge and thus liberation from, the weight of responsibility. As described previously, the participants have a penchant towards facilitating, supporting and parental roles. However, attached to these

⁸⁴ This support the notion that participants coped with painful experiences and feelings of powerlessness (during their work and conversationally) by avoidance or being un-explorative.

roles is the significant weight of responsibility, namely the accountability for the residents' safety, daily routines, happiness and their overall quality of life. Just as they gain significant reward from these positions they may simultaneously receive an elevated level of responsibility. Indeed, adopting the 'ideal carer' position carries with it a consequence; power and liability. Further, the weight of this responsibility is magnified if the residents do not have family, friends or a support network. Support workers may not just be important in the residents' life; they may be the only meaningful relationship that they have⁸⁵.

Interestingly, the direction of blame and delegation was most frequently directed up the hierarchy, towards the participants' superiors, the organisation or government. This is consistent with Menzies Lyth (1959) who described that in learning disability services, nurses directed their blame up the chain, or up the hierarchy⁸⁶. How might we understand this penchant towards upwards delegation of blame?

Firstly, the direction of blame towards individuals or a service which is not actually located at the workplace means that the fear of direct reprimand or punishment is reduced⁸⁷. Secondly, that the blame is directed more vaguely at a broadly categorised group of people, such as the organisation or government, reduces the intensity of individual focus and condemnation. Thus, should the blame be traced back to the support worker, they may divert the blame to different sections of the large organisation, hence escaping reproach. I was particularly struck in Anne's description of blame towards the government for being unable to finance political drives towards choice, autonomy and empowerment with regards to meal times. Upon probing for specifics, she withdrew her blame from the government to the organisation, before subsequently, withdrawing her blame from the organisation. This may indicate her need to release the burden of responsibility by the act of blaming; as oppose to the explicit need to blame a particular person.

Concern to appear positive and not express negative feelings in relation to the residents may also be linked to the belief that it is not professional to have negative feelings and that these emotions should be managed rather than expressed (Hochschild, 2003). Accordingly, the safe way for support workers to express negative feelings was to project and displace them onto the organisation or government. This finding is consistent with Storey, Collis & Clegg (2011) who described that participants coped with painful and anxiety provoking experiences by either repressing and/or projecting them out onto the organisation. McWilliams (1994) described that projective identification entails elements of projection (attributing one's own feelings, thoughts, and motives to others)

⁸⁵ This is exemplified in Anne's account: *'When somebody has nobody, and you know you have got a rapport with somebody. And you get on well with them. And they look to you for reassurance. You know that you have got to step up to the mark.'*

⁸⁶ She contrasted this to other work environments where superiors delegate a task and the direct responsibility for its performance to their subordinates.

⁸⁷ Furthermore, if blame comes too close to home, it implies there is more opportunity or implicit pressure to address this.

and introjection (incorporating the feelings, motives, and thoughts of others). This projective identification, ultimately, validates one's projection by making the projection real (Kleine, 1946); this is the benefit of the defence. By inducing the projected experience in another, one is more able to avoid the reality that the projected content is part of one's own experience (Grotstein, 1977). Thus, the support worker experiences unacceptable feelings of fear and anger at their impotence in being unable to heal, support and care for the residents. They thus project this impotence into the organisation and other professionals, blaming, admonishing and finding weakness in all and any aspects of any other professionals.

Blame as projective identification

The blame may also be communicating the magnitude of the participants' pain, distress and frustration at the powerlessness of their position to support the residents. However, support workers may be unable to express these feelings to the residents or other support workers, due to a fear of being perceived as heartless or unable to cope with caring. For instance, Lloyd and Williams (2003) observed the tendency of support workers to be reluctant to display or express pain, fear or disgust, for concern peers may see them as incompetent and unable to cope. The two-way aspect of the projective identification particularly emerged in Francesca's description of telling the GP what medication the residents needs⁸⁸. As Francesca tells the GP what to do, and admonishes their attempts at different medication or diagnosis, she forces the GP to lose trust in their own abilities, instincts and thoughts. For Anne, this emerges in her constant questioning of staff⁸⁹. The childlike, repetitive questioning and condescending tone of her words force staff into positions of powerlessness. Thus the projection of this 'impotence' and blame towards others prevents the support workers from attending to their own denigrating and distressing impulses, thereby keeping them out of awareness.

Finally, the tendency towards blame may be understood as engaging in the psychological defence mechanism of denial (McWilliams, 1994); the support workers pretend to themselves that they were in a position of power. Acknowledging on a conscious level that they have no power may have been too painful.

5.6 CONTEMPTUOUS BLAME

⁸⁸ Francesca described: *'You tend to tell the GP what's wrong with your client, rather than the other way around [laugh]. Just to get the medication that you think that they need and to be honest 99% of the time you are right because you know their traits or it's an obvious thing.'*

⁸⁹ Anne described: *'They [staff members] go well, they live here because they have a learning disability. And I say, yeah [condescending tone], then they go yeah but bla bla bla, but do they have to do so and so? And I say 'yeah [condescending tone] its part of their daily routine that's what they do'.*

Throughout the interviews I was drawn, not just to the high levels of blame, but the character of this blame; namely one of attacking and condemnation (section 4.3.2.2). This blame emerged as implicit and explicit. This is consistent with Lloyd & Williams (2003) who found that a common RR in learning disability services was contemptuous to contemptible. Thus I began to question what caused support workers to express such a degree of condemnation? Moreover, their descriptions seemed incongruent with their personal and intimate descriptions of believing in working with care, kindness, heart, soul and indeed love.

To address this contempt I would like to refer to Symington's (1992) seminal paper on 'Counter-transference with mentally handicapped clients'. Symington, whilst conducting a group workshop on the psychotherapy of people with learning disability, described the sudden realisation that psychotherapists treat these individuals with contempt; a contempt that they did not experience toward 'normal people'. He explained that various psychotherapists described subtle and unconscious incidences of patronisation and contempt. For instance, one therapist decided to wear her shabby dress because she was 'only' seeing her learning disabled client, another being late for a session because their learning disabled client 'wouldn't mind', or a receptionist who forgot the individual's cup of tea but remembered the therapists.

Deconstructing this contempt, Symington (1992) argued that in the animal kingdom the flock of birds attacks and kills the one that is wounded, similarly with wolves. Thus in humans, is there the instinct to kill off the person with learning disabilities; the handicapped member? He posed that the fundamental question of people with learning disability is: 'in truth would you prefer to blot out my existence?' Indeed, this question bears similarity to Sinason's (1992) unspoken question for a person with learning disabilities is 'Why was I born like this?' Symington (1992) elucidates his argument, that the feeling of contempt is not singularly decisive (indeed many therapists experience feeling contemptuous at some point); but what was distinctive about this client group was that the same feelings were experienced towards the whole group, by all the psychotherapists involved. Thus, is it the learning disability itself that evokes contempt, but why?

The instinct to be 'rid of'

Let me return to Symington's notion of the human instinct to kill off the handicapped member. Whilst this may be seen as an extreme, dark and indeed violent presumption to some, including myself, other authors have described such an inclination. Mannoni (1973) argued that in the presence of learning disability the parent may feel narcissistically affected by the infirmity of their child and the finality of the diagnosis. The parent then engages in a passionate battle for the health and life of their child with a learning disability. This passionate battle bears a distinct parallel to the zealous solicitude of participants in this

study, more so by the similarity to a parental relationship. Mannoni (1972) proposes that the parent-child relationship will always have, in such a case, an aftertaste of death, of death denied, of death disguised usually by sublime love, sometimes pathological indifference, and occasionally, as conscious rejection. She suggests that the idea of murder is there, even if the parent is not consciously aware of it. This can be seen as the ultimate struggle between life and death instincts (Mannoni, 1972).

Symington (1992) argues that we inherently want to be rid of the person with learning disabilities because of their egocentric focus on themselves; attributing all of their surroundings and peoples actions to being about themselves. This focus prevents the freedom of our own identity, whilst causing exasperation due to its extremity. He argues that in our attention to the person with learning disabilities' detail and idiosyncrasies; they experience themselves as very powerful. Symington (1992) argues that it is the presence of this omnipotent god-like ego structure that causes exasperation, contempt and a desire to get rid of. Thus, ultimately, it is not the learning disability that generates this contempt, but rather the perceived god-like figure within.

I would like to elucidate on the terms 'omnipotent god-like ego structure' or 'god-like figure' within the context of this research, and because they hold a pejorative connotation that sits uncomfortably with me. Stern et al. (1998a) argue that the meaning and impact of a child with a learning disability is often overpowering for the parents⁹⁰, particularly the loss of a freedom to anticipate the future of your baby and yourselves. Thus the infant with learning disabilities comes to look into their parent's face for self-reflection and finds the gaping void of no imagination when feelings find no way to be thought and regulated (Linnington, 2002). This may lead to difficulties developing a sense of self or what Linnington (2002) describes as a 'void of subjectivity'. I contend⁹¹ that working with people with learning disabilities may involve working with people who struggle to integrate themselves⁹²; to integrate with (and learn to separate from) their parents' emotional world, their own thoughts, feelings and identity, and the particular culture and community. This disconnection is reinforced by society's attitudes towards people with learning disabilities; namely that they rarely hold jobs (Symington, 1992). Due to this struggle to integrate, the person with learning disability is forced into a position of centrality⁹³. For instance, if the person with learning disability is

⁹⁰ I do not contend that all parents may be like this. Some may integrate their child's 'differences' early on and respond as if they were relatively 'normal'; or more aptly understand or have a construct system based around different ideas; not the dichotomy of 'disability' and 'normality'.

⁹¹ This is my belief and not those of the participants, or at least was not discussed or explored in the interviews.

⁹² However, I am aware that in my initial section 'How I came to this study' I described myself as situating 'the space between'; i.e. between cultures, between languages, between interests, between people and, perhaps, between myself. This bears a striking similarity to the 'struggle to integrate' that I am describing now. Thus it may be that I am myself (the researcher) projecting my 'lack' into the residents. However, other authors (Linnington, 2002; Symmington, 1993) also describe this propensity, although employing different terms.

⁹³ Symminton (1993) describes this as omnipotence.

unable to feel integrated⁹⁴ and connected with other people, groups and society, then they thus feel pertinently detached and separate. Within this acute experience of separation they are forced into experiencing themselves as central or omnipotent⁹⁵. This, I believe, is what Symington (1992) refers to as the omnipotent god-like ego structure.

It follows that feelings of contempt and resentment are stirred up in support workers by their response to the omnipotent ego structure. However, I contend that due to the arbitrariness of whether one has a learning disability or not, the support worker is unable to blame the person with learning disability for this structure or our response; and thus the contempt must be discharged elsewhere. Therefore, the high levels of blame described in the results, which feels fused with denigration, condemnation and admonishment, are a dislocation and displacement of the contempt and anger that support workers experience in response to the residents' omnipotent ego. Indeed, that they cannot express this contempt towards the individual only further magnifies its intensity. Symbolically, just as there is a 'circularity of blame', which limits the scope for acknowledgement and acceptance; there is a 'circulation of contempt'.

Considering language, individuality and context

Before further exploring the ideas of blame, I would like to discuss the terminology and structure of my theorising and assumptions. I am not declaring that the participants in this study (or other support workers) harbour a desire to be rid of or kill the residents they work with. I do believe, however, that the experience of working with disability and handicap can raise immensely painful, conflictual and traumatic existentially-orientated questions regarding damage, deficit and dysfunction. These challenges (allied with working in a field which is often under-resourced) may lead to subtle but powerful feelings of resentment and contempt. These are magnified by the conflict of balancing these feelings with the concurrent sympathy, empathy and powerlessness of the residents' experiences. Finally, I am not suggesting that all support workers experience the same projective conflict of 'lack' or 'unwanted' parts, or that all people with learning disabilities experience the same challenge of inter-subjectivity. Indeed, this is a complex association and the multitude of different identities and senses of self may, and will lead to different experiences, reactions and interactions.

However, I contend that underlying and uniting these experiences may be a fundamental dilemma between resident and support worker; which emerges and develops in numerous

⁹⁴ One hypothesis is that integration occurs as children are provided with a contained space to develop the ability to reflect on themselves and consequently reflect on others. Without such a space it can be difficult to develop this. Various factors, such as abuse, neglect, linguistic or cognitive difficulties, may prevent infants from being 'mirrored' as a self. This can be paralleled to theory of mind (Bruner, 1983).

⁹⁵ Another, perhaps less pejorative, way of saying this is that people with learning disability struggle with theory of mind and are thus less able to provide for any unacknowledged needs the carer may have.

different ways. This conflict is that just as the imaginary child is destined to repair the wounds suffered by the mother in their childhood (Mannoni, 1973), the residents and their symbolical child-parent relationship with the support worker, may always be disappointing with regard to this fantastical image. This is because the support worker has projected their 'unwanted parts' or 'lack', which whilst symbolically carried by the resident, results in them also seeking to repair their wounds. Thus, if the resident is unable to find another place except one in which he fills up the 'lack' in the support worker, they cannot exist for themselves. I would hypothesise that the support worker may not know themselves what they want from the resident, their demand is the envelope of their lost desire (Mannoni, 1973). This accounts for the repeated references in this research to the resident not being to blame, but the '*problem*', '*learning disability*' or '*diagnosis*'; the support worker themselves are never to blame. Thus in interactions, it is the learning disability that fails: the learning disability of the resident dissimulates the disability ('unwanted parts' or 'lack') in the support worker⁹⁶.

Finally, various literatures have postulated the negative consequences of such powerlessness and avoidance on learning disability services. Bromley and Emerson (1995) explained the feeling helpless to 'cure' and 'influence behaviour' deters staff from intervening at all, avoiding clients or taking quick but ineffective action. Hastings and Brown (2002) argue that staff experience the most positive outcomes if they cope and manage with the emotional challenge of the work through forward planning, positive reframing, humour and using emotional support. Hastings (2002) argue that support workers who repress and deny the emotional impact on themselves, vent their own emotions, blame themselves or disengage from the task.

Circulation of blame on the system

I would like to conclude this section by drawing together the different strands of blame and describe the overall impact on the service. As support workers cope with the unmanageable experiences of guilt, blame, anger, hopelessness and contempt by projecting the blame responsibility onto others, it creates and reinforces a work culture in which no individual actually takes any responsibility, ownership or agency of the difficulties, conflict and struggles. Or alternatively, that no one actually acknowledges and takes ownership for the conflict, pain and trauma of what they are experiencing. The problem is that circulation of blame is crippling and ineffective, leading to a sterile situation in which no change can take place. This circularly leads to increased powerlessness and helplessness. The residents are not to blame because it is their '*disability*', '*diagnosis*' or '*problem*' which causes their behaviours; and the staff are not to blame because they do not have sufficient support from the organisation or government to implement strategies that would facilitate staff

⁹⁶ Thus, attempts to promote independence, autonomy, control or choice (DOH, 2009) in the resident must include an attempt to identify the 'lack' in the support worker.

happiness. As the staff project their blame and delegate responsibility onto higher and external influences, they remain static within their support worker roles; and indeed the support worker-resident power dynamic remains static.

5.7 STUDY SIGNIFICANCE

This study provides a contribution to an understanding of the relational and interactional dynamics between support workers and people with learning disabilities in care homes, pertinent in the current political and policy-driven climate on increasing right, choice, inclusion and independence. Furthermore, this study appears to be one of the only qualitative research pieces which explore the support workers experience from the perspective of emotionality, motivation and fulfilment.

Clinical implications

After the recent Panorama expose (Kenyon & Chapman, 2011) of brutal and violent practice in a private hospital for people with learning disabilities, many commentators have focused on two issues: person-centred planning and closure of all institutions in favour of single-person community services (Claes et al., 2010). However, many authors have questioned the effectiveness of person-centred planning (Claes et al., 2010) and have further suggested that institutional closure does not itself prevent abuse (Trent, 1994). Thomson (1998) argued that such administrative reorganisation is not at the essence of the difficulty, but the organisational factors appear to be the primary problem for staff. I contend that another element that requires attention, irrespective of the care home size, is the emotional and psychological experience of the support worker. Specifically, what motivates and drives the individual to work in this field, their experience and challenges of working with people with learning disabilities (unwanted parts and 'lack'); and how they may cope (and are supported by others) with such struggles. For instance, it is important that some fundamental premises, namely being unable to fully cure residents or the irreversibility of difficulties, be explored and acknowledged. This will facilitate support workers sense of expectations and thus that hitherto perceived 'small' gains are seen as large.

The results of this research suggest that within the relationship of support workers and their clients it can be difficult for staff (and clients) to be open and honest about their feelings and experiences. For instance, it can be difficult for staff to express feelings of tension between 'ideal' and 'insincere' care (sub-theme 4.2.1.2), feelings of powerless and injustice (sub-theme 4.2.2.1), feelings of being constricted (sub-theme 4.3.1.1) and confusion around blame (sub-theme 4.3.2.2), to name but a few. Staff may feel pressured by social norms and expectations about how they should be feeling, such as the view that carers should be altruistic, unconditionally caring and extensively patient. These pressures may prevent staff from expressing their true feelings to both other staff and clients. Problematically, as staff

are often the only source of interaction (or at least a significantly primary one) that clients have, this may promote a view of the world that people do not experience problems, difficulties or make mistakes. Thus when clients experience difficulties they may feel an inflated sense of inadequacy and pain, as it seems that other people in the world do not have problems.

One clinical implication of this research would be to emphasise to staff teams the value of facilitating more congruent and honest relationships with clients, wherein difficulties, responsibility for actions and making mistakes are openly discussed and explored. This seems in line with what one might experience in a family system, which is consistent with how such small home care services may be run and understand themselves. This transparent exploration of ideas of blame and responsibility would marry well with encouraging staff positions of caring and nurturing, perhaps preventing staff from needing to pursue 'ideal' and idealised caring positions, which as discussed may have a detrimental impact on the clients. For instance, open discussions of struggles, responsibility and challenges may release staff feelings of blame and impotence to fully help clients, thus perhaps decreasing the need to be the 'ideal' carer.

Thus, one explicit recommendation that I would make is for staff teams to develop policies, care plans and procedures wherein a reflective space is opened for clients and carers to openly discuss struggles and the value base of caring and protection. This space could be a dedicated time during team meetings, care reviews or CPA reviews. Given that support staff may struggle to express their difficulties to both clients and staff teams, and that this may have an impact on their client and the relationships, it is particularly important that such feelings and dynamics be also expressed in official meetings, such as CPA reviews. It is important that this 'struggle' have a voice at such meetings to promote a more in-tune, honest and accurate picture and understanding of the support worker and client relationship. Given the sensitive and suppressed nature of these 'struggles' it would also be important for support staff to be given time in advance to consider how they may want to express these feelings.

Storey, Collis and Clegg (2011) argue that it would be unwise to try to alter or remove the defence mechanisms that help staff to manage difficult working environments, namely referring to the ambivalence about talking about feelings and emotions. They assert the importance of facilitating staff to understand why such ways of coping are utilised and explore what can be performed to ameliorate these conditions. Consistently, I would argue the importance of staff learning to use their emotional reactions to help deepen their understanding of their own and the residents' inner world. Similarly, an understanding of how the systemic discharge of responsibility onto the organisation, to cope with painful emotions, may actually create a static, castrated and immobile work space. It is important to acknowledge this in the context of very real resource issues, which often do impact of learning disability services. A possible area of further research could be the exploration of blame more systemically within systems, such as examining the experiences and views of

people at different parts in the system, such as managers, organisational leads, social workers, family members etc.

Finally, I would argue that these results have implications for therapists and interventions of people with learning disability, as an understanding of the more implicit and unconscious processes (such as the projection of 'lack' or condemnation) may facilitate a greater understanding of the resident-therapist relationship.

5.8 METHODOLOGICAL CONSIDERATIONS

A particular area of bias that may have emerged was through the recruitment process. Two managers of care homes refused to pass the research information sheet onto their support workers. One might hypothesise the various reasons for this, such as fear at what may be revealed. Thus, it may be that the support workers involved in this research may be biased towards care homes which are currently settled and managers feel confident about what the support workers may reveal. This is further relevant given the sub-theme protection (section 4.3.2.1). This theme may also indicate a particular limitation of this study, namely the problem of obtaining data from participants who work in a field with salient issues of persecution⁹⁷. This is likely to have impacted on how confident participants felt in revealing potentially sensitive and distressing information⁹⁸; perhaps implicitly perceiving me as a threat or potential persecutor. Another important consideration is the context in which languages were acquired. Whilst some participants described their native language as English, others did not, and described growing up in different cultures and having a different native language. Findings, therefore, may not only reflect experiences in different languages but also experiences of being brought up in different cultural contexts.

While all participants showed an interest in the study, the degree of willingness to explore their personal experiences varied. On reflection, I wonder if I should have been more explicit about my interest in *their* experiences, and particularly the ideas of emotions, motivations and fulfilment; although this may have discouraged people from participating. It may have been useful to conduct a follow-up interview focused on reflecting on the experience of participating, particularly how they perceived me. Whilst this might have facilitated greater engagement, this would have also required participants to dedicate more of their time to the study.

I feel it is important for me to take some reflexive ownership in this research. In section 4.4 I described my experiences of self-blame and incompetence during the interview process. However, just as the participants may cope with blaming others, might I have coped with these painful experiences by blaming others, namely the participants? May this have

⁹⁷ Namely the Panorama (2011) expose.

⁹⁸ This is exemplified in Habika's refusal to comment on the organisation she worked in.

impacted on the generation, choice and titling of sub-themes, such as ‘Circulation of blame’ or ‘Constricted and unelaborative’? From the outset, my choice to study this area (section 2.2 – How I came to this study) was influenced by my own empathy towards people who are ‘marginalised’. Thus, given my empathy towards the residents how might this reciprocal role (‘marginalising’ to ‘marginalised’) have played out with the participants? With some concern and unease I wonder if I may have reacted negatively to my perception of them as ‘marginalising’; perhaps reciprocally, using this research as a way to ‘marginalise’ or ‘blame’ the participants? However I gain some comfort through processes of member validation, namely that various literatures confirms the created themes, and through verification with my supervisor and IPA groups of the thematic makeup of the analysis.

Participants were offered a financial incentive of £10 to participate which may have biased selection of participants towards financial gain⁹⁹. It is important to consider issues of power involved in research. Support workers are often in a lowly-paid, disempowered position, having had numerous negative experiences of a system that does not understand or appropriately support them. In addition, whereas in many western countries participating in research in varying forms is an everyday occurrence, for example feedback questionnaires or census, this may not be in non-Western countries or cultures (Yu & Liu, 1986). Therefore some of the support workers in this research may not have been used to being asked to give their opinions and this may have made it more difficult for them to give a full account of their views, experiences and feelings.

5.9 A FINAL WORD

This research employed an IPA methodology to explore the emotional and psychological experience of being a support worker in a learning disability. Reflecting on the overall process, I return to my initial explanation of ‘How I came to this study’ (section 2.2), namely an empathic connection and sympathy with the support workers’ challenging role. Noticeably, this empathy and sympathy bears a striking and symbolic resemblance to the participants’ experience of the residents (section 4.3.2) in this research, suggesting the possibility of an isomorphism¹⁰⁰ (Weir, 2009). Furthermore, my poignant reaction to the interviews, that I began to question my own abilities as a researcher and lost confidence,

⁹⁹ However, this is a relatively limited amount and not sufficient to be considered an ‘inducement’ to participate.

¹⁰⁰ Isomorphism, otherwise known as ‘parallel processing’ (Everett & Koerpel, 1986), is the similarity of the processes or structure of one [organisation](#) to those of another, be it the result of [imitation](#) or independent development under similar constraints. Systemically, isomorphism in clinical training and supervision also incorporates the similarity of structure and process at the client/family level, therapist/trainee level, and supervisory level in both directions (Getz & Protinsky, 1994). Deveaux and Lubell (1994, p. 297) define the isomorphic process in supervision with the following: ‘The pattern of the relationship between the family therapist and the family in treatment is often reflected in the pattern of the relationship between the supervisor and family therapist’. This has been extended to include the emergence of patterns of relationship between different systems, for instance from the residents-support worker to the researcher-support worker.

may also bear a symbolism to residents' reactions to the support workers, such as allocating the blame and responsibility as within themselves (the disability) and the concurrent feelings of doubt.

Listening to the accounts of support workers, I now think that their role is about the mutual experience of an unwanted self, handicap or a negated self, with another. What strikes me as the challenge of working in this role, for extended hours and years indeed, is both acknowledging this unwanted self and subsequently attuning to its reverberations. I sincerely believe that attunement to this negated self, and allowing oneself to be open to this experience whilst working with residents will create a space of liberation; for the resident and perhaps even the support worker. Liberation from the pain of marginalisation; liberation from the need to hide, repress and protect oneself of unwanted parts and 'lack'; ultimately, liberation from and the acceptance of 'difference' and deficit.¹⁰¹

My fear is that mis-attunement may lead to people with learning disabilities being forced to manage their own experiences of handicap and disempowerment, as well as the support workers' unmanageable unwanted selves. By hiding away or projecting our unwanted selves into people with learning disabilities, we create an unbalanced world for these individuals in which they do not learn that we all have negated and unwanted aspects of ourselves; we all have our own disabilities or handicaps. Being a support worker is about being open, allowing oneself to be recognised and experienced in all their completeness (all their parts), and simultaneously allowing people with learning disabilities to recognise themselves, in all their fullness.

¹⁰¹ I am not denying the existing of learning disability, but rather am concerned with the way we (as a culture, society and profession) confront it, aggravate it, and through defensive reactions may perpetuate the individual's struggles.

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RESEARCH INFORMATION SHEET

Outline of study:

This study aims to explore the experiences of Support Workers caring for people with Learning Disabilities. The research seeks to find out how Support Workers cope with, understand and make sense of their different experiences and roles, such as working with people with Learning Disabilities and their families, facilitating daily-routines, social interactions, occupational activities, behavioural support plans, working in teams, working with management etc.

What is involved?

This research involves an interview, lasting approximately 1hr 30minutes – 2hrs, in which we will discuss your experiences of being a support worker caring for people with Learning Disabilities. Although there are some standard questions, most importantly we are interested to hear about your thoughts, feelings and experiences of this role.

What will happen after the interview?

The interview recording will be stored on a password protected and encrypted USB drive and backed up on a password protected and secure computer. I will pay a transcription service to transcribe my interviews, which involves typing up the interview verbatim. I will gain a signed non-disclosure / confidentiality agreement from the service prior to giving them my recordings. With this transcription I will look for common themes and ideas within yours and other Support Workers conversations.

This information can be used to: (1) better understand the relationship between Support Workers and service-users, (2) allow a more systemic and holistic understanding of care systems, (3) provide information to guide Support Worker training programs, and (4) lead to the better care of people with Learning Disabilities. This information will be written up as part of a

University Research Thesis with an aim to being published in an academic journal.

Will the interview be confidential?

All information you provide to us will be kept confidential with only members of the research team having access to it, in compliance with the Data Protection Act 1998. Information emanating from the evaluation will only be made public in a completely unattributable format or at the aggregate level in order to ensure that no participant will be identified. The exception to this confidentiality clause is in the event of disclosure of evidence of poor/illegal practice, where there is serious concern of risk to self or others. In these circumstances the relevant line manager, organisation or external body will be contacted in accordance with the British Psychological Society's (BPS) code of conduct.

Contact details of Researchers:

Leon Simpson (Trainee Clinical Psychologist)

Nick Wood (Chartered Clinical Psychologist)

Sandra Fortuna (Chartered Clinical Psychologist)

Address: University of Hertfordshire, DCLINPSY Programme,
College Lane Campus, University of Hertfordshire,
Hatfield, Hertfordshire, AL10, 9AB.

Email: L.Simpson3@herts.ac.uk

Telephone: 07534664082

Ethical approval:

The project has been approved by the Psychology Ethics Committee at the University of Hertfordshire. Registration protocol number:

APPENDIX 2

SCHOOL OF PSYCHOLOGY ETHICS APPLICATION FORM

Status: ~~STAFF~~ ~~PhD~~ DCLin ~~MSc~~ ~~BSc~~ (delete inapplicable categories)

Course code (if student): DCLINPSY

Title of project: **'Where angels fear to tread': the emotional landscape of
working in a learning disability service.**

Name of researcher(s): **Leon Simpson (student number: 09212295)**

Contact Tel. no: **07534664082**

Contact Email: **L.Simpson3@herts.ac.uk**

Name of supervisor **Nick Wood (primary) and Sandra Fortuna (field)**

(for undergraduate and postgraduate research)

Start Date of Study: **26th September 2011**

End Date of Study: **1st September 2012**

Number of participants: **6-8 people**

		YES	NO	N/A
Q1	Will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect?	✓		
Q2	Will you tell participants that their participation is voluntary?	✓		
Q3	Will you obtain written consent for participation?	✓		
Q4	If the research is observational, will you ask participants for their consent to being observed?			✓
Q5	Will you tell participants that they may withdraw from the research at any time and for any reason?	✓		
Q6	Will you tell participants that their data will be treated with full confidentiality and that, if published it will not be identifiable as theirs?	✓		
Q7	Will you debrief participants at the end of their participation (i.e., give them a brief explanation of the study)?	✓		

IMPORTANT NOTE: If you have indicated **NO** to any question from **1-7 above**, but do not think this raises ethical concerns (i.e., you have **ticked box A** on page 3), please give a full explanation in **Q19** on page 2.

YES	NO	N/A

Q8	Will your project involve deliberately misleading participants in any way?		✓	
Q9	Will your project involve invasive procedures (e.g. blood sample, by mouth, catheter, injection)?		✓	
Q10	Will the study involve the administration of any substance(s)?		✓	
Q11	Will the study involve the administration of a mood questionnaire (e.g. BDI) containing a question(s) about suicide or significant mental health problems? (If yes, please refer to Psychology Ethics Guidelines for a standard protocol)		✓	
Q12	Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort?		✓	

Q1 3	Does your project involve work with animals?			✓	
Q1 4	Do participants fall into any of the following special groups? If they do, please refer to BPS guidelines.	Schoolchildren (under 18 years of age)		✓	
	Note that you may also need to obtain satisfactory CRB clearance (or equivalent for overseas students)	People with learning or communication difficulties		✓	
		Patients		✓	
		People in custody		✓	
		People engaged in illegal activities (e.g. drug-taking)		✓	

IMPORTANT NOTE: If you have indicated **YES** to any question from **8 - 14** above, you should normally **tick Box B** below. If you ticked **YES** but think that your study does not raise ethical concerns, please, provide a full explanation in **Q19** in the section below.

There is an obligation on the lead researcher to bring to the attention of the Psychology Ethics Committee any issues with ethical implications not clearly covered by the above checklist

Please answer **Q15-19** below. Provide appropriate information with sufficient detail. This will enable the reviewers to assess the ethical soundness of the study without asking you additional questions and will speed up the review process (**PLEASE, PROVIDE AT THE END OF THIS FORM AN EXAMPLE OF THE INFORMATION AND CONSENT FORMS, QUESTIONNAIRE(S), IF USING, AND ANY OTHER RELEVANT FORMS, E.G., DEBRIEF SHEET, ETC.**)

Q15	<p>Purpose of project and its academic rationale (preferably between 100 - 500 words):</p> <p>Despite an abundance of quantitative research into the role of being a support worker (SW) for people with Learning Disabilities (LD) there remains a dearth of qualitative literature into this role. This study aims to explore the emotional and psychological world of SWs caring for people with LD. The principal research objectives are how SWs cope with, understand and make sense of the range of emotions that they experience, such as happiness, sadness, hopelessness, elation, anxiety, depression, joy, anger, envy and stress.</p> <p>Such information can be used to: (1) better understand the relationship between SWs and service-users, (2) allow a more systemic and holistic understanding of care systems, (3) provide information to guide SW training programs, and (4) lead to the better care of people with LD.</p>
Q16	<p>Brief description of methods and measurements:</p> <p>To address the research objectives I will use qualitative methodology, with 6-8 semi-structured interviews to be carried out with SWs who have worked with people with LD for more than 5 years. The rationale for this qualitative approach is that it will allow a greater focus on the sense-making, meaning-making, interpretative and phenomenological processes within the SW's role. The interviews will be transcribed and analysed using Interpretative Phenomenological Analysis (IPA).</p> <p>Research questions / areas to explore:</p> <ul style="list-style-type: none"> ➔ How do SWs make sense of why they came to work in this field? ➔ How do SWs make sense of people with LDs quality of life? ➔ What do support workers see as their main responsibilities? ➔ What emotions and feelings arise for SWs in this role? ➔ What kind of job satisfaction do SWs get? ➔ How do SWs feel about the support systems in place?
Q17	<p>Participants: recruitment methods, study location, age, sex, exclusion/inclusion criteria:</p> <p>Participants: Will be any staff members within the capacity of titles such as support worker, residential worker, nursing assistant, etc. at care homes for people with LD.</p>

	<p>Their roles will involve supportive and caring functions and they will not be formally trained, such as a nurse or occupational therapist. They will have been in full time employment and working at the particular centre for more than 5 years – to ensure that experiences are not due to the stressors of starting a new job and to access long-term coping styles. The staff member will have had no prior contact with any of the researchers and it will be explained that their participation will not affect involvement from any services.</p> <p>Recruitment: This research will be conducted within the area of Hertfordshire. Given that most people with LD live in twenty-four hour care/residential homes that are private or charity organisations, the focus of recruitment will be at these centres. Whilst there are numerous disorders identified as co-morbid, care homes will be selected with a focus on LD, as opposed to homes for people in acute states, with autism spectrum disorders or other specialisations. Care homes will be contacted and explained full details of the current study.</p> <p>Data collection: A semi-structured interview will be completed with all participants lasting approximately 2 hours. The interview schedule will entail a variety of questions allowing a thread to run through the interview but with scope for in-depth exploration of material. Interviews will be held off-site in a private environment (The Orchards, Hemel Hempstead) to limit the impact of other staff members on the participant's responses.</p>
Q18	<p>Consent and participant information arrangements, debriefing:</p> <p>An information sheet about the purpose of the study will be provided to care homes/relevant staff. This will outline the study, whilst also explaining issues of confidentiality and the right to withdraw at any time. Written consent will be taken from all participants prior to the beginning of their interview so they will understand the risks, benefits and burdens of the study following a discussion centred on the information sheet. Participants will be paid £10 for their involvement.</p> <p>To protect participant's confidentiality all identifiable information provided during the interviews will be anonymised, only the researcher will be aware of the participant's real identity (unless there are exceptional circumstances), and names of other identifying information will be kept securely and separately from audio-recordings and the subsequent data analysis. Further, participants will not be identified in any report or</p>

	publication. Any quotes used as part of a write up will be fully anonymised.
Q19	<p>Any other relevant information:</p> <p>Through my past experience in therapeutic roles I have experience of dealing with people who are highly distressed and I will endeavour to conduct the interviews as sensitively as possible. If a participant becomes distressed I will remind participants of their right to decline to answer difficult questions. If need be, I may stop the interview and only continue when the participant feels comfortable. And finally, the interview can be terminated if need be. Following the interviews I will provide participants with time to debrief and provide directions towards useful contacts for the future should they wish to talk about their experiences in more depth.</p> <p>Despite the minimal risk I am optimistic that participants will find it useful to have the opportunity to talk about their experiences which are often unheard. Research has shown that expression of difficult experiences can provide a positive opportunity for personal growth when accompanied by the presence of support and a space for reflection.</p>

PLEASE TICK **EITHER** BOX A **OR** BOX B BELOW AND PROVIDE RELEVANT ADDITIONAL INFORMATION IF YOU TICK **BOX B**. THEN PASS THE FORM TO YOUR SUPERVISOR

Please tick

A. I consider that this project has no significant ethical implications to be brought before the Psychology Ethics Committee.	<input type="checkbox"/>
B. I consider that this project may have ethical implications that should be brought before the Psychology Ethics Committee	<input checked="" type="checkbox"/>
<p>Please provide a clear but concise statement of the ethical considerations raised by the project and how you intend to deal with them.</p>	

It may be that during the interview a participant will disclose evidence of poor/illegal practice by themselves or by the institution within which they work. In such a case of the need to breach confidentiality, the British Psychological Societies (BPS) professional code of conduct will be adhered to, e.g. confidentiality may be breached if concern is raised regarding serious risk to self or others. This confidentiality protocol will be explained in the introduction and is cited on the consent and information form. In this incidence, the relevant line manager, organisation or external body will be contacted.

If a YES answer has been given to any of the questions 8-12 above, please state previous experience of the supervisor, or academic staff applying for a standard protocol, of investigations causing hazards, risks, discomfort or distress. If it is likely that medical or other aftercare may be needed by participants, please, indicate who will provide the aftercare, and whether they have confirmed that the aftercare can be provided free of charge to the participants.

This form (and all attachments) should be submitted (via your Supervisor for MSc/BSc students) to the Psychology Ethics Committee, psyethics@herts.ac.uk where it will be reviewed before it can be approved.

I confirm I am familiar with the BPS Guidelines for ethical practices in psychological research.

[For those using a shared online data collection account such as Survey Monkey]:

I have discussed with my supervisor and am aware of the issues concerning anonymity and confidentiality in using online data collection. I confirm that I will access no survey or data other than my own.

Name ...**Leon Simpson**.....Date.....

(Researcher(s))

Name...**Nick Wood**.....Date.....

(Primary Supervisor)

Name...**Sandra Fortuna**.....Date.....

(Field Supervisor)

CHECKLIST FOR REQUIRED APPENDICES (appended at the end of this form)

Sample forms can be obtained from Psychology Ethics Committee website at:
<http://PsyNeS.herts.ac.uk/ethics/index.html>

1. YOUR CONSENT FORM
2. YOUR INFORMATION SHEET
3. YOUR DEBRIEF SHEET
4. QUESTIONNAIRE(S) IF USED
5. SAMPLE MATERIAL(S) USED (e.g., pictures, stories, etc)
6. A SAMPLE OF ADVERTISING MATERIAL (e.g., email sent to staff and students, or external organisations)
7. LETTERS TO HEADTEACHERS (if the study is conducted in schools)
8. A SAMPLE LETTER TO PARENTS (if the study is conducted in schools)

Student Investigator: Leon Simpson

Title of project: 'Where angels fear to tread': the emotional landscape of working in a learning disability service.

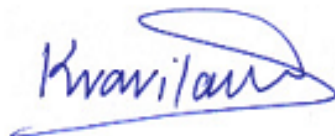
Supervisor: Nick Wood

Registration Protocol Number: PSY/09/11/LS

The approval for the above research project was granted on 15 September 2011 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.

The end date of your study is 1st September 2012.

Signed:



Date: 15 September 2011

Professor Lia Kvavilashvili
Chair
Psychology Ethics Committee

STATEMENT OF THE SUPERVISOR:

From my discussions with the above student, as far as I can ascertain, s/he has followed the ethics protocol approved for this project.

Signed (supervisor):

Date:

APPENDIX 3**RESEARCH CONSENT FORM****Research aims:**

This study aims to explore the experiences of Support Workers caring for people with Learning Disabilities.

Principal researcher:

Leon Simpson (Trainee Clinical Psychologist)

Address: DCLINPSY Programme, College Lane Campus, UH, Hatfield, Herts, AL10 9AB. Email: L.Simpson3@herts.ac.uk. Tel: 07534664082.

Participant consent:

1. I agree to participate in this research.
2. I have had the opportunity to ask any questions about the study.
3. I realise that I may withdraw from the study at any time, without giving a reason.
4. I have been given full information regarding the aims of the research and have been given information with the researcher's names on and a contact number and address if I require further information.
5. All personal information provided by myself will remain confidential and no information that identifies me will be made publicly available. The exception to this confidentiality agreement is in the event of disclosure of poor/illegal practice in which case the British Psychological

Societies (BPS) professional code of conduct will be adhered to.

6. I understand I will receive £10 for partaking in the research.

Print name:

Signed:

Date:

Statement by Investigator

- I have explained this project and the implications of participation in it to this participant without bias and I believe that the consent is informed and that he/she understands the implications of participation.**

Investigator's name:

Investigator's signature:

Date:

APPENDIX 4

**RESEARCH DEBRIEF FORM****Outline of study:**

This study aims to explore the experiences of Support Workers caring for people with Learning Disabilities. The research seeks to find out how Support Workers cope with, understand and make sense of their different experiences and roles, such as working with people with Learning Disabilities and their families, facilitating daily-routines, social interactions, occupational activities, behavioural support plans, working in teams, working with management etc. There is a particular focus on the emotional experience of this role, such as how you make sense of feelings of happiness, sadness, hopelessness, elation, anxiety, depression or stress.

This information can be used to: (1) better understand the relationship between Support Workers and service-users, (2) allow a more systemic and holistic understanding of care systems, (3) provide information to guide Support Worker training programs, and (4) lead to the better care of people with Learning Disabilities. Further, this information can be used to better understand the emotional and psychological experiences of caring for people with learning disabilities, and how people cope with the range of emotions that arise.

Further contacts for support:

If you would like some further support or wish to speak to someone regarding your experiences then please see below for the contact details of various charity organisations.

Watford Mencap – 01923 713620, development@watfordmencap.org.uk

BILD – 01562 723 010, enquiries@bild.org.uk.

Do you have any further questions?

Do you wish to be informed of the outcome of the study?

THANK YOU FOR PARTICIPATING IN THIS STUDY

If there is anything you would like further information on in the future you may contact us at:

Leon Simpson L.Simpson3@herts.ac.uk
07534664082
(Trainee Clinical Psychologist)

Nick Wood N.1.Wood@herts.ac.uk
(Chartered Clinical Psychologist)

APPENDIX 5

INTERVIEW SCHEDULE

The research seeks to find out how Support Workers **cope with, understand and make sense** of their different experiences, such as working with people with LD and their families, facilitating daily-routines, social interactions, occupational activities, behavioural support plans, working in teams, working with management etc. There is a particular focus on the emotional experience of this role, such as how you make sense of feelings of happiness, sadness, hopelessness, elation, anxiety, depression or stress.

(1) *INTRODUCTION*

(2) *UNDERSTANDING INITIAL ROLE ATTRACTION*

1. How did you come to work as a support worker for people with learning disabilities?
2. What appealed to you about this role?
3. Have your ideas about what appeals to you in this role changed since then?
4. Do you feel that other staff members came into the field for similar reasons to you?

(3) *EXPERIENCE OF THE ROLE*

5. What you do on a day-to-day basis?
6. What do you feel is the most important part of your role?
7. What are the parts of your role that you most like?
8. What are the parts of your role that you least like?
9. What emotions/feelings arise for you during these times?

Fused within sections (3) (4) and (5) are questions such as:

- How do you cope when feeling ...?
- How do manage when feeling ...?
- Who do you tell when feeling...?
- What keeps you going despite feeling...?
- Do other people know about those feelings?
- Are the clients aware of how you

(4) *EXPERIENCE OF FAMILIES*

10. What are your experiences of working with families of people with LD?
11. What kinds of feelings are raised in your work with families?
12. How do family members receive your way of working?
13. How do family member's feelings towards you impact on your work?

(5) *EXPERIENCE OF ORGANISATIONS OR STAFF STRUCTURE*

14. How have you found working in this team?
15. How do you feel management perceive you and your work?
16. What are your experiences of communicating the feelings/emotions you have discussed today in teams?
17. Do you feel understood by your colleagues/team?
18. How are difficult emotions of staff managed/supported within the team?

(6) *CONCLUSION*

19. Has anything stood out for you about the interview today?

(7) *DEBRIEF*

PARTICIPANT 7 TRANSCRIPT WITH EXPLORATORY COMMENTS AND EMERGENT THEMES

Original transcript	Exploratory comments	Emergent themes
<p>Int: Can you just to, begin with, say a bit about how you came to work as a support worker for people with learning disabilities?</p> <p>P7: [Umm] basically, I think the first thing that made me to want to be a support worker because I used to do I used to work for the elderly, in a care home for the elderly. It was just, it was just less work because I, I just realised that when you're looking after the elderly it's more of person, personal care but with people who have learning disability or mental health issues it's more of adding value to their lives, it's more involving in their day-to-day routine than trying to make [umm] trying to make them more, how can I put it? More... giving them a more fulfilled life in the community [pause]. So and for me I found out because I compare to things I used to do I found out that the work here with the elderly was, was good, rewarding but tiring in the sense that it was heavier to do really really heavier.</p> <p>Int: The elderly work was heavier?</p> <p>P7: Yes exactly it was heavier because it was more personal care, you know personal care, washing, feeding you know, toileting? You know and sometimes they care for them and they don't go out for like six or seven months but with people who have learning disabilities it's more it's more enabling and it gives you that excitement, that joy, that fulfilment, that satisfaction that you can actually add value to someone's life so that's the reason why.</p>	<p>Elderly care was 'less work', 'more personal care' but 'tiring in the sense that it was heavier'. → What does 'heavier' mean? 'Heavier' as in more physical type work, or 'heavier' emotionally, working more closely with death/decline possibly.</p> <p>Prefers work that is 'adding value' to people's lives, 'giving them a more fulfilled life' and is 'more involving in their day-to-day routine'. → Why does she prefer this type of work? How does she make sense of 'adding value'?</p> <p>'Heavier' is more personal care in the role Conflict/dislike/pain in seeing people not get out into the community</p> <p>Experiences 'excitement', 'joy', 'fulfilment' and 'satisfaction' in the role, namely from her position of 'adding value to someone's life'. She describes 'enabling' - is she adopting the role of the 'enabler'?</p>	<p>Fulfilment through 'adding value'</p> <p>Pain at seeing people not get out.</p> <p>Excitement, joy and satisfaction</p>

<p>Int: And what made you kind of get into kind of I guess, caring? You said you worked in elderly before, what made you kind of go into that in the first place?</p> <p>P7: Honestly it's it's more easier to to get a job doing care because they're short of staff and again it's more flexible. So those were the two main reasons.</p> <p>Int: And now that you're in it have those kind of ideas changed at all? I don't know how long you've worked in?</p> <p>P7: Eighteen months and [sighs] yeah they have. They've changed in the sense that I love what I do and, and I think I want to do that for a long time but not at the level at which I am at the moment you know. I, I don't see myself being a carer or a support worker for the next two years of my life you know, I want to get more skills and and take it up to another level.</p> <p>Int: What more skills and kind of what is the next level?</p> <p>P7: I'm just waiting, I've applied to do a Masters in Social Work, so I'm just waiting just waiting fingers crossed, waiting.</p> <p>Int: And what's made you want to do that?</p> <p>P7: Because I, I know I've got the potentials, I've got the ability and and why should I limit myself to what I'm doing now you know if, if I've gone to school and I've got a First Degree, why don't I you know take it to the next level and you know take it from there and see how it looks. You-you-you can't just limit yourself to just one point I started as a carer for the elderly, I've</p>	<p>Initial reasons for working in caring: 1) easier to get a job in this, 2) flexible hours</p> <p>'Love what I do' and 'Want to do it for a long time' suggests lots of pleasure and fulfilment in the role</p> <p>'not at the level at which I am at the moment' = How does she perceive her role? Does she see herself as above this role? Sense of aspiring to be better, wanting to develop professionally ('take it up to another level')</p> <p>'Know I've got the potentials' – confidence in self and ability. 'limit myself to what I am doing' – does she conceptualise the SW role as 'limiting' and 'restraining'? Sense of her feeling she is above/better than the role.</p> <p>'Can't limit yourself to just one point' – sense of wanting to progress, not be bound by limitations... always moving forward.</p>	<p>Pleasure and love of role</p> <p>Aspiring to develop professionally</p> <p>Perceives role as limiting</p>
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<p>moved to a support worker and I just have to see how I could take it forward.</p> <p>Int: Is there anything particular about kind of adults with learning disabilities that you enjoy or was it more just this particular role?</p> <p>P7: That's why I said, I, I do enjoy because it's just that aspect of, of adding value to someone's life that, that gives you that, how can I explain it? That fulfilment, that joy that makes you sometimes you're home, you're just thinking, oh I'm happy to go to work the next day or I've taken two days off and I just want to or just maybe call and ask how everyone is doing or I'm just passing around [town name], I could just nip in to ask, are you guys alright there? That's just how it is and I could could honestly say [care home name] where we are, we really really work as a team so so it is amazing, we do support them with loads of commitment. Commitment like [staff name], she's been here for like ten odd years. [staff name] fifteen years, even some of the casuals they've been here for like seven or eight years, so when, when you come you do support the residents, we, we are like a family, a family.</p> <p>Int: Can you say a bit more about that idea of a family when you say, that you kind of work together as a team?</p> <p>P7: Umm the first aspect that I've realise coz I've been working here for like eighteen months or so is the aspect of communication, we don't do any gossiping around here. Everyone is very very [emphasis] professional and we do we do communicate you know and it's like the communication book, we read it all the time and the</p>	<p>'Enjoy', 'adding value to someone's life', 'fulfilment', 'Happy to go to work the next day' → Describes lots of pleasure, reward, fulfilment and joy in the role. Repeated phrase ('adding value') emphasises where she gains a lot of her reward/motivation from.</p> <p>'Call and ask how everyone is doing' + 'Are you guys alright?' → Sense of adopting this caring role both at work (professional identity) but also out of work (personal identity). Linking/enmeshment of professional and personal life... boundaries? → Perhaps sense of desire (or need) to make sure residents are okay, where does this come from? What role is she maintaining? What happens if she didn't call in or nip in?</p> <p>Experiences team as supportive, amazing and 'committed'.</p> <p>Metaphor of a family – which parts are the family? Does this include the residents?</p> <p><i>Reflection during interview – I sensed that she reacted somewhat to my repetition of the word 'family'. I wondered why? May she have felt this was too informal a word to use? What did she think of why I used it? Was she fearful that I might perceive her as too informal/not professional?</i></p> <p>'Don't gossip', 'very professional', 'good communication', 'know what is happening' → Is this a reaction to above? Describing very professional qualities of the team... (Possible sense of protecting herself?) → How does she perceive me the researcher?</p>	<p>Role as fulfilling, pleasurable and rewarding.</p> <p>Desire to know residents are okay beyond working hours.</p> <p>Importance of being professional</p>
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<p>staff's verbal communication and there is you know, phone calls so you, you know what is happening you know because one thing I've realised about, about adults who have got learning disability. Something could happen and immediately you just walk in and just because they know you're not in, they know very well, all of them are very I could say, it's just maybe little things we need to support them with but they know our names. They know when you're on holidays, they know when you're not well, you know, they are quite with it in so many aspects, you know? And the support we give them it depends, it really depends on the individual but it's, it's [erm] more of you know maybe managing their money for them. You know maybe we read their letters for them, we don't normally open the letters, they open it and bring it to us because they are quite you know we give them that respect, a lot of respect and choice and stuff like that so it's more of maybe taking them out maybe explaining stuff to them but you know like. They're quite, they're quite, very very, very very intelligent, really really intelligent. What was I saying I forgot?! What was I saying before I got to there? So [uhm] so like when they see you yeah, that's what I was saying, when they see you coming in if something has happened and it's just like... for example one of the ladies we-we-we support her. Manage her money because I've gone into where, where she earns from her pension her learning disability allowances, and she hasn't got any inheritance because she hasn't got any family because it's so it's really really small, and normally they do pay their rents from what they earn from the government so each month we set a standing order for how much they have to pay every week so for their rent. And every week because she likes, she's very generous very kind she like spending, it's really difficult for her to understand that if you go out</p>	<p>Sense of residents knowing a lot about you, 'they know when you're on holidays', 'when you're not well' → what is this like for her? Sense of surprise that they are 'quite with it'</p> <p>Role entails 'managing their money for them', 'we read their letter for them' → Repetition of word 'for them', what role is this? → Interesting how immediately after saying she 'read their letter' she quickly follows with 'we don't normally open the letters', then describes importance of choice & respect. Why? Protecting herself? Aware of confidentiality in the context of vulnerable adults? Contradiction – 'quite' to 'very intelligent... Why?</p> <p>I recall her being slightly flustered here... why? Was she anxious? Is this further evidence of her anxiety around protecting herself?</p> <p>Contradiction → She describes the importance of 'respect' and 'choice', yet uses somewhat controlling terms... 'manage their money for them' (repeated) & 'read their letters for them',</p>	<p>Need to be cautious and protecting the self</p> <p>Advocating for respect and choice</p> <p>Contradiction of advocating for respect/choice but describing 'doing for them.'</p>
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you buy sweets and stuff for everyone you won't be able to pay your rent [*Int: 'yeah yeah'*] so and you-you could explain that to her about ten times in a day when she's going out and she's like, yeah yeah yeah I understand what you say. She says the next staff coming in, she'll go, could I withdraw £60 and she does every week, every single week all the time, because of the money that comes in and what she has to do with it, we we feel for her own best interest she could just have you know, every week £35. If there is something that comes up like she is going for a party or something we could assess how much that would cost and give her additional maybe £10 or £15 so but when she sees someone walking in and she'll just go, is it Okay for me to withdraw £70? [*both laugh*] so that's the aspect of communication, we do communicate a lot so.

Int: So everyone has a consistent approach?

P7: Mmm so it's like in the message book we know Wednesday she's going out, this Wednesday she's going out and needs to contribute a little bit for petrol, she has to pick up her coat from the dry cleaners so all that would cost about £9 something so giving her extra £10 today so that's already in the communication book so once I come in that's already in there, and they're like, oh right I'll speak to you know who's in charge and you know, if they've been on a shift and I haven't actually had time to talk to her. It's in the communication book so and she's been telling me, oh I'm going to withdraw £60 today and I say, no you know, it's not that you can't you're trying to save, if you do this, if you do that and she start walking and she knows you now because she has to get her coat and these it's just an extra £10 today and she see [*manager*] walk in and she just went to her,

Sense of having to say/repeat things over and over. May this become tiring? How does she cope with this? How does it make her feel towards the residents?

Importance of communication.

Need to repeat yourself over and over

Importance of communication

<p>[manager] I'm going to withdraw £60 today [both laugh]. So so that's the aspect of communication how we do it, we really do try our best and I know it's difficult to really communicate to an external one hundred per cent but we really really do.</p> <p>Int: But it's really important to you?</p> <p>P7: Yeah it's really important and and it helps us.</p> <p>Int: You were saying that you like this role or you, you get that real sense of fulfilment in that you're doing something and you're supporting people. Does it feel like other staff kind of work for similar reasons to that?</p> <p>P7: I can't really tell the reasons why [sighs] some people like to do this job, I can't really tell, I can't really tell I don't really know, I, I can't really comment on that but for me, for me that's the reason.</p> <p>Int: I was just wondering if you thought other people were kind of come into this work for similar reasons to you or different?</p> <p>P7: I don't think, maybe in other homes but not in this one because to get the permanent post for [charity name] to be permanent to work for [charity name] it's quite, it's quite difficult. They are umm application and commitment process is quite lengthy and it puts you to a period of testing to an external way when you when you're giving the permanent position they know you're going to stay and they know you want doing the job and you've got the qualities they are looking for and most of all I don't think anyone would really works for [charity name], just is doing it because they live around the corner, I don't think so because to be honest with you their recruitment procedure is tough,</p>	<p><i>Reflection during interview – Seemed as though she was almost pleading and trying to justify that they are doing a good job. Use of word 'external' made me feel like I was almost adjudicating or examining her?</i></p> <p>Why can't she state this? What does she believe will happen if she states a colleagues opinion, or gets it wrong?</p> <p><i>Reflection during interview – I recall feeling that she was quite proud and honoured to work for this charity because of the 'tough' interview process.</i></p>	<p>Caution and protection</p>
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it's tough. It is [emphasis] very tough, it could be a bit easier to come in and be a casual worker before.

Int: Like a bank?

P7: Like a bank staff but before you become permanent it is tough. It is very tough. It is tough, we go through about three process of interviewing the first, the second the third [sounds as though participant bangs whilst saying 'first', 'second' and 'third'] and before you even meet payment and you know you have to work in maybe three or four homes and they ask you which do you want so, so it's not as if you know they are telling you go and walk somewhere, maybe you really wanted a job it's been a long process and so you start working somewhere you didn't actually like and maybe you have to leave the job because you know and it's cost them money and time it's cost you time as well and you don't want to work there anymore so they really

Int: Make sure you wanna work here...

P7: The process they send you out to work in about four homes and you come back to them and say, ok this is where I want to work.

Int: Can you say a bit about what you do on a day-to-day basis?

P7: Okay like in [care home name] like in [care home name] let, let me start from a Monday or doing the week on the Monday because we're made up of eight rooms eight residents and each of them with different needs and abilities but most of them do go to the day centre. Just one of them she doesn't she's, she's gone to the day centre for quite a maybe twenty years

'Tough' interview process – what is she trying to communicate here?
Her ability, toughness, competence or dedication to working here?

Interesting, she interprets this as me asking about the residents' day-to-day routine. Why? Is this symbolic of her frame of mind, 'external' people (professionals/world) are only interested in residents not the support workers. Tentative interpretation - in this sense do they experience themselves as 'below' the residents, least priority?

and she's now fed up and she doesn't enjoy it anymore you know, it doesn't tailor her needs anymore and what she prefers to do at the moment is like shopping, cup of tea and so she won't actually want to go to the day centre, she'll be doing reading.

Int: [interrupts] I guess I was wondering what you [emphasis] do on a day-to-day basis?

P7: OK sorry [laughs] so on a day-to-day like in the morning when we come in?

Int: Yup.

P7: What we do in the morning is **support** those going to the day centre so for persons going to day centre making sure whatever stuff they are supposed to take or-or-or what they're doing, **remind them** for example if on the Monday, one of the ladies she's going to maybe not wear that week and they're doing maybe farming or just whatever you **just need to make sure** that she's got the right attire because she might you know she could really remember she's doing farming today but she hasn't got the right dress or maybe they're going to the gym so that's just what we do in the morning and we've just got one lady, we do **support her with personal care** in the morning and **making a packed lunch for her**. The **rest we just remind them to** and you know, support, not like support them we might remind them make their sandwiches and make sure they've done it, **make sure they do it properly, we don't do it for them**. For example this, one of the ladies she could you know do her sandwich and forget to put anything in and so she would just get like two bread and just [makes one clapping sound-perhaps showing the action of two slices of bread being placed together] she just needs

Describes the aspects of her role as:

'support those'

'remind them'

'you need to make sure'

'support her with personal care'...

→ I wonder what type of role she is describing... facilitating for them, doing for them, or facilitating them to do things themselves?

'Support' versus 'remind them'

Sense of scaffolding (Vygotsky) – filling in the bits that that the residents cannot do.

Importance of
'facilitating' not

to think about maybe put filling in it so it's like, oh, you know we've got you know so many stuff in the fridge, which one do you want to put in and it's just that and again sometimes they don't need to like take in a sandwich, maybe you will need to have a lunch in there and we like give you money.

Int: So you're prompting and making sure?

P7: Yeah making sure they've got the right maybe you need extra money to go somewhere from the day centre so we give you that money and just remind you, or maybe they don't even need to go to the day centre on that day because you've got, maybe they just have appointment or hospital appointment and you know we call the day centre and tell them you know they're not coming in and we taking you there so that's just like what happens in the morning.

Int: And how do you find that, kind of supporting the residents, is that the right word? How do you find supporting the residents to do those things?

P7: I find it, it's alright you know. I find it **involving** and I like being involved, and it gives you that [erm] **I think it makes them happy to see you do things with them like that's how I feel** because if I go upstairs and I tell one of them, you know they've got a rota so they know today I'm doing the bins, I'm doing the toilet, I'm doing this OK I'm going to support you guys you know do the cleaning and I find they are quite happy oh you do the hoovering, oh I'm I'm oh your sink, oh I'll help you because maybe to scrub it a bit I'm scrubbing well you know I'm doing something, they're doing something. That **involvement** I find I quite like it.

Int: What do you think they like about having

Repeated use of the word involving – what does this mean? She likes being busy, she likes being important, likes having a role?

Reflection from interview - I recall being confused during this passage at what she was describing. Is she saying that she enjoys being 'involved' and doing things for the residents or is she saying that the residents like her doing things for them?

Perhaps the residents would prefer it if she did it for them?

'involving' – repeated use of this word... what is she communicating? 'makes them happy to see you do things with them' → Why? Why does she switch from 'I find it involving to 'I think it makes them happy to see you do things with them'

doing for the residents.

Enjoyment in involvement

<p>someone else doing it with them?</p> <p>P7: [pause] I think most of them don't really like doing it. I think they'll be really really happy if they could just sit down and people do things for them so and.</p> <p>Int: It feels like the residents would just be happy if you just did everything for them?</p> <p>P7: Yeah yeah you just you just do everything for them they'll be quite happy but because they know, they have to Hoover your room, you know make sure you do this and sometimes maybe they feel oh because sometimes they do really it could be like, someone says no I did it last week, I did it this week but there's a rota and oh calm down guys, maybe it makes them feel like oh I'm not alone in this, in this thing or that's how I feel and maybe that's how they feel but there are others who go and well she's quite she's quite if she wants to do something she's got that, she's got that pride I think in her like, I can do it I do not want anybody to help me even if she can't do it you know she'll struggle to the end. You know if she's emptying the dishwasher she doesn't want anyone, whereas other people if they is emptying the dishwasher they will be quite happy if you, you're doing the cups, you're doing the plates and we did it together or like you know there's another lady who just you know, she wants to do it on her own, she doesn't want anyone to give her help.</p> <p>Int: I'm just wondering what do you feel is the kind of most important part of what you do?</p> <p>P7: [pause] The most important? What I feel like you know, the lead with [staff name] or you know or just what part I really like?</p>	<p>Role conflict – residents would be happy if the support workers just did things for them. However, she has to advocate for independence and autonomy...</p> <p>Residents would prefer to do less → Conflict between expectations of professionals vs residents' wants.</p> <p>I recall being slightly confused here. What exactly makes them feel 'oh I'm not alone in this'. Is that because she does not want to do the hovering either? Repeated use of this, sense of keeping the residents company, so they are not alone (lonely?)</p> <p><i>Reflection from interview – I remember wondering whether I had phrased my question wrong here? Was the question too vague or didn't actually make sense? Was I not communicating myself well?</i></p>	<p>Residents don't like doing chores</p> <p>Conflict between residents' wants vs professional demands</p> <p>Values doing things together</p>
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<p>Int: Just your [emphasis] role, what do you think is the most important part of what you do?</p> <p>P7: The cooking [laughs]. I like cooking, I think for me that's for me.</p> <p>Int: So you enjoy the cooking?</p> <p>P7: Yeah I like it.</p> <p>Int: But what do you feel is the most important part of your role?</p> <p>P7: As a support worker at [care home name] I think the most important part of my role is that I know that there's somebody somewhere that needs my support to be able to fulfil a daily task and I'm happy to know that somebody needs me to support them achieve something in their lives so that alone gives me that that anxiety or that happiness for me to come to work. Okay for example let me just make this clear like today I'm supporting you know, to be able to go out shopping, to the bank etc it's just an, it's an 11 to 5 shift and she knows for over a week now that I am taking her out, she knows and and for a week now she's been telling everyone because when she goes out with me today and we come back she'll ask me, who's taking me out next week? I will tell her so she knows who is taking her out so for like a week she'll be saying, oh I'm going out with this, I'm going out with [staff name], I'm going out with [staff name], I haven't been out with [staff name] and if I do not come to take her out, I'm going to be letting her down and that really makes me, really unhappy except you know it's due to something beyond and if I can't you know, I'm shocked notice if I phone in this morning and say I</p>	<p>Why does she laugh? Did she interpret 'important' as what do you enjoy? Or is there any underlying reluctance to state what is important in the role? One interpretation is that she is fearful of getting it wrong.</p> <p><i>Reflection from interview – I experienced myself as slightly badgering here, asking the same question three times to get an answer. I recall wondering if I wasn't being a good researcher, should I have gone with her description of the cooking?</i></p> <p>'Somebody somewhere that needs my support' 'needs me to support them achieve something in their lives' → Describing the role/feeling of being 'needed', conceptualises her role as being integral to another. → Needing (resident) vs needed (SW) 'Alone gives me that anxiety or that happiness' → Sense of this role (being needed) either makes her happy or anxious? Why? If she fulfils her role then she is happy, if she is unable to fulfil this carer role how does she experience that?</p> <p>Sense of responsibility in her role, she is very meaningful to the resident's happiness and life.</p> <p>'I'm going to let her down' → Sense of a mistake equating to letting someone down / failure. 'Makes me, really unhappy'</p> <p>Sense of the importance of her role and being there, 'it wouldn't be</p>	<p>Happiness in being needed</p> <p>Mistake as letting down the resident.</p> <p>Being pivotal to the</p>
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couldn't come, she will still go out **but it wouldn't be the same** because you have to take because you have to put her on the floor every morning and I'm just like, just start to take her out it's just like once a week for her so they'll have to take someone from the floor to take her but it's not going to be the same because I am supposed to have like a full five or four hours with her but if they are taking somebody from the floor who finishes at two or three, it will be like one hour and she's rushing you know, we'll just get the money from the bank, we'll get your cigarettes, we'll get a few bits and we'll come back. But when I take her out like how the shift is supposed to go, we could do eye shopping, window shopping, we sit down and eat, relaxing, we feed the birds, we feed the ducks, she tells me whatever and where she wants to feed them so, so and if I do not come and I know just today no-one will be able to do what I you know, have been put down to do and you know she'll, **she'll come back home feeling really sad and I could not really help her [sighs]. I, I really feel sad myself.**

Int: If you weren't able to kind of be there for support?

P7: Hm-hmm. I will really feel sad, I can remember one day I forgot I was on the rota to do it I totally forgot. I totally forgot, I'd taken the shift and forgot to put it down and everyone was waiting for me and everyone was waiting for me, it was like, [laughs] I had to come all the way from London and I'm like, **oh honestly it's haunted me all this time** [both laugh]. I'm like, oh should I turn up? And they were like, no one of us, don't worry really. Oh my **my I can't forget that day I just can't and-and it's like.**

Int: What is it you can't forget?

the same' without me... implicit understanding that she is pivotal and important to the residents' life and happiness. Is this an embellishment at all? Is she over-emphasising the importance of her position? What would be the consequence for her if she was away and someone else filled in without any problem? Is there an implicit suggestion – they can't lives without me?

If make a mistake equates to 'failing' 'upsetting' the resident → resident will feel sad, I will feel sad. Sense of experiencing what the resident is feeling. Vicarious experience of pain/conflict/feeling = sadness. Strong sense of blaming dynamic, 'Blaming' → 'Blamed', Why does this emerge?

'It's haunted me all this time' = Lasting impact of a single mistake ('I can remember one day') – seems to have significantly effected her. 'I can't forget that day'... why? Why does it stay with her for so long?

Sense of blaming herself.

residents' lives

Experience of sadness if she is unable to fulfil her care/supporting role.

Experiences her mistakes as very painful and lasting.

<p>P7: Because I was like, well why didn't I put it on my rota, ooh I've let I've let [resident name] down I've really let her down I have, oh and it's not like just letting her down, it's let everybody down, it's it's if I'm not well it's different it's really different not that I forgot to put it down and and I didn't have anything to do I just felt let me visit family in London and I'm going and she is there waiting for me all day.</p> <p>Int: And you were saying something that you enjoy in the role is the cooking.</p> <p>P7: Yeah I love cooking.</p> <p>Int: I'm wondering what part of the role you kind of least enjoy, least like?</p> <p>P7: [short pause] I can't really complain at the moment I can't I can't per say, the reason why I can't complain because where we are we've got really really I think the residents are quite very very friendly and we haven't actually got any resident I could really say have got challenging behaviour. Nope none. I've worked in maybe few shifts in other homes where they've got really really serious challenging behaviour but here I can really really say we've got anyone who's got so it's quite</p> <p>Int: How does that change things do you think?</p> <p>P7: Yeah it does, it does, it does.</p> <p>Int: How does it impact kind of having challenging behaviours or not?</p> <p>P7: Because like some of the areas are for just like for maybe with the agency, you've come to work a day</p>	<p>Expands from letting one resident down to letting 'everyone' down → Sense of one mistake being cataclysmic to her sense of identity (personal + professional). Why? Sense of if not able to be the 'ideal' carer/caring' then she has 'let everyone down' + is to blame. One hypothesis is that she has a rigid or rght construct system... which when one construct is knocked, it triggers others.</p> <p>Unwilling to state any negative aspects of the role... why? Hypothesis:</p> <ul style="list-style-type: none"> • Sense of appreciation for the friendly residents – particularly in comparison to other care homes with 'challenging behaviour'. • Protection – unwilling to say anything bad for fear of persecution or it getting back to the organisations? • May this hesitancy also be internalised / symbolic of the resident's feelings? Residents feel grateful towards staff so are reluctant to express any negativity. Staff are grateful towards residents for being 'friendly' so do not want to 'complain'? How might this impact on the service and workplace? 	<p>Cataclysmic mistake, one carer mistake is letting everyone down.</p> <p>Reluctance to state any negativity</p>
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<p>and you don't, I don't think for fact or maybe let me say for example like the elderly, we've got well elderly and we've got challenging behaviour in looking after them in the care home and it's really quite difficult administering personal care to them because they're really really violent and you're trying to use the best possible means to administer that and they're not cooperating and you're trying to talk to them and they're not saying you know they're not saying towards and you're seen and and sometimes they get really really violent, spit on you, punch you, kick you and there's just nothing you can really do about that, the only thing you can do is to fill in an incident form and that's it. That's it and sometimes you come to work and they're telling you, oh you walk in and you're like just thinking, how is so and so today? Has he been alright? Or has she been alright? Oh right she's been very very unsettled, opening doors going out, pushing chairs, punching other residents and and so and so is one three to one today, and you come back home feeling really tired and stressed. Really stressed. It all, uhm, builds up continuously. It's really tiring.</p> <p>Int: What are the kind of like, I don't know, feelings and emotions that arise for you working here?</p> <p>P7: Working here? [arhh] It's just like when you think that you might have to leave and work somewhere else and you just ask yourself, will I be able to find such lovely residents, such lovely staff somewhere else and it just gives you that fright [Int. laughs] yeah. Or when you think of you know one of them are leaving, someone is maybe like just think, ohh I'm going to miss so and so person and...</p> <p>Int: What's that like for you when you know someone</p>	<p>Contradiction – she just stated that there wasn't anybody with 'challenging behaviour', now describes this and 'violence'. Does this suggest a reluctance to describe negative aspects... of the residents, staff team or organisation?</p> <p>'administering personal care to them' → Sense of quite a controlling / directive role. Is this the response/defence to conflict /challenge?</p> <p>'there's nothing you can really do about that' → Sense of feeling powerless / hopeless to manage/cope with the resident's behaviours.</p> <p>Sense of stress/struggle in the workplace</p> <p>Impact of work / 'challenging behaviour' = can be really tired + stressed. How does this fit with her fulfilment and enjoyment in the role? How does she integrate the two factors?</p> <p>Very quick transition from 'pushing chairs', 'punching', 'violence' to describing 'to find such lovely residents'? Why? Does this suggest a very polarised perspective on the residents? Or how does she understand the 'challenging behaviours'? Sense of residents either being idealised (lovely residents) or 'challenging' → Is there a middle ground?</p> <p>Leaving = 'fright', sense of fearful and unsafe, care home = protective?</p> <p>Sense of being attached to the residents, 'ohh i'm going to miss' if they leave.</p> <p>'quite sad and emotional' + become attached to the person.</p>	<p>Conflict of – sense of administering vs facilitating personal care.</p> <p>Powerlessness and helplessness</p> <p>Struggling, tiring and stressful</p>
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<p>might be leaving?</p> <p>P7: It's it's quite it's quite sad and emotional because you get to know someone, you get to be you know involved with someone's daily activities and if the person has to go somewhere else and sometimes you think, will they be able to understand this person the way we have done and the way you know, what we've seen and what we've gone through and will they be able to give this person that care, that support and it's a bit sad.</p> <p>Int: So it feels kind of sad to know that they're moving on and will the next place be able to kind of provide for them the way we provide? [P7 agrees throughout this statement 'hmm']. What's it like for you kind of building up a relationship or rapports kind of with the client, with the residents here?</p> <p>P7: [Uhm] we we try we try and what we try to do is to be very professional with them, not to treat them as kids but to treat them as adults and and you know there's that boundary to, to that kind of relationship or to that kind of friendliness, friendliness way where there isn't any demarcation of you know, respect, respect. We try as much as possible to be to be very professional with them, very very professional with them. We don't do hugs and kisses here, we don't we always every day we tell them we don't do hugs and kisses.</p> <p>Int: What's that like for you?</p> <p>P7: Sometimes sometimes I do I do think that there is need for just an emotional but it's just that the policies and procedures and so we don't just we don't do it and sometimes somebody has a really big cry and</p>	<p>Sense of fear that the other care home will not be able to provide such a degree of support / care that they can. Thus, does she views themselves as the 'idealised carer' + no-one can support/care for them as well as they do?</p> <p>Repeated statement - finds residents leaving sad.</p> <p>Advocates for treating residents as 'adults' (consistent with Valuing Now). Intention/goal = 'be very professional with them', 'treat them as adults'</p> <p>Sense of needing a boundary against over friendliness which impedes on respect/professionalism.</p> <p>Conflict of managing difference perspective or demands: Policies/procedures (organisational/political), emotional needs of residents, reality of situation + her own beliefs ('sometimes I do think there is need for just an emotional'.</p>	<p>Belief in their home as providing the ideal care, fearful others cannot provide this.</p> <p>Needing to be boundaried</p> <p>Need to be emotional sometimes</p>
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<p>that person just might need just that hug [<i>Int: 'yeah'</i>] to just comfort the person but again we try as much as possible to treat them like adults and as an adult I don't think you-you-you want hugs every five minutes or or every day you come from the day centre you want hugs and kisses. It is difficult though.</p> <p>Int: How do you manage that when you have like a kind of policy and something saying kind of, no hugging but you feel to you that actually this person just needs a bit of emotional support? How do you kind of manage that?</p> <p>P7: I do I do believe [uhm] that with NICE practices an old an old an old [uhm] a bad practise and there should be a time where you could actually step out of the line and just do something which is right and justify what you've done and talking about [uhm] hugs and this... shake hands. You know at times they really come and they say, oh no no no we could shake hands I know you know but shake hands, at least that gives them [<i>Int.: 'something'?</i>] uh-hmm.</p> <p>Int: And you said that you, you do or you don't think routine is best practices? How do you feel towards that?</p> <p>P7: I feel you know for example, I feel we-we there is something people always see and there's something we try not to do here and we naturally do is oh we-we have to work, no we have to work together that's fine, we have to work as a team that's OK [uhm] we we have to work in the same way, we don't do that here also staff we don't have to work in the same way because people are different.</p> <p>Int: So everyone has a different kind of style?</p>	<p>Conflict of being 'overly emotional' (residents want hugs)' Vs treating them like adults (policies and procedures).</p> <p>Should be scope with work to 'actually step out of NICE practices (policies / political guidelines) and do what is intuitively right and justify what you've done and talking about hugs and this.</p> <p>Conflict of balancing NICE policies on boundaries/being respectful to their adulthood vs emotional needs of residents in the moment.</p> <p>Reflection from the interview – I recall feeling quite confused here, what was she trying to say or communicate to me?</p> <p>Conflict / contradiction - Procedures/policies do not take into</p>	<p>Difficulty</p> <p>Belief in going beyond procedures sometimes</p>
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<p>P7: Yeah but we work towards the same goal so that's what we try to do here, we don't work in the same way but work towards the same goal because they tend to relate to us differently, they tend to relate just differently and it just can't be the same. I am more of my own way and other staffs are more of their own way.</p> <p>Int: What do you feel, sorry to interrupt.</p> <p>P7: No it's OK.</p> <p>Int: What do you feel is kind of your way, how would you kind of describe that?</p> <p>P7: Would I say my own personality is?</p> <p>Int: Yeah.</p> <p>P7: It's just I'm more bubbly I could say I'm more, probably I'm more easy going I'm more and you know other people could be maybe more stricter or firmer and that's how they are but the truth is we all work towards the same goal, the same goal. Whereas we could come across differently so.</p> <p>Int: Umm, can you say about what your experiences are of working with the families of the residents here?</p> <p>P7: [Hmm] I think with families you have to be to be, how could I say it? The families over here they are quite, they need a lot of communication and a lot of answers and they have a lot of questions and sometimes they feel we could actually you know, do something like you know, like perform magic on something you, and-and-and I think it's it's really sad</p>	<p>consideration staff's individual differences and that residents 'relate' to the staff in different ways.</p> <p>Repeated use of term 'they' throughout the interview to describe the residents – is she grouping them all together, does she group all people with learning disabilities together? Or semantically, is this just how she refers to the residents?</p> <p>'I'm more bubbly' + 'more easy going' → I wonder if there is a subtle undertone of her looking negatively on people who are 'stricter' or 'firmer'.</p> <p>This is re-iterated throughout her extract... always returns to this. Is this illustrative of her belief in unity and togetherness or fear that others may hear of the comments she has made (such as 'stricter' and 'firmer'?)</p> <p>Sense of families having a lot of demands, questions, needs, answers. From 'quite' to 'need a lot of communication' – sense of her minimising, always be reluctant to state negative aspects.</p> <p>'perform magic on something'. Sense of unmanageable/un-resolvable pressure on SW's, impossible expectations. 'really sad' = feel that we are doing our best.</p>	<p>Residents relate to us in different ways</p> <p>Conflict of national policies vs realities that staff and individuals are different</p> <p>Reluctance to state negativity</p> <p>Impossible to meet the families expectations.</p> <p>Working really hard</p>
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<p>it's really really sad when you find we're doing our best we're working really hard and you could find the family's come in and they're just trying to look for little little things to and they do not understand that they way because because I think they expect us to to be like Mothers or parents to the service users whereas</p> <p>Int: They expect you to be like Mothers or parents?</p> <p>P7: Parents like you know, like they are kids, we need to babysit them whereas it's difficult for them to understand that they've got what we call choice and rights and you know, we could just prompt and say things but if they say, I'm not doing it I'm not doing it and there's just nothing we can do, absolutely nothing, for example they've got their rooms, most of them have to go over their rooms and make their beds or and we could just tell you, don't forget you need to go over your room once in a week and if he says or she says, I'm not doing it, they are not doing it and if their sisters or their Mother comes in and it's not tidy, so they think it's our fault but you know we've got the books to show them, we have said this and we have reminded and it's up to them if they want to do it or they don't want to do it so they fail to understand that it's just a extra tuition we could actually we could we could actually help, we don't impose we don't so actually and sometimes they feel we don't care enough.</p> <p>Int: What's that like for you?</p> <p>P7: It's-it's it is sad it's really sad because because everyone we try to explain to them that it-it you know I could go to prison for forcing someone, they don't understand, They don't understand that you know doing the shop you just have to be careful what you</p>	<p>Sense of families nitpicking for little / idiosyncratic things – families do not understand/appreciate us and our role. Sense of being forced by families to adopt mother/parental type roles? Why? Is this projection? Is this indicative of how she positions herself to the residents, namely as their mother or parents? Or why does she think the parents want them to be parental figures?</p> <p>Conflict between families understanding/desires of role (parent / mother) and policy demands of choice/rights.</p> <p>Feeling powerless</p> <p>Families blame staff for rooms being untidy → Why? Hypotheses:</p> <ul style="list-style-type: none"> Families see the responsibility as in the staff, not the residents. May this facilitate a culture of residents having no control, power, responsibility? Blame circumnavigates the residents. Why? <p>Use books/procedures/documentation to back up (protect) themselves from families blame.</p> <p>Construe's families blame as 'feel we don't care enough'. 'Care' and being perceived as 'caring' feels important to her.</p> <p>Repeat of 'they don't understand' – Sense of feeling family members do not understand. Is this symbolic of residents experiences – that staff and other people do not understand the residents experiences? Interpretation - what perpetuates a culture of people feeling 'under-appreciated' and 'misunderstood'?</p>	<p>Expected to be parents</p> <p>Conflict of families demands vs policies on choice.</p> <p>Feeling powerless</p> <p>Families blame staff for residents' difficulties.</p> <p>Documentation protects the staff.</p> <p>Sadness</p>
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<p>say, how you act, your actions and-and-and-and your principles and your values and how you have to perceive other people's principles and values and you just have to try every, every single day that you're doing the right thing.</p> <p>Int: What is it you kind of tell yourself to kind of to cope with those kind of dilemmas?</p> <p>P7: I've only done this job for so many months, it makes you really struggle to tell the family you know? OK for example, [uhm] we've got people who self-medicate and they've got like creams and the only thing you could say is you could, you could prompt, you could only prompt don't forget to use it, don't forget to do that or don't forget and sometimes they'll say, I don't feel like doing it and they will not do it and if maybe it's a rash or something and the family members come in and they see you know it's still there and he or she has not been using it as regular as they should do, it it's really difficult in that situation because you're like you, at the moment I can't do it for her I can't force her to do it and the family but it's oh look at what is happening! The one or whoever has to tolerate it and you're in that position where he or she even if it's me and that's the pressure of oh I feel like I've got my person in your care and you are not able, that's how I feel and you are not able to care for our or as the carers we are there, we are telling you, there's just nothing we could actually do, we can't hold her hands behind and put cream or whatever and you sometimes, they cry and-and-and-and at that moment you could be feeling, oh someone is in my care and I'm not allowed to look after them properly but it shows and there's nothing you can really do at that moment. It's just that if someone says they are not going to take medication you can't force you can't convert the</p>	<p>Sense of a constant struggle – needing to do it 'every, every single day'</p> <p>'Really struggle' – communicating with the family.</p> <p>Sense of helplessness</p> <p>'and you are not able' – experiences pain at others thinking she is not able to care. 'pressure' to be seen by families as 'caring' → I wonder what is at the other pole of caring... Uncaring? Abuser? Rejecting? Incompetent? 'there's just nothing we can actually do' = helplessness.</p> <p>'I'm not allowed to look after them properly' → Pain of being unable to care. 'nothing you can really do at that moment' (repeated) = powerlessness</p>	<p>A constant struggle</p> <p>Helplessness</p> <p>Feelings stuck</p> <p>Families blame us and don't understand</p> <p>Helplessness and powerlessness</p>
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<p>medication and</p> <p>Int: Does it feel like sometimes you're trying to get people to do things that they don't want to do?</p> <p>P7: No. For me I don't feel like that because I'm one of those kind of persons where if I if I say oh you-you here's your tablet and water, no I don't feel like taking it. You know I could go and come back and you know change the person maybe and if you say no, that's fine we just put it in the record.</p> <p>Int: Sounds like you are kind of flexible to try different things?</p> <p>P7: [Hhmm] But we try as much as possible not to-to like be on your case if for example, if I am doing medication and I come and I tell you or ask you do you want to take your medicine and you refuse and I come back after maybe ten minutes and you refuse and the other staff you know say you refuse you know, we stop at that level because that could, lead to other stuff you could be angry if you feel we are forcing you and we try as much as possible not to. Maybe when you calm down the next day when the manager comes in and we tell her, maybe she speaks to you, you know maybe she's just having a bad day and it's dangerous for us to take it if it carries on over and over but that's up to the manager to move the professionals you know to consult and you know what else can be done in that particular case.</p> <p>Int: And what's, just say a bit more you were kind of talking about families and it feels like sometimes the families kind of want you to do more or want you to do specific things and it's kind of really sad.</p>	<p><i>Reflection from interview – it felt like I had unintentionally attacked her with my previous question. I felt like I am made this re-phrase, almost as an attempt to praise and validate her position, to show I wasn't attacking her. Did I fall into the RR of 'attacking' to 'attacked'?</i></p> <p>Interesting switch of tenses to 'you', not using 'them' or 'the residents' (used throughout this paragraph). Why? What is she trying to communicate to me? She may be positioning me as the resident here, or trying to emphasise her point?</p> <p>'what else can be done in that particular case' - powerlessness</p> <p>Repeated use of work 'sad', 'it's really sad, there's just a limit to what we can do' = powerlessness</p>	<p>Powerlessness</p>
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<p>P7: Yeah it's really sad where we know there's just a limit to what we can do. I think before, many years ago you know [laughs] people could really force people to [laughs] take medication [both laugh], I know it's bad practises but and to because most of them over here they are like fifty and above any maybe you know maybe fifty or sixty years ago you know those things people could really force on somebody, you don't choose what you have to wear and maybe that was done in the past and for them to-to feel, now you just can't you know? Everyone's got that right, that choice and-and-and I find it it's nice it's good because that's what I wouldn't want someone to do to me and I don't really expect to do that to somebody and for the family members to, to try and put what used to happen in the past and what is happening now together it's quite a bit, I just feel, I just feel there should be training for family members as well if they could go to some of this refresher courses and I think it would be better for them to understand that you know things have actually changed and I think one, one family member he particularly feels that, that the new care system and the new way you know people do things now is a let-down, and he keeps on saying you know sixty years ago it wasn't like this or sixty years ago it used to be like that or</p> <p>Int: Which is the bit he doesn't like?</p> <p>P7: Oh he just feels [erm], one-he complains and complains and complains about you know staff changing. I think people have become more flexible in doing their job, they do it for three years you have to move and whenever he comes for example he finds new staff, new recruits and it just feels like, [ohh] you know and again the sister she's got you know, her own issues and he relates it to like, oh maybe the</p>	<p>Compared how she treats the residents to how she would want to be treated herself... internal model... how would I want to be treated? Why/impact? Sense of putting herself in the residents' shoes... Interpretation - may this be implicitly also stating how she positions herself? As someone marginalised?</p> <p>Feels that family members require training...? Why? To facilitate their knowledge that things have actually changed... Sense of not being able to explain herself why they do things this way? Positions the responsibility and blame in the family members</p> <p>Family members struggle with the constant change in staff members – they blame this is on the SW's.</p>	<p>Blame towards the family members for not understanding.</p> <p>Families do not understand our struggle</p>
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<p>staffs have changed or maybe the policies have changed and I think in those from what I've heard, they used to have lots of parties and it was actually misusing their funds for those parties so but now you know things have changed, you give an account of everything, you can't just decide on a Friday, oh we're having this every Friday that no no, it would be like [uhm] I think the duty of care wouldn't be there you know because now we have to tell them, oh you save it for holidays, at first I think the company used to pay for their holidays and everything was, so for him to say like, no, you are taking them for holidays, the pay is also to take them for holidays you know, that fund, that money is not there anymore and it just feels like [ohh] before it used to be better, now and he and he blames it on us.</p> <p>Int: Really?</p> <p>P7: You see at-and every time he comes in you're trying to explain to him that this is how it is now, there's no budget for holidays. If we go on holidays with the residents they pay for our holidays so for that reason we can't have parties every Friday and use their monies on parties, inviting everyone and people around, that can't happen anymore so and he doesn't understand, he really doesn't and he should.</p> <p>Int: How do you kind of cope or what do you kind of tell him then?</p> <p>P7: Just what I've told you. You explain to them just like that and they sit back and they don't like it but it's just, it's just nothing you can do, you're just telling them the truth.</p> <p>Int: Does it kind of affect you at all when they say,</p>	<p>New policies mean residents now have to pay for staff as well to go on holiday with them – she feels this is an injustice + family member feels this is wrong... [impact of external world]</p> <p>Experiences family members as not understanding the changes in policies.</p> <p>'he doesn't understand and he should' – blame towards the family members.</p> <p>Sense of powerlessness 'it's just nothing you can do, you're just telling them the truth'</p>	<p>Families blame us</p> <p>Blames family members</p>
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<p>when someone like that may say things?</p> <p>P7: It used to but not anymore. It used to but not anymore. It used to but not anymore. It's just like you know, this is what is happening now [laughs] it's, it's beyond me to-to do anything else or I just can't, this is what this is what it is, the government has done</p> <p>Int: You said that previously it affected you but now not so much. What do you think you've learnt or what's kind of changed?</p> <p>P7: I just think you just need to be tough and just you know explain things to people, not everybody will actually understand or get you but you know some will do, some, some will do some will do.</p> <p>Int: In what way do you kind of be tough?</p> <p>P7: It's just like for example, whenever I meet this particular family member he always goes like, so many years ago it was different, and I'll just let him you know, it's different because policies have changed. You know, the project it can't be the same so we're just trying to work with the limited funds we have and in, in-in-in the most appropriate and humane manner so and he he'll be like, [ohh] I understand I understand but next day he comes in and he'll still you know, worry about it and just keep on telling him. Over and over again.</p> <p>Int: How do you find, how do you find kind of family members receive your kind of style and your way of working?</p> <p>P7: I think some are really really appreciative, some are really really they know what you're doing, the good</p>	<p>Sense of powerlessness / lack of control to change things → Forced acceptance is the only way to go.</p> <p>Blame towards the government. (She goes from describing powerlessness to blaming the government – is this indicative of how she copes with feelings of blame? Blaming others? Why the government?)</p> <p>Coping = 'need to be tough'. Tough emotionally or physically? I wonder what this 'tough' symbolises for internal world?</p> <p>Sense of having to explain over and over again the same things, repeating oneself.</p> <p>Dichotomy – some are really appreciative vs some expect magic.</p>	<p>Blame towards government</p> <p>Having to say things over and over</p>
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<p>job and they really understand whereas some they expect, as I told you the magic and-and it's not possible. It's not possible. It's not possible [pause] and-and-and-and to again on that point I think family members you know, it's it's like me if I've got like my Mum in a home, when they come in they forget you're not looking after one person you're looking after everybody and they are like, oh you know no-one cares it's just this particular person, when is she going up, when is she doing this, when is she doing that? No, you know she has this allocated days or time during the week we've got other people we have to, it's a bit difficult for them to understand that, you know? It's we're working for the benefit of everybody and each of them have got that one-to-one time and we can't give somebody four, four four maybe four times in a week, one-to-one if you've got eight, if you've got one day for your one-to-one that's fine or the other day could be like three-to-one and take three people out, it just can't be you every day and it's difficult for them to understand that it's just hard and especially, OK their ages are like fifty and above and their Mums could be like eighty and above so it's really, it's as if you are dealing with two residents, it really is. It's really hard, you sit them down you explain things to them, you see their family and everyone is just not understand, you go around and it's tiring, it is.</p> <p>Int: I'm just wondering what's it like for you kind of, how have you found working in this particular team? You said before that it feels really</p> <p>P7: It feels really like a family. It feels like a family and I think the other senior staff they're really really supportive. They are really really supportive they are willing to listen, they are willing to-to-to-to show you stuff you know, take you through stuff and it's-it's-it's</p>	<p>Repeat of 'it's not possible' – Emphasising the conflict/constraint/ challenge and pain of her role → The strong sense of helplessness and powerlessness. 'they forget' – blames family</p> <p>Repeated use of the phrase 'care' – experiences families as thinking she does not care. Suggest being viewed as 'caring' is integral to her.</p> <p>Blames family for lack of understanding</p> <p>Challenge/conflict of balancing the families demands with the realities of the current situation.</p> <p>'It's as if you are dealing with two residents' – Experiences the family member as a client/resident too. Is this a somewhat derogatory or attacking phrase? Sense of being surrounded by residents. 'you sit them down' – slightly derogative description of family members as clients, like children.... Placing their role as parental. Tiring → The result of having to explain to family members...</p> <p>Describes the work team as a family... Experiences work team as very supportive, willing to listen, willing to show stuff to you, take you through stuff = 'it's really beautiful, really beautiful' → She quickly goes from describing the struggles of working with family members to 'it's really beautiful', she seems to do this sudden</p>	<p>Conflict of supporting the individual vs everyone</p> <p>Blame towards family members.</p> <p>Care home and staff is beautiful</p>
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<p>really beautiful, really beautiful. Sometimes I think if I have to leave this place will I ever find.</p> <p>Int: If you get a Masters?</p> <p>P7: [Hm-hmm] yeah I really really it's sad because I think you everything you've been working with them for like you know, ten fifteen years and sometimes you're like, oh don't worry you know, this is just calm down and I think the first two years I started working here I think at about four o'clock they come back from the day centre and that's like four people, five and all of them are back and you could be cooking and about five people tuck into you at the same time, please can I finish, and they're just and everyone carrying on because they're been out and they just want to tell you how it was and-and someone can just be angry because somebody's talking to you for more than five minutes, honestly! And it could just lead to a-to a situation especially you could be doing incident form from somebody lashing up and crying, someone breaking something and I think the first time it happened to me I was I was, did I say anything wrong? I was just upstairs talking to [resident name] [mumbles words purposely] and I was like, calm down you know, they'll really take you, don't worry. When she calms down she'll come and talk to you and she'll tell you she's sorry, that's how they are you know? You could just tell someone to make a cup of tea and sit down and quickly talk to somebody for five minutes and talk to another one but if you're like want to talk to someone for like twenty minutes and the others have they you know, make them angry and they really take you through this process of how they are because most of them have been living here for twenty thirty years so they are really know them and they are quite good, they understand they are quite good, [hmm].</p>	<p>shift easily? What is she communicating? Is this the dichotomy that she experiences... beauty to unmanageable? Possible RR of idealised staff/care home to damaged resident/family member?</p> <p>'Honestly' - Sense of frustration / tiredness in being surrounded by residents demanding attention.</p> <p>Initially, when working in this field, she experienced this difficulty as blaming herself → 'did I say something wrong' → Initial way is to blame self.</p> <p>'that's how they are' → repeated grouping of all people with learning disability → May this be interpreted as de-individualising?</p> <p>Residents seem to struggle (anger at staff) with attention being given to other residents. 'really take you through the process'</p>	<p>Possibility of an 'incident' if not careful</p> <p>Sense of a relentless struggle</p>
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<p>Int: How have you found working in this particular organisation?</p> <p>P7: [Hmm] I think it's very flexible [uhm] and I think it's, it's a good company, they give you so many opportunities, so many opportunities to, the money isn't great but you get to-to, learn a lot and, it's really good that you get to improve your skills a lot and those opportunities and there [uhm] So you can help the residents even more.</p> <p>Int: What kind of like opportunities?</p> <p>P7: It's like so many like charity organisations, we've got like the children's centre, we've got like voluntary work at the head for example starting next week for to work with the advice and information just as a week so we've got their advocacy so is once a month so it gives you that experience, I think for the experience but [erm] it's really good it's a good opportunity.</p> <p>Int: And does that interest you? It sounds like</p> <p>P7: It does but I haven't got the time [both laugh]. I haven't got the time. I-I love it, I love it, I just love it. I wish I had the time I would do like maybe two hours at one of the charities, maybe do once a week one shift voluntary at the children's day centre so I think I will try others [uhm] alternatives another time.</p> <p>Int: In what way, is that the way they kind of support you they offer lots of opportunities?</p> <p>P7: Yeah they offer opportunities for you to-to learn, for me it's like a learning process for you to learn, for you to meet other categories of people with learning</p>	<p>Values the organisation = flexible, many opportunities, improve your skills.</p> <p>Particularly values the opportunity to develop, improve and learn new skills to help the 'residents even more'</p> <p>'I love it' repeated.</p> <p>Sense of valuing the opportunity to learn, develop and progress.</p>	<p>Values the organisation</p> <p>Striving to develop, improve so 'you can help the residents even more'</p> <p>Fulfilment, pleasure and reward</p>
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<p>disability and mental health and it-it does in a way.</p> <p>Int: It sounds like you're comparing interests in learning with getting experiences, where do you see your kind of self heading towards?</p> <p>P7: I just want to be vast with knowledge and [Int. laughs] just have a good job, you know, help people in a most professional way, that'll give me really really good joy, yeah! It will.</p> <p>Int: What is that kind of great joy that you kind of talk about?</p> <p>P7: It's just like that kind of joy I've explained to you when you know that there is somebody somewhere that really that's looking up to you like Jesus Christ, others like, oh I've got my support worker to help me out and-and-and you prove to that person that you could help them out for example, if someone needs to go to the bank they use a wheelchair, they can't ride their wheelchair to the bank and that person is waiting for you because they have to go to the bank and to get that money out to do my hair and I'm waiting for my colleague to come and help me and you come and they see you, that person is so happy, smiling and let's go to the bank and when they come back they are very very good and they tell you thank you and it's just that thank you and love and you go and you feel so I've helped somebody that in a way is, thank you for taking me out, thank you [sounds happy].</p> <p>Int: It sounds like the residents are very grateful.</p> <p>P7: They are just amazingly are but I know other areas [laughs] it's rough but..</p>	<p>Continual theme – aspiring to be more knowledgeable, and help people in the 'most professional way', that'll give me really good joy.</p> <p>Joy from being experienced as 'Jesus Christ' → Idealised saviour / rescuer. Thus how does she position the residents? As followers? 'you prove to that person that you could help them out' → Sense of needs to PROVE to another that you can do something, who is the parent here? Who is proving what to whom? Sense of needing to be idealised by another...</p> <p>Sense of joy at having reciprocated 'thank you', 'love you' → In being openly admired by the residents. Could this possibly be the RRs of 'helped' to 'helper', 'admired' to 'admiring' or 'idealised carer' to 'ideally cared for'?</p>	<p>Aspiring to develop and be the best she can be at her job.</p> <p>Joy in being in helping people</p> <p>Joy and pleasure in being admired by residents</p> <p>Joy in being admired by residents</p>
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<p>Int: Do you think it would be different if you worked somewhere where you didn't get as much kind of...</p> <p>P7: Yeah I worked in a dementia unit for about three years so</p> <p>Int: And is there not kind of as much</p> <p>P7: Oh my yeah it's quite it's quite hard and [phwoos] it's quite different but again it's got its own way of not everyone's got just one or two people who are very very challenging but all the residents were very [claps here] very, at least they, they knew somehow that you know</p> <p>Int: You were supporting them?</p> <p>P7: You were supporting them. Maybe there were none said about but you could see them stretching out their hands and saying thank you and at least you understood them that they really appreciated what you did for them so.</p> <p>Int: And it sounds like it feels really good to get that appreciation.</p> <p>P7: Yeah yeah it's not every time you could get it [laughs] every time but yeah it's quite it's quite like I said it got challenging behaviour so.</p> <p>Int: And what's it like when you don't get it back?</p> <p>P7: [sighs] It just shows that not everyone will appreciate, some appreciate some wouldn't and that's just how life is but if you do what you've done is right and it's justified you know, then you know you've done it, you've done it, I've done all I could do in the most</p>	<p>Experienced working in dementia as 'quite hard' and with 'very very challenging' residents.</p> <p>Repeated theme – values having people say 'thank you' and being 'really appreciated'</p> <p>[Sighs] – Why does she sigh at this point? What is the meaning of this? Is there an underlying frustration, anger or even resentment that people do not show their appreciation? Hypothesis =</p> <p>Acceptance and fulfilment if she knows she has done 'all I could do in the most possible, kind manner and I am happy' → Sense of this being her overriding measurement... 'all I could do in the most possible, kind manner'</p>	<p>Joy, reward and fulfilment in being appreciated and acknowledged.</p> <p>Acceptance once known they have done everything they could possibly do.</p>
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possible, kind manner and I am happy.

Int: And is it easy to kind of know when you've done things to the kind of [participant: 'yeah'] yeah, you just know?

P7: You know, you know, you know, you know! Take for example, somebody's had loose bowels the whole day and you're just cleaning and cleaning and cleaning and the person is like, I'm really sorry but you know I just can't help it, I just can't help it [says in a low, slow tone as if imitating a resident] and you doing, at times you just wish he or she could just stop but they can't really stop and at the end of it you know, I've done it. I've done it. I've I've helped someone who could not actually do it by his own self.

Int: And what, I'm just, can you say something a bit about, you kind of talked about making sure people have kind of the most quality of life that they can and can you say a bit about, how do you kind of understand the kind of lives or the quality of lives that some of the residents here have?

P7: By their likes or their dislikes. You know we've got just one male resident this year. He's so much interested in computers, because they send people using computers essential but he hasn't got a clue of what's it about so just like everything in more detail and ask him you know, do you want, do you want us to play around here on your computer and he'll, oh yes please yes please-just teaching him how to put it on/off you know? He feels really happy even if he says to me and he knows the keyboard doing something so that's what he likes and-and if you go to him and you're like, could we? Because not every time he'll come and ask you most he wouldn't, he likes football

Feel easy (emphasised) to know when you have done everything possible (offered the ideal carer role)

Reiterated – the role of helping someone do something 'they could not actually do it by his own self'.

Understands quality of life as 'by their likes or their dislikes'. Does she understand quality of life with how much one engages in their interests / hobbies (likes)?

'teaching him' = adopts role of teacher, guider.

Resident may find it difficult to ask for the support they require

Joy and rewards in enabling someone to do something they couldn't have otherwise done.

and it's just for you to check when you work for this plan and you remind him, he's so happy and you know, Saturday I looked in the diary and the manager would normally put one person on duty just to take him out there and he'll be really glad, that's what he likes, he likes swimming. We used to take him and now he knows the way because we've done assessment where showing him it's not far so now he knows his way to the swimming pool, he goes there he comes back and why he hasn't done that is because it's cold. I've got an ear infection and the moment [both laugh].

Int: We are just coming to the end now. I was just wondering how you have found talking today?

P7: [short pause] Just [erm] it's quite nice because it makes you, it makes you reflect on your everyday, everyday life, everyday coming to work life and it gives you, it gives you the opportunity to really like, have a look at you know, your work life [laughs] and what it's all about and everything, it's quite it's quite nice.

Int: Do you think there's anything that I, any particular parts of your role or what you do and how your experience it that I've missed or not I haven't asked about that feel important to you?

P7: [Hmm] No I think you've got everything so [both laugh]

Int: Was there anything that's kind of stood out for you that we've talked about today?

P7: I think everything has been important actually. [laughs]

Enjoyment/reward in seeing the residents happy.

Experienced the reflective element of the interview as 'nice'.

Int: Well thank you very much for kind of answering my questions and for taking part.

P7: Thank you too and I wish you good luck.

APPENDIX 6B**AUDIT TRAIL - LIST OF EMERGENT THEMES FROM INTERVIEW 7**

Fulfilment through 'adding value'
 Pain at seeing people not get out.
 Excitement, joy and satisfaction
 Pleasure and love of role
 Aspiring to develop professionally
 Perceives role as limiting
 Role as fulfilling, pleasurable and rewarding.
 Desire to know residents are okay beyond working hours.
 Importance of being professional
 Need to be cautious and protect the self
 Advocating for respect and choice
 Contradiction of advocating for respect/choice but describing 'doing for them.'
 Need to repeat yourself over and over
 Caution and protection
 Importance of 'facilitating' not doing for the residents.
 Sadness
 Enjoyment in involvement
 Residents don't like doing chores
 Conflict between expectations of residents vs policies
 Conflict between residents' wants vs professional demands
 Values doing things together
 Happiness in being needed
 Mistakes as letting down the resident.
 Being pivotal to the residents' lives.
 Expected to be parents
 Sadness at being unable to fulfill her care
 Experiences mistakes as very painful and lasting.
 Mistakes are cataclysmic
 Contradiction of 'administering' vs 'facilitating' personal care.
 Powerlessness and helplessness
 Struggling, tiring and stressful
 Belief in their home as providing the ideal care, fearful others cannot provide this.
 Needing to be boundaried
 Difficulty
 Conflict of managing demands from different sources.
 Conflict of national policies vs realities that staff and individuals are different
 Reluctance to state negativity
 Impossible to meet the family's expectations.

Working really hard
Conflict of families demands vs policies on choice.
Feeling powerless
Families blame staff for residents' difficulties.
Residents relate to us in different ways
Documentation protects the staff.
A constant struggle
Helplessness
Conflict in balancing demands of the family, policies and the residents.
Helplessness and powerlessness
Powerlessness
Blame towards the family members for not understanding.
Families do not understand our struggle
Families blame us
Blames family members
Blame towards government
Having to say things over and over
Conflict of supporting the individual vs everyone
Blame towards family members.
Care home and staff is beautiful
Possibility of an 'incident' if not careful
Sense of a relentless struggle
Values the organisation
Striving to develop, improve so 'you can help the residents even more'
Fulfilment, pleasure and reward
Aspiring to develop and be the best she can be at her job.
Joy in being in helping people
Joy and pleasure in being admired by residents
Joy in being admired by residents
Joy, reward and fulfilment in being appreciated and acknowledged.
Acceptance once known they have done everything they could possibly do.
Joy and rewards in enabling someone to do something they couldn't have otherwise done.

APPENDIC 6C

AUDIT TRAIL – INITIAL CLUSTERING OF THEMES

PLEASURE IN THE ROLE

Fulfilment through 'adding value'
 Excitement, joy and satisfaction
 Pleasure and love of role
 Role as fulfilling, pleasurable and rewarding.
 Enjoyment in involvement
 Joy in being in helping people
 Joy and pleasure in being admired by residents
 Joy in being admired by residents
 Joy, reward and fulfilment in being appreciated and acknowledged.
 Happiness in being needed
 Joy and rewards in enabling someone to do something they couldn't have otherwise done.
 Fulfilment, pleasure and reward

ASPIRING TO AND BEING THE IDEAL CARER

Aspiring to develop and be the best you can be at your job.
 Striving to develop, improve so 'you can help the residents even more'
 Aspiring to develop professionally
 Being pivotal to the residents' lives.
 Care home and staff is beautiful
 Belief in their home as providing the ideal care, fearful others cannot provide this.
 Acceptance once known they have done everything they could possibly do.

THE PAIN OF MISTAKES

Experiences mistakes as very painful and lasting.
 Mistakes are cataclysmic
 Mistakes as letting down the resident.
 Desire to know residents are okay beyond working hours.

PROTECTION

Possibility of an 'incident' if not careful
 Importance of being professional
 Need to be cautious and protect the self
 Caution and protection
 Reluctance to state negativity
 Needing to be boundaried
 Documentation protects the staff.

THE CONFLICT OF MANAGING MULTIPLE EXPECTATIONS

Importance of 'facilitating' not doing for the residents.
 Conflict between expectations of residents vs policies
 Conflict between residents' wants vs professional demands
 Expected to be parents
 Contradiction of 'administering' vs 'facilitating' personal care.
 Residents don't like doing chores
 Conflict of managing demands from different sources.
 Conflict of national policies vs realities that staff and individuals are different
 Impossible to meet the family's expectations.
 Conflict in balancing demands of the family, policies and the residents.
 Conflict of families demands vs policies on choice.
 Residents relate to us in different ways
 Conflict of supporting the individual vs everyone
 Advocating for respect and choice
 Contradiction of advocating for respect/choice but describing 'doing for them.'
 Values doing things together

POWERLESS AND THE EMOTIONAL REACTION TO INJUSTICE

Powerlessness and helplessness
 Feeling powerless
 Helplessness
 Helplessness and powerlessness
 Powerlessness
 Sadness
 Pain at seeing people not get out.

THE RELENTLESS NATURE OF STRUGGLE

Struggling, tiring and stressful
 Difficulty
 Working really hard
 A constant struggle
 Having to say things over and over
 Need to repeat yourself over and over
 Sense of a relentless struggle

THE CIRCULATION OF BLAME

Blame towards government
 Families blame staff for residents' difficulties.
 Blame towards the family members for not understanding.

Families do not understand our struggle
Families blame us
Blames family members
Blame towards family members.
Perceives role as limiting

APPENDIX 7

TABLE OF MASTER THEMES FOR ALL PARTICIPANTS

Superordinate Theme	Main Theme	Sub-theme	Supporting quotation
Emotional Motivation	Personal Fulfilment and motivation	Pleasure in the role	<p><i>'I always used to get a kiss and cuddle from her [past resident], every time I came on shift... she would give it to me, she was always sweet. It made me really happy.'</i>(Caroline)</p> <p><i>'I really enjoy seeing the families. It's just nice to be able to talk to them, on a personal level, because they can understand we have worked with their child, for so long, so we pretty much know them, not on the same level, but pretty much getting to where they are. So they can understand how we feel as carers and such so we can make a bond with the parents.'</i> (Caroline)</p> <p><i>'when you see someone will give the affection back to you, that's when it becomes the most rewarding, but it's not only getting that affection back, it's when you know you are the only one getting that affection back from then. I think that's what's really like the gold star for me.'</i> (Caroline)</p> <p><i>'it's just nice when you see her doing her little bits and pieces just for you. And you see other staff members, and they are kind of trying but they just don't quite get it right, it's that kind of nice feeling, you just think that was only just for me, so I am special to someone.'</i> (Caroline)</p>

		<p><i>'And I thought of it, and I said, to whom much has given, much is expected, and one good turn deserves another. And to be those things, because she [grandmother] did that for me when I was very young and I did it... all along I have been trying to think about how to help people, how to help people. I think the idea of helping people came into mind. And I was looking for something to contribute my quota to humanity... helping them and you know, you help them to live their life, because you are contributing part of your life to them, and in the future, I say that I believe there is nothing you do in good, that it will not come back to you in good. So that makes me happy to know that.'</i> (Nnamdi)</p> <p><i>'When they appreciate it. I will be so happy I tell you. Umm... I am always very very happy when I do something and they appreciate it. It makes me feel happy. I feel home and dry. And I know for that day, I've got my, my my [pause]. I would say like a gift. It's just a gift that give me a kind of please to me.'</i> (Nnamdi)</p> <p><i>'Because you are working so closely with somebody. Some of the clients are really good fun to work with and they enjoy so many activities that I enjoy, like swimming, walking, shopping, and they love that, and going to the pictures and dinner, I like doing all that, I like socialising'</i> (Anne)</p> <p><i>'I will be off two weeks on holiday, come back with a really nice tan and... a couple of them go 'ah your back' and that really does make you smile. Because it makes you think, well at least somebody missed me.'</i> (Anne)</p> <p><i>'...it's just nice, a nice job, a lovely job to do. Hard but lovely.'</i> (Anne)</p> <p><i>'All I know is that, every day is different, umm... and every day I quite like work. Which is sad I just do love coming to work.'</i> (Anne)</p>
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			<p><i>'...and to see that look in their faces when they think Santa has been [laugh]. There are 18 huge Santa sacks under the tree and it's just chaos. Its mad [laugh]. It's lovely and I much rather, maybe not so much now I have my own child, but before I loved to be here on Christmas morning. It's really good you know.'</i> (Francesca)</p> <p><i>'But at least with adults with learning disabilities you can teach and give them quality of life. You see the enjoyment on their faces when you are out and about. And one of the things that I do here a lot, is I do all the day trips, and organise things like that. So it's getting them out in the community.'</i> (Francesca)</p> <p><i>'I like to show people a good time. I like to go home at the end of every day knowing that one little thing I have done has made somebody's life a bit better, and if I can make someone laugh, or make someone smile or give someone an opportunity, every day I work then that's really rewarding.'</i> (Francesca)</p> <p><i>'It makes me feel like you're helping someone who can't do something, yes? Yeah I get a lot of comfort from that, yes'</i> (Habika)</p> <p><i>'She said oh Habika it's the way you are with them here, that's why yeah. Anytime you come back from holidays they are all like that, come back from holidays, 'Oh we've missed you so much', you've been gone for two weeks and they are just they are all over you whenever you come back... Well it's nice, isn't it?'</i> (Habika)</p> <p><i>'with people who have learning disabilities it's more enabling and it gives you that excitement, that joy, that fulfilment, that satisfaction that you can actually add value to someone's life'</i> (Zarina)</p> <p><i>'When they come back [from the community] they are very very good and they tell</i></p>
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		<p><i>you 'thank you' and it's just that thank you and love and you go and you feel so, I've helped somebody that in a way is, 'thank you for taking me out', 'thank you' [sounds happy].'</i> (Zarina)</p> <p><i>'It feels really like a family. It feels like a family and I think the other senior staff they're really really supportive... they are willing to listen, they are willing to show you stuff you know and it's-it's-it's really beautiful, really beautiful.'</i> (Zarina)</p> <p><i>'That's just how it is and I could honestly say [care home name] where we are, we really work as a team so it is amazing'</i> (Zarina)</p>	
		<p>Tensions of 'ideal' versus 'insincere' care</p>	<p><i>'I suppose it's selfish to some degree to jump around and act like an idiot to try and distract yourself [from her problems]. My only distraction to me would be a very selfish act, especially since I would be trying to do it for someone else, but yet it would be mainly for me, to me that would be a very selfish kind of feeling.'</i> (Caroline)</p> <p><i>'But you should try and do everything you can when you are out there, to make the present better'</i> (Caroline)</p> <p><i>'But you do just get the odd member of staff you can just tell really deep down inside it's just a job to them, it's just money, and that what's kind of disturbing'</i> (Caroline)</p> <p><i>'Even if it's just silly things even if it makes our jobs twice as hard. It doesn't matter because as long as it puts a smile on their face, that's what should be done really.'</i> (Caroline)</p>

		<p><i>'Umm... I think some do... some couldn't really give two tosses. They are quite literally are just here for the job, they are here for money. They do what they need to do on their daily level and they leave.'</i> (Caroline)</p> <p><i>'I still look for room to help people more. That's it.'</i> (Nnamdi)</p> <p><i>'It has to be something you give yourself to, you help people, you give your life to, and yeah it never changes I tell you.'</i> (Nnamdi)</p> <p><i>'Other staff might not see it the way I am coming from. Because they might say that maybe it is because of the money, which isn't good. I just want to, just to keep me going. Err... just to do something you know. I could see from other, they could see from other angles. But, you know, we got different varieties, and different choices, and I know not everyone in this setting that really like what they are doing. I know it for sure.'</i> (Nnamdi)</p> <p><i>'Yeah you know it could be a bit tedious sometimes. Because you keep telling them you know, you're not just here, to collect money or to pay the bills. There is more to life than money.'</i> (Nnamdi)</p> <p><i>'I mean it's something that it's so important to me because we have got to satisfy them, you know. Everything that we got is just for their satisfaction.'</i> (Nnamdi)</p> <p><i>'When people are meant to do this, do that, because every hour we spend here, is for this people. You know. In order to make them happy in what they do, everyday. And if, at the end of the day, we are here and we can't make them happy, there is no point'</i> (Nnamdi)</p> <p><i>'...the client being happy really. As long as they are happy and their needs are being</i></p>
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		<p><i>met. Then that's all I can say. The minute they are upset that's when you know you have sort of failing in some area and... make sure it's not happening any more'</i> (Anne)</p> <p><i>'When somebody has nobody, and you know you have got a rapport with somebody. And you get on well with them. And they look to you for reassurance. You know that you have got to step up to the mark and do a little bit more.'</i> (Anne)</p> <p><i>'Other side of it, it's a job to them and its money. And that always amazes me why they stay in the role because I just think, if you have got no no ambition in the work. Why not go and work somewhere like Tesco's... or a job where you haven't got to think be on your toes, you haven't got to... you just go and work. Whereas this you don't. This is people's lives. And you are making a difference to their lives.'</i> (Anne)</p> <p><i>'If I see a client not happy for whatever reason I would always always try and improve that and find out why, what's happening?'</i> (Anne)</p> <p><i>'...it's a job to them and its money. And that always amazes me why they stay in the role because I just think... this is people's lives. And you are making a difference to their lives.'</i> (Anne)</p> <p><i>'We did have a manager many years ago, and I had to stand up arguing with her because she said, you haven't got to have a heart to do this job. It's just a job... but if you have no heart how can you put your soul into it and do it properly. And I had an argument with her over that.'</i> (Anne)</p> <p><i>'People seem to think you do it because you like helping people. That annoys me a little bit because it's almost like you are doing it for your own satisfaction and gratification, and it's not that at all.'</i> (Anne)</p>
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		<p><i>'Their needs are what is important to me, and their enjoyment. It's about them having fun, you know, you don't know how long they have got to live, you don't know how their disabilities are going to increase or decrease. You don't know how long they are going to enjoy their lives, so my role here is to give them a happy day.'</i> (Francesca)</p> <p><i>'If someone is ill I worry, I worry all the time. I phone up every day and make sure they are alright. I have been with a couple of chaps in ambulances, one having a heart attack, with a defibrillator and out. I have sat in there, holding their hand all night [laugh]. The staff here told me to go home, and I was sat up in hospital all night because it just didn't want to leave them on their own up there. And you know you are not getting paid for it but that's just, you know. That to me is part of my job.'</i> (Francesca)</p> <p><i>'No, no I knew that I had to do it for my own peace of mind and his. To just be able to carry on with my work.'</i> (Francesca)</p> <p><i>'No one in care can say they're in care for the money. No one, because the money, it does not pay for what you do. You know the amount of hours through the night I have been up the hospital where I have had to go to the mental health departments and have people sectioned in the night, you know, all unpaid till 3 or 4 o'clock in the morning. You wouldn't do that if you were here for the money. You do that because you care.'</i> (Francesca)</p> <p><i>'Today I should have finished at 12, but I organised to stay on and be interviewed by you. But now, a doctor's appointment has turned up so I have called my mum to see if I can organise someone to pick my little one up so I can stay on and take him to the doctors and save him walking up there, and save him paying £4 for a taxi to go 200</i></p>
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			<p><i>yards up the road because he is just not capable of walking 200 hundred yards. You know. That's just the way it is. I'm a bit glutton for punishment, perhaps they abuse it, the management might abuse my good will. They know I will do that's why they ask.'</i> (Francesca)</p> <p><i>if I do not come to take her out, I'm going to be letting her down and that really makes me, really unhappy'</i>(Zarina)</p> <p><i>'Because I was like, well why didn't I put it on my rota, ooh I've let I've let [resident name] down I've really let her down I have, oh and it's not like just letting her down, it's letting everybody down'</i> (Zarina)</p> <p><i>'It's just like that kind of joy I've explained to you when you know that there is somebody somewhere that really that's looking up to you like Jesus Christ'</i> (Zarina)</p> <p><i>'Hmm yes if any person needs it I will do it for that person. It doesn't matter what I am doing at home, I will have to come and not that I would have to, I will do it.'</i> (Habika)</p> <p><i>'I used to go there all the time anyway so and one of them went to the hospital and stayed in hospital for about at least three weeks or four weeks and sometimes they don't have anyone to just go and just sit with him and talk and and he used to like me, that's what I thought. So whenever I told them I say 'if you can't get anyone and I'm not working ring me and I will go in yes.'</i> (Habika)</p>
	The emotional struggle	Powerlessness and the emotional	<p><i>'Sometimes it's not fair, sometimes it's not fair to them'</i> (Emeka)</p> <p><i>'I feel sorry for them. It's not their choice. They were just born like this so it's not</i></p>

		<p>reaction to injustice</p>	<p><i>their choice... There is nothing we can do. Other than just help them.'</i> (Emeka)</p> <p><i>'Because this people they can't say anything, they can't talk, they can't challenge, they can't stand up for themselves'</i> (Emeka)</p> <p><i>'I just put them some trousers and trainers maybe. Doesn't wear them she doesn't want to wear them then nothing is fair to them. Nothing is fair. You can't do anything, you have to do it.'</i> (Emeka)</p> <p><i>'It's just like I said, it's just trying to get people to understand, like head office with extra staff members, that could actually help us. But it's just the way the rules work, way the system works unfortunately. It's... nothing can really be changed about it, you just have to grit your teeth and bare it.'</i> (Caroline)</p> <p><i>'It's like when I get reminded of it, the feeling engulfs me, it's the best way to describe it, it's literally like a suit that you slip on. It like rises in your stomach, and it just sets off everywhere... and I think that's where the feeling of violence comes from, just wanting to protect that person.'</i> (Caroline)</p> <p><i>'They will sit down in front of the TV, they will be watching TV most of the day. They might have the opportunity to go outside, over to Asda for a quick 10min, with the staff. Other than that they are at home. And I just don't think it's fair because they don't get to do the things they want to do.'</i> (Caroline)</p> <p><i>'It's really gutting. When you know that they have family literally 10min up the road, but umm... it won't take long for them to come and visit and see their son, and they just choose not to... I think the main feeling is just disappointment'</i> (Caroline)</p>
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		<p><i>'You know you can't help when you are working with people day in day out, seven days a week, you know entire years, you do get attached, you can't help it.'</i> (Caroline)</p> <p><i>'they are people that are different from us. So... why are they treated so differently? [said loudly] Why are they not given the same choices and independence as the rest of us? And that's what I feel about the role, that's how they should [emphasis] be treated.'</i> (Anne)</p> <p><i>'some of them can only go out with the support of us. And that's really, really like it is a form of imprisonment, they are trapped inside their own shell really. And that's really sad for them... But I would love to be in their brain for just one day to know how it must really feel. Because it's sad I think.'</i> (Anne)</p> <p><i>'The dietician says, oh no she shouldn't be having this that and the other one. But it is hard, what much else have they got in their life? So, I you just get on with it. Yeah, so what else have they got in their life?'</i> (Anne)</p> <p><i>'You can't do anything with it. You just got to accept that's who they are and that's their choice. Umm it is horrible because I think actually there is people here that don't have a family and there is people here that have huge family that don't bother with them and you know.'</i> (Francesca)</p> <p><i>'It's society isn't it. It's politics. We are fighting red tape all the time anyway, everything is about what's right and what's wrong so you just, you can't fight that. You can't. The policies and procedures unfortunately you just have to work within them.'</i> (Francesca)</p> <p><i>'It annoys me. It really angers me because I just think there is some... there are</i></p>
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		<p><i>residents that could then have two holidays if they didn't have to pay for the staff member.'</i> (Francesca)</p> <p><i>I would say 80% of our chaps have either come from institutions settings or umm [pause] or have been abused in whatever way shape or form, whether it's financially, sexually or physically... They have had such tough lives... It breaks my heart'</i> (Francesca)</p> <p><i>'Yeah, especially those of our chaps that don't have any family or even friends. You know some of our people here don't have anyone that isn't paid to be in their life. They don't have any outside social people to respond to. Umm, you know everybody in someone's life is paid to be in their life that is quite a sad thought.'</i> (Francesca)</p> <p><i>'It's just like you know, this is what is happening now [laughs] it's, it's beyond me to do anything else or I just can't, this is what this is what it is, the government has done.'</i> (Zarina)</p> <p><i>'they get really violent... and there's just nothing you can really do about that... it's really sad where we know there's just a limit to what we can do'</i> (Zarina)</p> <p><i>'you know, we could just prompt and say things but if they say, I'm not doing it I'm not doing it and there's just nothing we can do, absolutely nothing'</i> (Zarina)</p> <p><i>'it it's really difficult in that situation because you're like you, at the moment I can't do it for her I can't force her to do it and the family but it's oh look at what is happening!'</i> (Zarina)</p>
	The relentless	<p><i>'It's just constant. Constantly having to do the cleaning, constantly, making sure you</i></p>

		nature of struggles	<p><i>document things, constantly arguing with the staff. It never ends.'</i> (Caroline)</p> <p><i>'It's really hard, I don't think it's the best things they should have to deal with. You know they have a lot of their own problems, so I don't really think having staff having issues with each other should really be pushed on them. So it's really kind of hard when you are working with someone, who in all honesty, you really just don't want to have to work with, you know you grin and bear it, you swallow it up, and then you get on with it.'</i> (Caroline)</p> <p><i>'Really shitty. Really really shitty is the only way to describe it... I can argue as much as I want [about getting money for resident holidays] but I will just be blue in the face, won't get any further with it. I keep and keep trying but you know.'</i> (Caroline)</p> <p><i>'You don't only just give your physical side of things, you have to give your mental side as well, you have to give your heart in your job'</i> (Caroline)</p> <p><i>'basically we are here to clean a lot of the time, that's what really kind of gets me frustrated. It is a constant battle to do housework & chores'</i> (Caroline)</p> <p><i>'...can be frustrating because, you have to constantly say to them, why do you think they live here?'</i> (Anne)</p> <p><i>'it can be challenging because [pause] to try and keep people motivated all [emphasis] the time'</i>(Anne)</p> <p><i>'And we are working 24 hours round the clock on holiday. We come home absolutely shattered. We end up spending more money of our own than what we earn out there. And then when you come back you know, you have to come back and fall straight back into your shift pattern. You can't have a couple of days off to</i></p>
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			<p><i>recover... you come home and you are shattered.'</i> (Francesca)</p> <p><i>'You know, what we do here, you know, we are dealing with people's bodily fluid, we are dealing with their emotional needs. We are dealing, you know, it is blood and guts and sweat and tears every day'</i> (Francesca)</p> <p><i>'Annoying, because you know that they shouldn't be doing it, but you can't change them, you can tell them one day keep it down a bit, you just making everyone high, then 20min later they come in open the door, hey everybody, you think argh [laugh]. You just end up telling them over and over.'</i> (Francesca)</p> <p><i>'she's been very very unsettled, opening doors going out, pushing chairs, punching other residents and so and so is three-to-one today, and you come back home feeling really tired and stressed. Really stressed. It all, uhm, builds up continuously. It's really tiring.'</i> (Zarina)</p> <p><i>'Mums could be like eighty and above so it's really, it's as if you are dealing with two residents. It's really hard, you sit them down you explain things to them, you see their family and everyone is just not understand, you go around and it's tiring, it is.'</i> (Zarina)</p> <p><i>'you-you could explain that to her about ten times in a day when she's going out and she's like, yeah yeah yeah I understand what you say. She says the next staff coming in, she'll go, could I withdraw £60 and she does every week, every single week all the time'</i> (Zarina)</p> <p><i>'when you find we're doing our best we're working really hard'</i> (Zarina)</p>

Demands and Coping	Safety and Conflict within Coping	Constricted and un-elaborative	<p>Int: <i>What parts of the role do you most like?</i> Emeka: <i>In the morning, everything... [pause]. Everything.</i> Int: <i>Is there a particular thing you like the most?</i> Emeka: <i>Not really. I guess I am enjoying everything at the moment.</i></p> <p>Int: <i>What do you feel are the things you are good at as a support worker?</i> Emeka: <i>I think I am good at helping people with their personal care.</i> Int: <i>What are the things you are good at, what kind of abilities, strengths or skills do you have, that make you good at working with personal care?</i> Emeka: <i>I have done this quite a long-time so I think I can do anything.</i></p> <p>Int: <i>What's it like for you talking about these kind of things?</i> Emeka: <i>Yeah it's alright, talking is good.</i> Int: <i>Is there anything that has stood out for you?</i> Emeka: <i>Yeah, I think all the questions you asked, made me think.</i> Int: <i>I guess I am wondering what or is there anything that we have talked about that stands out?</i> Emeka: <i>What do you mean?</i> Int: <i>I don't know. Is there is anything that came up that maybe was particularly interesting?</i> Emeka: <i>Umm. I think everything was fine. Everything was fine.</i></p> <p><i>'There is no one that doesn't know the wrong thing and the right thing... So I think everybody should know the right thing and everybody should know the wrong thing... every human being' (Nnamdi)</i></p> <p><i>'You know, if you're not satisfied with what you do, then you quit it, so simple. So</i></p>
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		<p>simple.’ (Nnamdi)</p> <p><i>‘Yeah, it’s umm... They way I see it, because they know that we are here to help, and with that. They like it. And they so love it. So they wouldn’t say otherwise because they know we are looking after them. Yep, so that’s the way.’ (Nnamdi)</i></p> <p><i>‘I just find them quite negative people. I don’t know, I’m just not like. I think if you are negative your miserable, simple as that, and I can’t stand being miserable for long, so I’m just not negative you know’. (Anne)</i></p> <p><i>‘But she couldn’t do my job because she is not very good with people. She loves animals. I like animals, but I like them, I don’t love them like she does... I can do the job and that’s what I am good at, that’s why I do it.’ (Anne)</i></p> <p><i>‘I have only ever been met with positivity from families. Umm. Yeah, I have only been met with this.’ (Anne)</i></p> <p><i>‘There is conflict. And we had a situation with two staff members. No matter what you did, they couldn’t not get on. So you met with them and said ‘right, I don’t expect you to be mates and go to each other’s weddings but whilst you are at work. You stay professional’. And it’s working out okay. Yeah, that’s it then.’ (Anne)</i></p> <p>Int: How do you find kind of doing that? Habika: Well, we just you have to assess that person to know that you know, that person is not capable of doing that, hmm.</p> <p>Int: Is it kind of easy to find the balance or? Habika: Oh it’s easy! [emphasis]</p> <p>Int: How do you find that, kind of managing and like sorting out that kind</p>
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			<p>of relationship and how it works?</p> <p>Habika: Oh it's fine, it's fine because [short pause] it's family isn't it?</p> <p>Int: How do you find working in this particular team with this kind of particular set of staff?</p> <p>Habika: Oh it's fine, I don't have a problem with anyone so I hope they don't have problem with me.</p> <p>Int: How do you find kind of like working as a team and things like that?</p> <p>Habika: Yeah we work well, we do work well.</p>
		<p>The conflict of balancing multiple expectations</p>	<p><i>'It is a constant battle to do housework & chores, which if we don't do we get in trouble for. But we get in equal as much trouble if we ignore the activities for the service users... its quite literal a case of one or the other, there is no room for both.'</i> (Caroline)</p> <p><i>'Three or four bathrooms to clean, kitchen to clean, dusting to do, laundry, oh my word the amount of laundry we have to do. But it's just really really hard, it's literally just a case one or the other. Either way I get shouted at for not doing something'</i> (Caroline)</p> <p><i>'You know they are adults so you treat them like adults. That's how I would want to be treated myself if I was in that situation... I pull the toys out the box, the hand puppets, and the stupid stuff like that and I will just start acting like an idiot. I'll start singing, I'll start dancing, I'll basically try and do anything'.</i> (Caroline)</p> <p><i>'I try and get them to be as independent as humanly possible. I really hate when I see an old member of staff babying a resident... you know, one of the girl's here, she is my baby girl, I call her that all the time. 'Alright gorgeous', 'alright beautiful',</i></p>

		<p><i>'how you doing baby girl?'... My little [baby name]'. (Caroline)</i></p> <p><i>'They [government] promote independence, rights of choices, when the bottom line is, if it comes down to money... the choices go out the window. Sorry we can't do that because we don't have money... how can we promote their independence, rights and choices, if the funding isn't put in place to make that happen?' (Anne)</i></p> <p><i>'So, you order in your food and because it's from umm, like a big company, it comes in bulk. But how can you promote their choices at meal times if they are not actually going out there in the community doing their shopping.'</i> (Anne)</p> <p><i>'You have got to be, got to be kind don't you, to want to work with people full stop because if you didn't, what's the point of doing that job... Everybody's different, and I except that everybody is different and I don't hold it against them.'</i> (Anne)</p> <p><i>'And you can walk through the door and get a big cuddle and a kiss. And it's so hard to sort of push them away, and say no you can't do that, you are not allowed to do that. You can, you know, say good morning, or shake my hand, but it's very hard because when they are upset and they are crying the first thing they do is put their arms out and cuddle you, its comfort.'</i> (Francesca)</p> <p><i>'Umm, but you have to give the residents the opportunity to decide whether they wish to go to the funeral or not. And most of the home went. When another resident dies, do the residents go to their funeral? Or is it just family? Some families don't want them there.'</i> (Francesca)</p> <p><i>'there are so many institutional things here as well, that we try our hardest as well to break the institutional setting, but then you also need routine and boundaries. Especially with the autistic chaps here.'</i> (Francesca)</p>
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		<p><i>'They [family] will come in and if you are on they will come and talk to you rather than go and see their [pause] and they, you know obviously having a baby as well, oh have you got a photo of your baby? Oh let's have a look, so you know, they encroach on your personal life as well. It's hard to say actually it's none of your business that's my personal life and I am paid to look after your family member, you can't do that.'</i> (Francesca)</p> <p><i>'Well you know what's going on with him or her so you don't let it get to you. It gets to you, you're human being, but you just let it go [pause] because you know she's got that problem, hmm.'</i>(Habika)</p> <p><i>'Well the only difficulty is [pauses] they [family] think it should just revolve around just hers or his here but there are so many people here. They expect that whenever you are here you are just his or hers... taking just that one person out, but what about the rest?'</i> (Habika)</p> <p><i>'We work towards the same goal so that's what we try to do here, we don't work in the same way but work towards the same goal because they tend to relate to us differently, they tend to relate just differently and it just can't be the same. I am more of my own way and other staffs are more of their own way.'</i> (Zarina)</p> <p><i>'I think most of them don't really like doing it. I think they'd be really really happy if they could just sit down and people do things for them.'</i> (Zarina)</p> <p><i>'Parents like you know, like they are kids, we need to babysit them whereas it's difficult for them to understand that they've got what we call choice and rights and you know, we could just prompt and say things but if they say, I'm not doing it I'm not doing it and there's just nothing we can do.'</i> (Zarina)</p>
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	Persecution and protective positions	Protection	<p><i>'if I say, private and confidential you don't have to like, for example what you see here you have to take it out and tell your friends. This person is not suffering from this, this and this. Doesn't want this, doesn't need this, wants this and this. You have to keep it to yourself... You have to be trustworthy, for example you can go out with someone, they might give you money to buy some stuff, some people they misuse the money, you know. You have to be trustworthy. You have to be careful.'</i> (Emeka)</p> <p><i>'I read it in the newspaper, in the news. Some people they misuse. For instance, money, which is not good... I think it makes you aware that something happened out there. Of which it was not supposed to be done... you have to be careful yourself as well.'</i> (Emeka)</p> <p><i>'I read it in the newspaper, in the news. Some people they misuse. For instance, money, which is not good... Once, in the end if you get sacked I don't think you can get another job somewhere else. Because CRB I don't think you can get it here.'</i> (Emeka)</p> <p><i>'For example, if you see someone treating a client bad, then you have to tell them straight away. Or you have to be careful yourself as well.'</i> (Emeka)</p> <p><i>'If you see something goes wrong you have to tell the person straight away. Before you report it to... umm the manager, or to the team leader. If you see someone doing wrong things, just talk to the person straight away.'</i> (Emeka)</p> <p><i>'I want to protect them to some degree.'</i> (Caroline)</p> <p><i>'I have even seen nearly a fight break out because you have got someone on the</i></p>
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		<p><i>street pulling stupid faces and shouting out horrible words like spastic, retard, vegetable, cabbage, I have heard some really horrible things and it is really really hard to fight that feeling you get when you just feel disappointed with the world and you feel really protective of the service users.’ (Caroline)</i></p> <p><i>‘You get no support at all with, because you are, here, unfortunately the other staff members, if you show a weakness, they are like vultures, they will like jump on that weakness. That’s how it got shown to me on the first couple of weeks being here so, the best thing you can is to try and show no weakness.... I suppose to some degree. That’s how everyone else seems to deal with it.’ (Caroline)</i></p> <p><i>‘Because we wouldn’t want any lapses. You know, outside our job. And we got a lot to think of. We got, you know, we got video, we got health and safety people. We got, we got inspectors, we got everybody, around us. It’s like err, people looking at us. So we wouldn’t want to let anybody down. So, that it’s self you know, gives us a kind of impression that you can’t just do otherwise. And it helps us.’ (Nnamdi)</i></p> <p><i>‘Maybe... I wouldn’t know, maybe there might be negligence. That’s why it is so important that people are checks.’ (Nnamdi)</i></p> <p><i>‘Because you have got to do your job and you must do it properly, there is not way, it mustn’t, if you are meant to do that, and because we are looking after people, if there is an negligence somewhere it could effect.’ (Nnamdi)</i></p> <p><i>‘It is so important because, even when they go out, when you take them out, for maybe activities out there. I believe the way they see them, it’s you. Do you understand? The way they see them, if I should go out with service user in a wheel chair, and I am there, the way they look, is the way I do. So I want to look out in my best way, so that people will see me and be able to relate to me. And you know, I</i></p>
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		<p><i>will be able to meet people out there, so that's why it's so important to me. And the health aspect is very important. There is no looking good, no LD, that means something is wrong with me as well.'</i> (Nnamdi)</p> <p><i>'Umm, the safety is the most important part. Umm, to protect them [residents] from abuse and harm. Umm, protect myself at the same time.'</i> (Francesca)</p> <p><i>'You hear and you see on the telly so much abuse still happening in homes and it's unbelievable that it is still goes on.'</i> (Francesca)</p> <p><i>'And we have so many checks and safeguards in place to stop them even walking down the street getting bullied from kids calling them names and you know'</i> (Francesca)</p> <p><i>'You have to make sure that the whole place is clean, yeah. Just everything is in place just not to have any accident so you make sure it's, that is done but [short pause] we don't obstruct ways and corridors, no. It' no no no no [emphasis]'</i> (Habika)</p> <p><i>'Well it's, it's if something is going wrong here they have to write it down and at the same time talk about it verbally, yes.'</i> (Habika)</p> <p><i>'Well we do their, we look after their money and we have receipt you have to account for everything on paper, yeah, that's important to keep a log of it all.'</i> (Habika)</p> <p>Int: <i>How have you found kind of [charity] as an organisation?</i> Habika: <i>Every company has got ups and downs but so far as I'm here to pay my mortgage [Leon laughs] yeah.</i></p>
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		<p>Int: <i>What kind of organisation are they? How do they kind of support or what are the kinds of ups and downs?</i></p> <p>Int: <i>Well [pause] no well I will leave that out [laughs] yeah I will leave that out... No I don't want to talk about that.</i></p> <p><i>'so they think it's our fault but you know we've got the books to show them, we have said this and we have reminded' (Zarina)</i></p> <p><i>'we really do try our best and I know it's difficult to really communicate to an external one hundred per cent but we really really do' (Zarina)</i></p>	
		<p>The circulation of blame</p>	<p><i>'Yeah all the top doctors, when you speak to people who are higher up in the professions, they try and come across with best intentions, but sometimes it's best of intentions but worst of outcomes.'</i> (Caroline)</p> <p><i>'But it's just very irritating when you are working with someone you have to tell four or five times over and over again the same thing, you know it should be done like this... I feel that strongly that it should be done in the correct way or it should be done in a different way as opposed to it is being done at the moment... Because he is just too pig-headed ignorant to actually listen to what someone else is trying to tell him.'</i> (Caroline)</p> <p><i>'We had an argument this morning, we shouldn't have argument in front of residents, in front of anyone, but yet he started shouting in the hall way. So... fair enough you want to shout at me go ahead, it's not going to change anything, simple as that. If you want to put in a complaint about me, feel free, that's what I am doing about you. So... unfortunately its just something I had to do today, it's just irritating knowing when you just go through it over and over again. Because he is</i></p>

		<p><i>just too pig-headed ignorant to actually listen to what someone else is trying to tell him.'</i> (Caroline)</p> <p><i>'Everything comes down to money. And they [government] promote independence, rights of choices, when the bottom line is, if it comes down to money, all umm... the choices go out the window.'</i> (Anne)</p> <p><i>'They [staff members] go well, they live here because they have a learning disability. And I say, yeah [condescending tone], then they go yeah but bla bla bla, but do they have to do so and so? And I say 'yeah its part of their daily routine that's what they do'... and some staff you have to keep reminding them that. And you sometimes wonder who has got the LD, the staff or the client? [laugh]'</i> (Anne)</p> <p><i>'But it's basically because there is a clash that's noticed and that client might not like that person, so you have to do what's right for the client. They don't, they do understand that now... taken them a while [sarcastic tone]'</i> (Anne)</p> <p><i>'You tend to tell the GP what's wrong with your client, rather than the other way around [laugh]. Just to get the medication that you think that they need and to be honest 99% of the time you are right because you know their traits or it's an obvious thing. The consultants it's very hard because a lot of them, like you, have just come out of university with all the new ideas, and all the new plans, and let's try this, but it doesn't work.'</i> (Francesca)</p> <p><i>'A GP is a GP, and they are what they are, they are general practitioners they are not advances in learning disabilities, Umm the dietician is a dietician, again is not advanced in learning disabilities. Umm, the consultants... the learning disability consultants they are, but then they are not qualified in general medicine.'</i> (Francesca)</p>
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			<p><i>'I have fallen out with several members of staff because my standards were slightly higher than theirs and I believed that they were quite lazy.'</i> (Francesca)</p> <p><i>'My family are all medical. Umm... and whenever someone was ill the whole family sort of chip in and help whereas a lot of people haven't got, live a busy lifestyle nowadays they have carer's come in. My family would not ever have carers come into to look after the members. We all just muck in and help out.'</i> (Francesca)</p> <p><i>'Parents like you know, like they are kids, we need to babysit them whereas it's difficult for them to understand that they've got what we call choice and rights and you know, we could just prompt and say things but if they say, I'm not doing it I'm not doing it and there's just nothing we can do, absolutely nothing, for example they've got their rooms, most of them have to go over their rooms and make their beds or and we could just tell you, don't forget you need to go over your room once in a week and if he says or she says, I'm not doing it, they are not doing it and if their sisters or their Mother comes in and it's not tidy, so they think it's our fault.'</i> (Zarina)</p> <p><i>'I just feel there should be training for family members as well if they could go to some of this refresher courses and I think it would be better for them to understand that you know things have actually changed'</i> (Zarina)</p> <p><i>'It's just like you know, this is what is happening now [laughs] it's, it's beyond me to-to do anything else or I just can't, this is what this is what it is, the government has done'</i> (Zarina)</p> <p><i>'OK their ages are like fifty and above and their Mums could be like eighty and above so it's really, it's as if you are dealing with two residents.'</i> (Zarina)</p>
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APPENDIX 8**Appendix 8 – Table of recurrence of themes**

Superordinate Themes	Main Themes	Sub-themes	PARTICIPANTS						
			1	2	3	4	5	6	7
Emotional Motivation	Personal Fulfilment and Motivation	Pleasure in the role		✓	✓	✓	✓	✓	✓
		Tensions of 'ideal' versus 'insincere' care		✓	✓	✓	✓	✓	✓
	The Emotional Struggle	Powerlessness and the emotional reaction to injustice	✓	✓		✓	✓		✓
		The relentless nature of struggles		✓		✓	✓		✓
Demands and Coping	Safety and Conflict within Coping	Constricted and un-elaborative	✓		✓	✓		✓	
		The conflict of balancing multiple expectations			✓	✓	✓	✓	✓
	Persecution and Protective Positions	Protection	✓	✓	✓		✓	✓	✓
		The circulation of blame		✓		✓	✓		✓