

THE UNIVERSITY OF HULL

The Caring Experience of Staff Carers Working with Adults with Learning Disability  
and Dementia

Being a Thesis submitted for partial fulfilment of the requirements for the Degree of

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By

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## **Overview**

This Portfolio Thesis consists of three parts, the first being a Systematic Literature review entitled 'A Systematic Review into the Factors that Affect the Experience of Residential Staff Caring for Adults with Learning Disability: a United Kingdom Perspective'; the second is an empirical paper entitled 'The Caring Experience of Staff Carers Working with Adults with Learning Disability and Dementia'; and the final part is the Appendices.

Part One: The Systematic Literature Review examines the factors that affect the experience of staff carers working with adults with learning disability within the United Kingdom, as reported by published research. A systematic search of the literature was conducted. Four databases were searched and 13 papers were found that met the inclusion and exclusion criteria that were set out by the researcher. The findings of these papers are set out within the review as well as a discussion of the limitations of these papers and the impact they may have on clinical practise.

Part Two: The Empirical Paper reports the findings of a qualitative study into the experience of care staff working with individuals with both a learning disability and dementia. Interviews were conducted with nine participants and then interpretative phenomenological analysis was used to analyse the transcripts of these interviews. The themes identified during this analysis are discussed, along with how these themes link to previous studies, the clinical implications of the findings, the limitations of the study and future areas for research.

Part Three: The Appendices contains additional information for the Systematic Literature Review and the Empirical Paper as well as a Reflective Statement.

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### **Word Count**

Systematic Literature Review: 9,755 (excluding references)

Empirical Paper: 7,248 words (excluding table, figures and references)

Total Portfolio: 40, 563 words

**Part One**  
**Systematic Literature Review**



**A Systematic Review into the Factors that Affect the Experience of  
Residential Staff Caring for Adults with Learning Disability: A United  
Kingdom Perspective**

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## **Abstract**

This review examines the factors that impact on the caring experience of staff carers working in the United Kingdom, caring for adults with learning disability (LD). A systematic search of four databases was conducted, and through this process 13 papers were identified that met the inclusion and exclusion criteria. The papers suggest that there is strong evidence that the level of challenging behaviour experienced by staff carers impacts on this caring experience. Modest evidence for: the personality trait of neuroticism, an individual's coping style, the availability of resources, training provision, role clarity, job security, pay scale and the amount of perceived reciprocity within relationships and available support; and inconclusive findings as to the impact of the four other personality traits, job role (manager or not) and perception of the organisation. The limitations of the literature are: variability between samples used and inconsistency in reporting the characteristics of participant samples, variation in the outcome used to measure the impact of the chosen factors, and an over-reliance on cross-sectional correlational designs.

*Keywords: Staff Carers, Learning Disability*

## **Systematic Review into the Factors that Affect the Experience of Residential Staff Caring for Adults with Learning Disability: A United Kingdom Perspective**

Over the years there has been an increase in the number of people employed by the NHS and the private sector as staff carers (National Health Services, 2009). These individuals play a vital part in the lives of the people they support (Felce & Emerson, 2001) as the research literature suggests that staff carers' behaviours directly affect the quality of life of the people they care for (Felce & Emerson, 2001). Along with this it is also suggested that their behaviour can have a more indirect affect on service users, through absenteeism and turnover, which impacts on organizational efficiency (Jacobson et al, 1996; Raiger, 2005). This can affect continuity of care as well as the skills and level of experience available within the work force (Hatton et al, 1999a; Hatton et al, 1999b). As a result there is an expanding literature on the caring experience of direct staff carers (Hatton & Emerson, 1993; Sharrard, 1992; Stenfert-Kroese & Fleming, 1992).

### **Stress and Burnout in Staff Carers**

Burnout has been defined as 'a persistent, negative, work-related state of mind' (Schaufeli and Enzmann, 1998, pg. 36), which manifests as exhaustion, distress, a tendency to depersonalize others and a reduced sense of personal accomplishment (Maslach, Schaufeli, & Leiter, 2001). It is thought to be the result of prolonged exposure to stressors at work (Schaufeli & Buunk, 2003) and the literature suggests that it can lead to deterioration in care provision and reduced quality of life for the carer (Courtenay, Jokinen & Strydom, 2010) as well as having a negative economic impact on the service as a result of absenteeism and turnover

(Jacobson et al, 1996; Raiger, 2005). As a result there is developing research into these stressors as potential factors that might affect staff carer's experience of caring. Stressors can be defined as either personal or external (Dyer & Quine, 1998).

### External Factors

Organisational factors such as role demand and training, along with the support received by individuals and their relationships with others can all be considered external stressors (Hatton et al, 1999b). A lack of social support has been shown to reduce staff carer's ability to cope with work-related stress (Lees & Ellis, 1990), as well as reducing the individuals confidence, collegiality and understanding of their own and others emotional reactions (Frost et al, 1991).

When considering factors related to service users, challenging behaviour has been suggested to be one of the most significant sources of staff carer stress (Bersani & Heifetz, 1985; Corrigan, 1993). With the literature suggesting that the more staff carers are exposed to challenging behaviour the more they are at risk of stress and/or burnout (Freeman, 1994; Hastings & Brown, 2002).

### Personal Factors

Health psychology research suggests that personality traits play a role in predicting carer's experience of stress or burnout (Vollrath, 2006). This is linked to Lazarus and Folkman's (1984) theory of Cognitive Appraisal. This theory suggests that an individual's personality affects how they perceive threat as well as their subsequent emotional and physiological reactions; in short, how stressful they find a situation (Vollrath, 2006; Suls & Martin, 2005). The healthcare research has now sought to broaden this concept investigating the relationship between stress and

other concepts of personality, including the five factor model (neuroticism, extraversion, openness to experience, agreeableness, conscientiousness) (Costa & McCrae, 1992).

Research looking into the experience of nurses found that those high in neuroticism and low in agreeableness had a higher chance of experiencing burnout (Vlerick, 2001). While high conscientiousness (associated with positive emotional affect) appeared to predict lower levels of burnout (Zellars, Perrewe, Hochwarter & Anderson, 2006). These findings suggest that different personality traits predict burnout differently (Zellars, Hochwarter, Perrewe, Hoffman & Ford, 2004).

### **Positive Experiences of Caring**

Research has also begun to develop investigating the other side of caring, looking into what factors contribute to a positive caring experience and its associated rewards (Grant, 2001). At this stage most of this research has been focused on *family* carers in the dementia literature (Toseland, Smith & McCallion, 2001) and the learning disabilities (LD) literature (McCallion & Toseland, 1993).

A large scale research project was conducted in the United States of America (specifically in Miami, Florida and Northern California) called the REACH (Resources for Enhancing Alzheimer's Caregiver Health) project (Coon et al, 2004). This project aimed to look at culture and ethnicity as mediating factors for those caring for a family member with dementia (Coon et al, 2004). This research compared multiple ethnicities on their well-being; appraisal of stress and caring benefits; and religiosity (Coon et al, 2004).

Multiple papers were published as a result (e.g. comparing Caucasian and Latino carers; comparing Caucasian and African American carers) and when these results are considered together it has been shown that *family* carers from ethnic

minorities are more likely to experience adaptation (Coon et al, 2004). Specifically they are more likely to report lower appraisals of stress, greater perceived benefits of care giving, and greater use of religious coping when compared to their Caucasian counterparts (Coon et al, 2004). The hypothesised theory for why this is the case is that within these cultures individuals are more likely to expect to look after the elderly; it is viewed as a duty (Lawrence, Murray, Samsi & Banerjee; 2008). In Western Caucasian culture this not expected in the same way and hence caring for those with dementia is often viewed as a burden, which makes adaptation less likely (Lawrence et al, 2008).

This interest in positive caring experience is echoed within the research around *family* carers for people with LD (again there is a focus on *family* carers). This literature has indicated that a positive experience of caring is more likely than it was previously thought (McCarron & McCallion, 2005; Grant, 2001). *Family* carers in this situation, particularly mothers looking after an adult child with an LD, report higher morale, better health, more social support, less subjective burden, and more effective coping strategies- in contrast with those caring for an adult with a mental illness (McCarron & McCallion, 2005; Grant, 2001).

Although interest is growing the literature base for positive experience of caring appears to be comparatively small and focused on *family* carers. Although there is some research into the mediating factors for the experience of staff carers. Studies have looked at factors commonly linked to stress such as poor organisational situations and lack of support. They have then investigated whether these factors can also act as mediators to work place stress and burnout. It has been found that personal coping (Schaufeli & Buunk, 2003) and social support (Stenfert-Kroese & Fleming, 1992) can both play a part.

Stenfert-Kroese and Fleming (1992) found that support from colleagues and their immediate manager are important mediators of levels of stress for staff in

community facilities. This finding is reflected in a model of staff stress in residential settings which was proposed by Rose and Rose (2005). The model incorporates the concept of support as a mediating factor for residential staff's experience of stress or burnout (Rose & Rose, 2005).

Literature also indicates that positive organisational factors may also have mediating role in staff's experience of stress (Kane, 2001). The organisational culture change research indicates that the physical characteristics of the setting, level of training, level of experience and sufficient support of the autonomy of staff members, all appear to act as mediating factors for stress among staff delivering long term care (Kane, 2001).

### **Current Review**

With the introduction of the Valuing People (Forbat, 2006) changes have occurred in the provision of service and the social policy for people with LD. For instance it reinforced the objective to move people from long-stay hospitals to community settings, promoting choice and control over living arrangements for the individual with LD. As a result services are more often community based changing the environment and the type of staff carers required to deliver appropriate care. Staff carers now play a vital role in enabling individuals within the community and evidence suggests that carers working with this population are susceptible to workplace stress and burnout (Skirrow & Hatton, 2007). Consequently, there has been a growing interest in the nature of the stress experienced by carers working in this area and as yet a systematic review of the literature investigating the factors affecting the caring experience of staff working with this population has not been conducted.

Reviews have to date been more specific looking at the impact or organisational factors on burnout (Thompson & Rose, 2011) or reporting the levels and correlates of burnout within this population (Skirrow & Hatton, 2007). So a broader look at research into all factors contributing to the overall experience, positive or negative, of staff carers working with adults with LD will be the focus of this review. The literature clearly indicates that the experience of staff carers affects not only the carer, but also the economic state of the service and the quality of life of the service users. This review aims to contribute to the literature by highlighting the factors that may impact, positively or negatively, on the caring experience of staff carers working with adults with LD within the United Kingdom (UK).

## Method

### **Data Source and Search Strategy**

Electronic databases were used to search the literature available up to and including April 2012. The databases CINAHL, Medline, PsychINFO and Web of Science were searched for relevant articles. These databases were chosen so that a range of disciplines that may conduct research in the area of caring for individuals with LD were covered.

The search terms used were adapted during initial searches, so as to include keywords used in relevant studies. The final search terms used were:

*(Staff OR Health Personnel OR Support Worker OR Health Professional)  
AND Care\* AND (Experience\* OR View\* OR Perception\* OR Account\*OR  
Stress\* OR Burnout OR Reward\* OR Positive OR Negative) AND (Down\*  
Syndrome OR Intellectual Disab\* OR Mental Retardation OR Intellectual\*  
Impair\* OR Mental\* Handicap\* OR Developmental Disab\* OR Mental*



*Deficien\* OR Learning Disab\*) AND (U.K. OR United Kingdom OR Britain OR Wales OR Scotland OR England)*

These terms were then entered into each of the databases used for this review. The titles of all the articles found were then reviewed, discarding all those that were not relevant. Those that had a relevant title then had the inclusion and exclusion criteria applied to their abstract. Full copies of the studies that met the inclusion criteria and none of the exclusion criteria were then obtained. If at this stage there was any uncertainty in regards to the suitability of the article a full copy of the study was requested. These articles retrieved were hand searched to include articles not found during the database searches. A full copy of the study was obtained if an article was thought to be relevant. All the complete articles obtained were then reviewed and any found to be inappropriate were removed.

Although reviews were not included in the chosen studies a search was conducted to ensure a similar review had not already been completed. This additional search did not find any similar reviews.

### **Study Selection Criteria**

The articles selection criteria were refined during the process of reading article abstracts. The studies included in the review had to meet all Inclusion criteria and meet none of the Exclusion criteria which can be seen in Fig. 1, with rationale provided in Appendix D.

Both quantitative and qualitative papers were included as there was a paucity of papers available. Also on reviewing the full articles, the two papers using qualitative design reported findings that linked to the quantitative papers, illustrating that the quantitative factors investigated could fit within the reported experience of staff carers, thus adding greater depth to the reviews findings.

<p>Inclusion Criteria:</p> <ul style="list-style-type: none"> <li>• Participants are adults (aged 18yrs+)</li> <li>• Participants are caring for an adult aged 18 years+ with a recognised LD</li> <li>• Participants are employed within a residential home with the job title Carer or Support Worker and receive pay for their work.</li> <li>• Papers which focus on the carer's experience of caring and/or what may impact on the carers experience</li> </ul> <p>Exclusion Criteria:</p> <ul style="list-style-type: none"> <li>• Literature reviews and book reviews</li> <li>• Focus on participants caring for an adult aged 18 years+ with a recognised LD and additional diagnosis such as Mental Health problems and Substance Abuse</li> <li>• Papers not written in English</li> <li>• Research conducted outside of the United Kingdom</li> <li>• Papers which are not peer reviewed</li> <li>• Participants who work in: <ul style="list-style-type: none"> <li>➤ a forensic setting</li> <li>➤ non-residential services</li> </ul> </li> </ul>
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*Figure 1- Inclusion and Exclusion Criteria*

### **Details of Included and Excluded Articles**

Figure two illustrates the article selection process. From searching the databases 386 articles were identified, title and abstract searches eliminated 344 articles that were not eligible for this review. The full texts of the 17 remaining articles were then reviewed in full, this lead to the exclusion of nine articles (Appendix C) based on the inclusion and exclusion criteria. Completing a hand search of the references of the remaining nine articles produced four further suitable articles; resulting in the 13 articles that are the focus of this review.

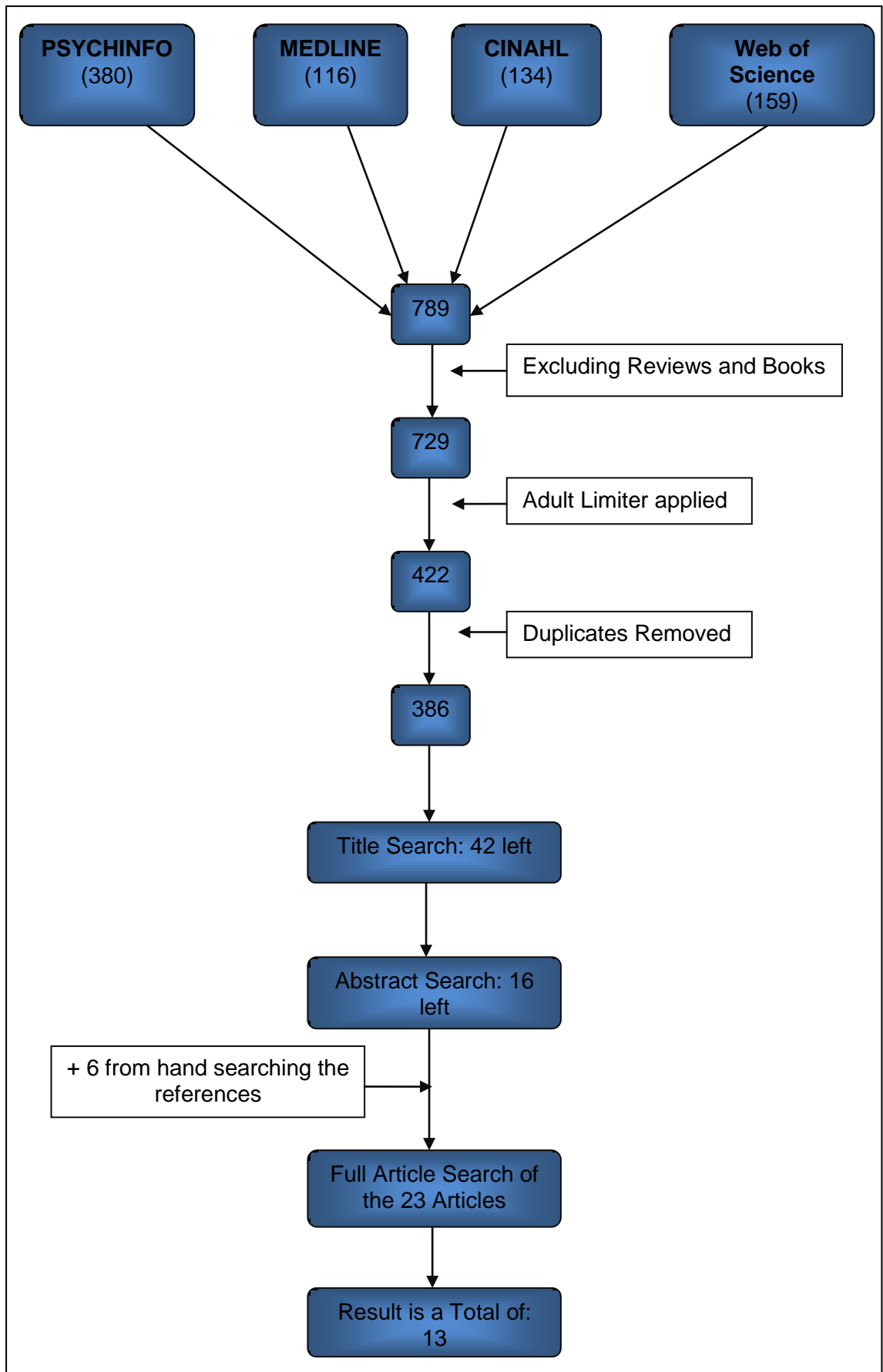


Figure 2- Article Selection Process for the Review

## **Data Extraction and Synthesis**

Data was extracted from the 13 studies discussed in this review using a template developed by the researcher (Appendix E). Then qualitative syntheses of the results were conducted, as there was too much variety within the papers of this review to conduct a meta-analysis. This is presented in Table 1.

## **Study Quality Assessment**

The quality of the 13 studies was assessed using a quality measure. This was not done in order to exclude articles from the review. The measure was designed by the researcher for the purpose of this review (Appendix F), in order to create a tool that could assess both quantitative and qualitative papers to allow for a better comparison of the papers considered in this review.

Two tools were considered and combined to create a measure, these were tools previously used by Downs and Black (1998) and National Institute of Clinical Excellence (NICE, 2007). Due to the nature of the quantitative papers, none evaluating an intervention, some of the Downs and Black (1998) questions were not appropriate for this review and were therefore excluded. Some of the NICE (2007) questions were also excluded due to appropriateness and to allow for the best combination of these two measures. The maximum score available for this measure was 22 and the scores can be seen in Table 1. Four of these papers were randomly selected and assessed using the quality measure by an independent reviewer. Inter-rater reliability was calculated and Cohen's Kappa was found to be 0.74, which is felt to be significant agreement (Landis & Koch, 1977).

## **Results**

### **Overview of Included Studies**

The characteristics of the 13 included studies can be seen in Table 1. Two of these studies used a qualitative approach, with one of these papers using Content Analysis and the other using Interpretative Phenomenological Analysis (IPA). The other 11 papers used a quantitative approach with a cross-sectional design. One paper focused on managers of residential services for adults with LD, two papers recruited both managers and direct residential staff, but made no distinction between the groups, and one paper recruited both groups in order to make a comparison. The remaining papers (N=9) recruited just direct care staff or chose not to report the nature of the job role of their sample. All 13 papers reported a female dominated sample, which is most likely a reflection of the staff carer population (McConkey, McAuley, Simpson & Collins, 2007).

Table 1- Characteristics of the Studies

Author and Date	Aims of Study and Study Design	Measures Used	Key Characteristics of Participants and Service	Findings	Quality Rating (Second Scorer)
Blumenthal, Lavender and Hewson (1998)	<p>The aim of the research is to:</p> <ol style="list-style-type: none"> <li>1. Investigate the relationship between role clarity, organisational perception and burnout</li> <li>2. To look at the difference between charitable companies and an NHS trust</li> </ol> <p>Cross-sectional design</p>	<ol style="list-style-type: none"> <li>1. Role Clarity and Perception of Organisation Questionnaire (researcher created)</li> <li>2. Maslach Burnout Inventory (MBI, Maslach &amp; Jackson, 1986)</li> </ol>	<p>101 participants (55 charity; 51 NHS)</p> <p>Eleven Group homes (6 NHS, 5 Charitable)</p> <p>All nurses or nursing assistants</p>	<ol style="list-style-type: none"> <li>1. No difference <i>between services</i> on; role clarity, or on depersonalization (DP) and Personal accomplishment (PA) as factors of burnout</li> <li>2. Inverse relationship between role clarity and burnout</li> </ol>	19/22
Chung and Harding (2009)	<p>The aim of this research is to Investigating the effect of the five personality traits on burnout and well-being in staff working with people with LD and challenging behaviour</p> <p>Cross-sectional design</p>	<ol style="list-style-type: none"> <li>1. The Aberrant Behaviour Checklist (Aman, Singh, Stewart &amp; Field, 1985; Newton &amp; Sturmey, 1988).</li> <li>2. MBI (Maslach &amp; Jackson, 1986)</li> <li>3. The GHQ-28 (Goldberg &amp; Hillier 1979)</li> <li>4. NEO-Five Factor Inventory (Costa &amp; McCrae, 1992)</li> </ol>	<p>103 participants were recruited; average age of 38 years (SD = 10.97); 70% Female, 30% Male;</p> <p>Recruited from 13 homes in 2 cities (5, 52 city 1; 8, 51 city 2)</p> <p>Over half were married and just over one-third were single. The rest were separated/divorced or widowed.</p> <p>15% had some basic national vocational training qualifications; 20% were qualified nurses.</p> <p>The average length of time working in the area of LD was 8 years (SD = 7.56).</p> <p>They had been working in the homes, on average, 5 years (SD = 4.81).</p>	<ol style="list-style-type: none"> <li>1. The more challenging behaviour (CB) experienced by staff, the more they experienced emotional exhaustion and the less they felt a sense of personal accomplishment</li> <li>2. There was no significant relationship between psychological well-being and CB.</li> <li>3. Personality traits appear to affect stress (burnout levels) and well-being of staff carers (confirms previous research). With the relationship between CB and burnout, in particular, emotional exhaustion and personal accomplishment, seeming to be moderated by agreeableness, neuroticism and extraversion.</li> </ol>	20/22 (20/22)

<p>Elliott and Rose (1997)</p>	<p>The aim of the research is to examine the stress experienced by managers of community homes for people with LD in relation to the social support model (Rose; 1995)</p> <p>Cross-sectional design</p>	<ol style="list-style-type: none"> <li>1. Powell's Questionnaire (Powell, 1992)</li> <li>2. Likert scales looking at areas of Stress and Support (Researcher designed)</li> </ol>	<p>Average of 8.1 years as a care worker and 2.6 years as a manger</p> <p>Average of 3.8 residents supported, 4.2 full time staff supervised and 4.6 part time staff (11.5 staff in total)</p>	<ol style="list-style-type: none"> <li>1. Reported levels of stress appear to be relatively low</li> <li>2. The pressures on manager's increase as the staff groups get larger.</li> <li>3. Managers are developing different coping strategies to direct-care staff.</li> </ol>	<p>14/22</p>
<p>Hatton, Brown, Caine and Emerson (1995)</p>	<p>The research aims:</p> <ol style="list-style-type: none"> <li>1. To provide descriptive information concerning direct care staff in two networks of staffed houses for people with LD</li> <li>2. To explore the relationship between potential stressor, coping strategies, perceived work stress and emotional distress, and the impact of stress on direct care staff work performance, social life and personal relationships.</li> </ol> <p>Cross-sectional design.</p>	<ol style="list-style-type: none"> <li>1. Demographic Characteristics</li> <li>2. Work Related Sources of Stress- Researcher created using 18 items drawn from Bersani and Heifetz (1985) and 10 items were drawn from Cooper and Marshall (1976).</li> <li>3. Client Related Sources of Stress- Researcher created, 10 item, 4 point likert scale, drawn from Bersani and Heifetz (1985)</li> <li>4. Shortened ways of Coping Questionnaire- Hatton and Emmerson (1995)</li> <li>5. The Malaise Inventory (Allen et al, 1990)</li> <li>6. Work Stress- Researcher created, single item, 4 point Likert scale</li> <li>7. Impact of Stress on Lifestyle- Researcher created, three item, 4 point likert scale</li> </ol>	<p>68 participants were recruited (33 from Network One, 35 from Network 2)</p> <p>Participants were recruited from two Networks from the same city; Network One- Voluntary agency, Network Two- Statutory agency</p> <p>Network One: average age 38 yrs</p> <p>Network Two: average age 34 yrs</p> <p>Network One: 82% Female;18% Male</p> <p>Network Two: 71% Female; 29% Male</p>	<ol style="list-style-type: none"> <li>1. Violent behaviour of service users, emotional impact of working with LD, difficulty combining the demands of work and other areas of staff's lives, uncertainty over job tasks and limited opportunities for personal advancement were reported as stressors.</li> <li>2. There is an indication that workplace stressors impact on the lifestyle of direct care staff outside of the work place.</li> <li>3. 'Wishful thinking' appears to mediate the relationship between stressors and emotional distress.</li> <li>4. Conflicts in an individual's personal life were the most crucial determinant of <i>distress</i> levels in direct care staff. But <i>stress</i> is affected by stressors and outcomes at work rather than an individual's personal life.</li> </ol>	<p>16/22</p>

<p>Jenkins, Rose and Lovell (1997)</p>	<p>The aim of the research is to:</p> <ol style="list-style-type: none"> <li>1. Investigate to what extent staff perceptions of challenging behaviour influence their psychological well-being?</li> <li>2. Investigate if expert opinion in the presence of challenging behaviour be used to predict psychological well-being?</li> <li>3. Investigate the relationship between staff and psychological well-being; and between resident characteristics and staff support, as well as looking at how these relationships interact with each other?</li> </ol> <p>Cross-sectional design</p>	<ol style="list-style-type: none"> <li>1. AAMR Adaptive Behaviour Scale- Residential and Community (Nihira, Leyland &amp; Lamben, 1994)</li> <li>2. The Checklist of Challenging Behaviour (Harris, 1993)</li> <li>3. Demands of Job Questionnaire (Rose, 1993)</li> <li>4. The Thoughts and Feelings Index (Fletcher, 1989)</li> <li>5. The Staff Support Questionnaire (Harris &amp; Thomson, 1993)</li> <li>6. Staff Perceptions of Challenging Behaviour (researcher designed) – One question, used only to assign to CB or non CB group</li> </ol>	<p>78 participants; 32.5% Male; 67.5% female; recruited from 14 houses</p> <p>59% of the staff members recruited were care staff or support staff, 14.6% were managers, 18.3% were deputy managers and 8% were relief staff.</p> <p>40 residents lived in the 14 houses. Their ages ranged from 26 to 71 years, with a mean age of 46.7 years. There were 19 female residents (47.5%) and 21 male residents (52.5%).</p>	<ol style="list-style-type: none"> <li>1. It appears that challenging behaviour (CB) can predict staff stress; and staff support can mediate the relationship between work based stressors and the experience of stress. <ul style="list-style-type: none"> <li>• The staff in the CB group reported feeling less supported, had lower job satisfaction and were significantly more anxious than the non CB group.</li> <li>• Level of staff support was the best predictor of depression</li> </ul> </li> </ol>	<p>17/22</p>
<p>Mills and Rose (2011)</p>	<p>The research aims to:</p> <ol style="list-style-type: none"> <li>1. To investigate the relationship between burnout and cognitive variables (causal attributions, general perceptions, beliefs and emotions)</li> <li>2. To confirm the relationship between high levels of challenging behaviour and high levels of burnout.</li> <li>3. To investigate whether cognitive variables act as a mediator in the relationship between challenging behaviour and burnout.</li> </ol>	<ol style="list-style-type: none"> <li>1. Checklist of Challenging Behaviour (Harris, Humphreys &amp; Thomson, 1994)</li> <li>2. MBI (Maslach &amp; Jackson, 1986)</li> <li>3. Challenging Behaviour Perception Questionnaire (Williams &amp; Rose, 2007)</li> <li>4. Controllability Beliefs Scale (Dagnan, Grant &amp; McDonnell, 2004)</li> <li>5. Fear of Assault (Rose &amp;</li> </ol>	<p>77 participants; average age 37 years (18-62 years); 29.87 Male and 70.13% Female;</p> <p>All staff recruited from 6 homes in central England.</p> <p>Average time worked with LD: 101 months (3-387)</p> <p>Average time in current job: 62 months (3-279)</p>	<ol style="list-style-type: none"> <li>1. The higher the level of challenging behaviour (CB) reported by staff, the higher the burnout reported and greater fear of assault</li> <li>2. The cognitive variables of: perceived consequences, perceived control, emotional representation, and fear of assault were the only variables to significantly correlate with burnout.</li> <li>3. Fear of assault act as a mediator in the relationship between CB and burnout.</li> <li>4. No relationship was found between length of experience and reported burnout.</li> </ol>	<p>17/22</p>



Cross-sectional design.		Cleary, 2007)			
Raczka (2005)	<p>The aim of the research was to gather information from direct care residential staff regarding their experience of stress when working with people with LD and challenging behaviour; using focus groups.</p> <p>Qualitative, Content Analysis Design.</p>	<p>Qualitative, content analysis.</p> <p>Thus used semi-structured interview for focus groups.</p>	<p>19 participants were recruited from three care homes (supporting 7-9 residents)</p> <p>Participants had, on average: Worked in home: 1yr 11 (1mth - 9yrs); Worked as carer: 5yr 2 (1mth -10 yrs); Worked in home &lt; 3 yrs 84%; Worked as carer &lt;6 yrs 78%</p>	<p>Theme 1: 'What kind of challenging behaviours have you experienced working in your residential care setting?</p> <p>Theme 2: 'How did you feel when you were involved in a challenging episode when a resident was aggressive towards you?'</p> <p>Theme 3: 'What are some of the longer term consequences of working with challenging behaviour settings on your emotional wellbeing?'</p> <p>Theme 4: 'What ways do you think that services could be improved?'</p> <ul style="list-style-type: none"> <li>• Staff members were exposed to high levels of work-related stressors and reported emotional responses related to stress. Some met the diagnostic criteria for PTSD.</li> <li>• The findings suggested that staff used 'wishful thinking' coping strategies.</li> </ul>	14/22 (12/22)
Robertson, Hatton, Felce, Meek, Carr, Knapp, Hallam, Emerson, Pinkney, Caesar and Lowe (2005)	<p>The research aims to collect descriptive data on levels of staff stress, strain, emotional distress, job satisfaction and intended job turnover in two <i>different</i> community based residential services for people with LD and challenging behaviour (Congregate and non-congregate)</p> <p>Cross-sectional design</p>	<ol style="list-style-type: none"> <li>1. Background Details (researcher designed based on the NHS Workforce Initiative Survey)</li> <li>2. Potential Sources of Stress (Researcher created based on the research of Hatton, 1999; factor analysed-shown adequate psychometric properties)</li> <li>3. GHQ-12 (Goldberg, 1978)</li> <li>4. 6 item job strain scale from</li> </ol>	<p>157 participants recruited (79 non-congregate and 78 congregate services); average age of 36 years (18-62 years); 73% Female; 27% Male;</p> <p>Participants were recruited from 32 different homes (18 non-congregate; 14 congregate) in England and Wales.</p>	<ol style="list-style-type: none"> <li>1. Participants showed a greater propensity to leave their employment; there were considerably more staff on fixed-term contracts; lower levels of emotional distress and sick leave; and higher job search behaviour than has been seen in previous research</li> <li>2. High levels of satisfaction were found for the immediate working environment; with the least level of satisfaction for rate of pay, opportunities for promotion, and management of the organisation.</li> </ol>	19/22 (19/22)

		<p>the NHS Workforce Initiative Survey ( Borrill et al, 1996)</p> <p>5. Intended Turnover: combining a two item measure of propensity to leave an organisation (Allen, Pahl &amp; Quine, 1990) and a one item measure of reported job search behaviour (Whybrow, 1994).</p> <p>6. 16 item work satisfaction scale from the NHS Workforce Initiative Survey (Hackman &amp; Oldham 1975)</p>		<p>3. Results suggests that the main drivers of intended turnover may not be related to the demands of working with CB, but to job insecurity and poor pay</p> <p>4. Few differences between the two settings.</p>	
Rose (1993)	<p>The research aims to investigate the difference in strain, demands, supports and constraints that influence staff in three types of residential staff caring for people with LD (hospital, community and group)</p> <p>Cross-sectional design</p>	<p>1. Researcher Constructed- Demands and support/constraints; rated via likert scale</p> <p>2. Thoughts and Feeling Index</p> <p>3. Demographic information</p> <p>4. Turnover Rates extracted from personnel records</p>	<p>139 participants were recruited (34 from a hospital setting, 74 from a community setting and 31 from a group home setting); all were NHS staff (all non-qualified and managed by qualified nursing staff)</p> <p>Participants were recruited from: One Hospital with 150 beds, three community units and eight groups homes</p>	<p>1. Medium size community units were the least stressful places for frontline care staff (compared to hospitals and groups homes).</p> <p>2. When comparing this data to previous research the group home and hospital staff's level of strain were similar. The community unit's levels of strain were lower.</p> <p>3. All three staff group perceived the greatest demand to be number of staff on shift and availability of resources/equipment.</p> <p>4. The least supportive factor perceived by all three staff groups was staff pay, with the role of other professionals and managers also rated low. A common supportive factor over the three groups was: knowing they were providing an essential service.</p>	14/22

Rose, David and Jones (2003)	<p>The aim of the research is to examine the relationship of personality, staff support and coping style on work stressors and psychological well-being.</p> <p>Cross-sectional design.</p>	<ol style="list-style-type: none"> <li>1. The Demands of Job Inventory (Rose, 1993)</li> <li>2. The Staff Support and Satisfaction Questionnaire (Harris &amp; Thomson, 1993)</li> <li>3. Eysenck Personality Inventory (Eysenck, 1988)</li> <li>4. The Shortened Ways of Coping Questionnaire-Revised (Lazarus &amp; Folkman, 1984)</li> <li>5. The General Health Questionnaire -12 (GHQ-12; Goldberg, 1978)</li> </ol>	<p>131 participants, Average age of 35; 58% Female, 42% Male.</p> <p>Employed by one independent charity (55 homes covering 5 geographical districts)</p> <p>89% cohabiting or married; 6% separated/divorced or widowed; 49% had dependants; 15% Managers; 96% received some training for their job.</p> <p>Average time employed in this type of work: 5.8 years (3 months to 28 years). In the current post the mean time was 3.2 years (3 months to 14 years).</p> <p>Mean number of hours: 36.64 (9-47 hours).</p>	<ol style="list-style-type: none"> <li>1. Staff members who reported many work based stressors and low levels of support were more likely to report higher stress levels. Although work based stressors and supports had little impact on psychological well-being.</li> <li>2. More 'wishful thinking' was linked to higher levels of stress; but no relationship between 'practical' coping and psychological well-being. Thus stress level determines coping style NOT coping style determine stress level.</li> <li>3. Neuroticism has a direct effect on psychological well-being and acts as moderator in the relationship between job demands and psychological well-being.</li> </ol>	18/22
Rose, Jones and Elliot (2000)	<p>The aim of the research is to examine the following hypotheses:</p> <ol style="list-style-type: none"> <li>1. Managers of group homes experience greater levels of stress than direct care staff</li> <li>2. Managers of group homes perceive higher levels of stressors than direct care staff</li> <li>3. Managers of group homes receive less support than direct care staff</li> </ol> <p>Cross-sectional design.</p>	<ol style="list-style-type: none"> <li>1. Areas of Stress and Support Questionnaire (researcher designed)</li> <li>2. Powell's Questionnaire (Powell, 1992)</li> <li>3. Thoughts and Feelings Index (Fletcher, 1989)</li> </ol>	<p>106 participants were recruited; 57 Managers and 49 Direct Carers; Direct care staff recruited from 10 of the homes where the managers were also surveyed.</p> <p>Managers recruited from South Wales only.</p> <p>M- Average years in profession: 9.73</p> <p>Average years as manager: 3.08</p> <p>DC- Average years in profession: 7.23</p>	<ol style="list-style-type: none"> <li>1. Managers reported significantly higher: levels of job satisfaction, ratings of work place stressors and levels of pressure than direct care staff</li> <li>2. Significant difference between managers and direct care staff on level anxiety, but not on level of depression.</li> <li>3. There were few significant differences in reported rating of sources of support between managers and direct care staff (except direct care staff reported significantly more support from their line manager than was reported by the managers who participated)</li> </ol>	15/22

3.49: Average no. of residents					
Thomas and Rose (2010)	<p>The aim of the research is to validate a proposed model by:</p> <ol style="list-style-type: none"> <li>Examining the relationship between reciprocity, burnout and emotional and physical withdrawal from the care that staff provide to service users</li> <li>Investigating the role of negative emotion and optimism as mediators in the relationship between burnout and helping behaviour.</li> </ol> <p>Cross-sectional design</p>	<ol style="list-style-type: none"> <li>Biographical Information (researcher designed)</li> <li>Global Reciprocity Measure (Van Horn, Schaufeli &amp; Enzmann, 1999)</li> <li>Specific Reciprocity Measure (Jeffcott, 2002)</li> <li>MBI (Maslach &amp; Jackson, 1986)</li> <li>Optimism Likert Scale (researcher designed)</li> <li>Helping Behaviour Likert Scale (researcher designed)</li> <li>Positive and Negative Affect Schedule (Watson &amp; Clark, 1984)</li> </ol>	102 participants; average age 39 years (19-63 years); 87.4% Female; 12.6% Male; 15 care homes were recruited from.	<ol style="list-style-type: none"> <li>Some staff experienced a lack of reciprocity in their relationships with the residents, their work colleagues and their employing organisation; with the largest imbalance in the relationship with residents.</li> <li>Lack of reciprocity in the relationships care-staff have with the service users, work colleagues and employing organisation is related to burnout.</li> <li>The strongest correlations between burnout and reciprocity were found with the relationship staff have with the organisation.</li> </ol>	20/22 (20/22)
Windley and Chapman (2010)	<p>The aim of the research is to discover how CTLD can best support the role of support workers by looking at:</p> <ol style="list-style-type: none"> <li>Support workers perception of their role</li> <li>Support workers perception of theirs and other's performance</li> <li>The value of training and its application to support workers</li> <li>Power relationships between support workers and service users, and between support workers and professionals</li> <li>Leadership and guidance available</li> </ol>	<p>Qualitative: IPA.</p> <p>Thus focus group using Semi-Structured interview</p>	8 participants; 5 women and 3 men; All White British, and recruited from one residential services,	<p><u>Theme 1- Values and Roles: Quality of Life, The Right Temperament &amp; Vulnerability</u></p> <p>Maximising quality of life was the primary aim with most favouring a 'facilitative' or 'care provider' role. Caring, empathy and the 'right temperament' were essential qualities for a staff carer.</p> <p>Participants saw service users as vulnerable.</p> <p><u>Theme 2- Skills Development, Management and Supervision: New Staff, Communication Skills, Training &amp; Role of Supervisor/Manager</u></p> <p>Lack of resources and risk management was reported as causing conflicts in their</p>	21/22

Qualitative IPA design

role.

Participants described trial and error as how new staff learnt, although training was valued.

Theme 3- Effective Working within Supported Housing: Role of CTLD

All valued input from the CTLD and felt the key to joint working was good communication. Maintaining interventions implemented by CTLD staff was often reported as an issue.

## Quality Assessment

Answers for each of the 11 questions on the researcher designed quality measure could either be: No (zero points), in part or unclear (one point) or Yes (two points). As a result the highest score that could be obtained was 22. The scores of the papers considered for this study ranged from 14 (Rose, 1993; Elliot & Rose, 1997; Raczka, 2005) to 21 (Windley & Chapman, 2010). Articles scored highest on the question measuring the extent to which adequate conclusions were drawn from the Results. This possibly reflects the fact that there was a clear link between the data and the conclusions which were plausible and coherent, with the clinical implication being clearly defined and alternative explanations and limitations being explored and discounted. The papers scored lowest on the questions measuring how the researchers addressed ethical considerations, with few papers sufficiently discussing these considerations and many not even mentioning them.

The paper by Windley and Chapman (2010), which achieved the highest score of 21 out of the possible 22, scored mostly two's throughout the measure. Only scoring one on one question, this was as there was no mention of a check to validate the researchers themes, such as a fellow researcher conducting a sample analysis. The strengths of this paper lay in the comprehensive consideration of context, clear aims; a clear rationale set out for the chosen methodology, rigorous analysis and clearly set out findings with appropriately drawn conclusions that were relevant to the aims of the research. This paper was also the only paper to sufficiently discuss ethical considerations (achieving a score of two).

The lowest scoring papers (Rose, 1993; Elliot & Rose, 1997; Raczka, 2005) attained scores of one on the majority of questions in the measure. This reflects the fact that these papers tended not to offer sufficient explanation or comprehensively set out information. For instance all these papers did not clearly set out the hypothesis of their research or provide a clear rationale for their chosen

methodology; also these papers did not comprehensively report participant, organisational and service user characteristics, or consider context bias. These three papers only achieved a score of zero on one question as none mentioned ethical considerations.

## **Main Findings**

Within the 13 papers considered in this review, a number of factors thought to affecting the caring experience of staff carers working with adults with LD are considered.

### Personality and Cognitive Variables

The two papers investigating whether aspects of personality have an impact on the caring experience of staff carers working with adults with LD, considered the five factors model (Costa & McCrae, 1992): neuroticism, extraversion, openness to experience, agreeableness, conscientiousness. Overall there was some consensus in results, particularly in regards to the impact of neuroticism. Rose, David and Jones (2003) found that neuroticism had a direct effect on psychological well-being and that it mediates the effect of job demands on psychological well-being. Similar findings were reported in the study conducted by Chung and Harding (2009). They reported that higher levels of neuroticism led to greater emotional exhaustion, poorer psychological well-being and a lower sense of personal accomplishment.

Chung and Harding (2009) also noted the impact of other personality traits. The findings indicate that more extraverted staff members experienced less emotional exhaustion and feel a greater sense of personal accomplishment. The study also reported that agreeableness, neuroticism and extraversion, mediate the relationship between challenging behaviour and elements of burnout (Maslach & Jackson, 1986).

Only one of the reviewed papers considered personal traits other than personality, and the impact they may have. This was the study conducted by Mills and Rose (2011), who investigated the relationship between burnout and other cognitive variables; including causal attributions, general perceptions, beliefs and emotions. The findings of this study were that; perceived consequences, perceived control, emotional representation, and fear of assault significantly correlate with burnout. Fear of assault was also reported as acting as a mediator between challenging behaviour and burnout.

### Coping Strategies

The type of coping strategies that staff carers implement was another factor investigated by the papers considered by this review. One of the papers to consider this was Rose et al (2003). This study investigated the impact of coping strategies on the caring experience of staff carers looking after adults with LD. The results show that staff who used 'wishful thinking' as a coping strategy reported higher levels of stress.

Hatton, Brown, Caine and Emerson (1995) reported similar findings within their study. Reporting that whether or not a staff member used 'wishful thinking' as a coping strategy, mediated the relationship between potential stressors in the work place and emotional distress. A further qualitative study, investigating the experience of staff carers working with adults with LD and challenging behaviour, was conducted by Raczka (2005). This study reported as part of the findings, that those staff reporting emotional experiences similar to stress appeared to be using 'wishful thinking' coping strategies.

### Challenging Behaviour



Challenging behaviour was the only resident characteristic considered by the articles within this review. The research conducted by Jenkins, Rose and Lovell (1997) investigated the impact of challenging behaviour on staff stress, by comparing a group of staff carers working with adults with LD and challenging behaviour, to a group of staff carers working with adults with LD and no challenging behaviour. The findings of the study suggest that challenging behaviour can predict staff stress, with staff in the group working with individual with challenging behaviour being significantly more anxious and reporting lower job satisfaction than those not working with challenging behaviour.

Raczka's (2005) qualitative investigation focused on the experience of staff carers working with adults with LD and challenging behaviour. The main findings of this study suggested that the staff carers who experienced high levels of challenging behaviour, reported emotional responses that could be interpreted as stress. Along with this it appeared that following a traumatic experience of challenging behaviour a number of the participants appeared to meet the diagnostic criteria for post-traumatic stress disorder.

Two papers looked specifically at the relationship between challenging behaviour and the concept of burnout. One of these studies was conducted by Mills and Rose (2011). They found that the higher the level of challenging behaviour reported by staff, the higher their reported level of burnout. This study's results also showed that higher levels of challenging behaviour correlated with high levels of fear of assault. However the direction of causality within this relationship is not known. The other research to consider burnout was conducted by Chung and Harding (2009). The findings of this study reported that the more challenging behaviour staff perceived, the more they experienced emotional exhaustion, and the less they felt a sense of personal accomplishment (factors of burnout; Maslach & Jackson, 1986).

### Support and Relationships

Thomas and Rose (2010) conducted some research into the impact on the caring experience of reciprocity within the working relationships of staff carers. Participants reported experiencing a lack of reciprocity in their relationships with service users, their work colleagues and their employing organisation. Stating that they felt they invested more in all three relationships than they received, with the largest imbalance being seen in their relationship with the residents. This lack of reciprocity across all three relationships was suggested to be related to burnout; with the strongest correlation between burnout and reciprocity seen when considering the relationship staff have with the organisation.

Windley and Chapman's (2010) qualitative research also found that staff reflected on their relationships and available support when discussing their experience of caring. Participants felt that the relationship between themselves and service users played a significant part in how effective the care they provided was. In regards to the support of colleagues it was felt that a key part in learning how to conduct their job was more experienced staff acting as role models. There was also discussion about the value of the relationship between staff carers and other professionals, namely the community team for learning disability (CTLTD).

Rose et al (2003) looked more directly at staff carer's experience of support and the impact that this had. They reported that low levels of staff support were associated with higher levels of stress, but not staff distress. Similar findings were seen within the study conducted by Jenkins et al (1997) with their research indicating that support may act as a mediator between a stressful environment and staff stress. The findings of this study also suggest that level of support was the best predictor of depression.

## Organisational Factors

Rose et al (2003) found that staff carers, who reported that organisational factors made their job more demanding, were more likely to report high stress levels. This finding reflects the results of other papers considered by this review, which also indicate that there is a link between organisational factors and the experience of direct staff carers.

This includes the research conducted by Blumenthal, Lavender and Hewson (1998). This study investigated the impact on burnout of role clarity and perception of the organisation. The results suggest that reduction in role clarity is correlated with an increased level of burnout. There also appeared to be an inverse relationship between the perception of the organisation and the level of burnout, although this was mostly a relationship between perception of the organisation and emotional exhaustion, which is only one of the factors of burnout (as defined by Maslach's Burnout Inventory- Maslach & Jackson, 1986).

Rose (1993) also investigated the impact of organisational factors on the caring experience of staff carers working with adults with LD. This research aimed to investigate the difference in levels of strain, demand, supports and constraints that influence staff in three types of residential services caring for adults with LD (hospital, community and group). All three staff groups perceived the greatest organisational demand to be the number of staff on shift and the availability of resources. Overall within this study the community unit was reported as the least stressful places for frontline staff carers. As a result these findings suggest that organisational factors in community units reduce stress levels of staff carers. However this may not be an accurate reflection of national service provision as this study's data did not match the findings of other comparable studies considered by Rose (1993).

Windley and Chapman (2010) conducted a qualitative investigation into the caring experience of staff carers working with adults with LD. Some of their reported findings reflected a consideration by staff on the impact of organisational factors. Participants reflected on how lack of resources and poor risk management caused conflict in their role and appeared at times to prevent the empowering of service users. There also appeared to be differing levels of confidence expressed about being able to confront any poor practice by their colleagues. It was for this reason that they reported valuing training, as it offered a way of thinking about what they do and why they do it. In regards to training Windley and Chapman (2010) also reported that; communication, behavioural management and skill development were seen as priority areas.

Robertson, Hatton, Felce, Meek, Carr, Knapp, Hallam, Emerson, Pinkney, Caesar and Lowe (2005) conducted a study looking at what organisational factors may have the biggest impact on staff carer's experience of their caring role. In order to do this, turnover data was used to indicate how staff rated their experience of being a carer within an organisation, i.e. high turnover indicated a negative caring experience. The findings were that research participants reported to be most satisfied with their immediate working environment (fellow workers, physical work conditions and the immediate managers) and least satisfied with their rate of pay, opportunities for promotion, and management of the organisation. Thus the results suggest that the organisational factors that have the highest impact are job insecurity and poor pay.

The impact of job role (being a manger) on the caring experience of staff carers working with adults with LD, is not clear when considering the two papers from this review that investigate this concept. Elliott and Rose (1997) conducted a piece of research into the experience of stress by managers of residential services for adults with LD. Their findings indicted that mangers levels of stress appeared to

be relatively low overall, with the pressures placed on managers increasing as the staff groups grew.

In contrast Rose, Jones and Elliot (2000) also conducted a study looking into the experience of being in a managerial role, by comparing the experience of direct staff carers and managers from residential services for adults with LD. Their results indicated that when compared to direct care staff, managers experienced significantly higher levels of job satisfaction, but; felt under more pressure, experienced significantly higher levels of anxiety and reported significantly higher ratings on all seven sources of work stress (as defined by Powell's Questionnaire-Powell, 1992). Although there was no significant difference between managers and direct care staff on levels of depression and few significant differences in reported sources of support, except that direct care staff reported significantly more support from their line manager.

### **Discussion and Recommendations**

This review suggests that there are both personal and external factors that can impact on the caring experience of staff carers working with adults with LD. Levels of psychological well-being and burnout were the elements most commonly used by the reviewed papers to conceptualise the caring experience, and investigate the impact of the chosen factors. The personal factors that the papers investigated included: coping style, personality and cognitive variables; and the external factors included: the presence of challenging behaviour, organisational factors, job role, relationships and the availability of support.

#### **Personal Factors**

##### *Coping Style*

The first personal factor, coping style, appears to have been investigated most within the health literature, with this research mostly considering the effects of 'wishful thinking' and 'practical' coping styles (Lazarus & Folkman, 1984). Overall it has been suggested that 'wishful thinking' is an ineffective coping style and is more likely to result in an individual not adjusting to a challenging circumstance, perhaps resulting in stress (Lazarus & Folkman, 1984). A 'practical' coping style on the other hand is suggested to be a more effective and realistic way of coping, allowing the individual to fully acknowledge a stressful event and develop useful, and sensible ways to address it (Lazarus & Folkman, 1984).

The current review indicates that this also appears to be the case for staff carers working with adults with LD. There was some evidence that 'wishful thinking' as a coping style was related to higher levels of reported stress (Rose et al, 2003; Raczka, 2005), perhaps acting as a mediator between stressors and the experience of stress (Hatton et al, 1995).

### *Personality and Cognitive Variables*

One of the papers (Mills & Rose, 2001) considered by this review attempted to investigate the impact of beliefs, perceptions and causal attributions on the caring experience of staff carers working with adults with LD. The findings go some way to indicate that personal perceptions and causal attributions can act as a mediator between challenging behaviour and burnout. These findings appear to be linked to Lazarus and Folkman's (1984) theory of Cognitive Appraisal, which suggests that an individual's personal traits, affect how that individual perceives threat, which in turn affects how they experience a situation.

Personality is another personal factor that has been previously found to impact on personal experience. Research conducted with other populations has

indicated that when considering the Five Factor model of personality (Costa & McCrae, 1992) high levels of neuroticism has a particularly strong relationship with high levels of stress (Vlerick, 2001). This review goes some way to confirming these relationships with staff carers working with adults with LD (Rose et al, 2003; Chung & Hasting, 2009). Neuroticism was also suggested to have a mediator role between job demands and levels of psychological well-being and burnout (Rose et al, 2003; Chung & Hasting, 2009).

This review also indicates that the more extraverted an individual; the greater their sense of personal accomplishment, and the lower their chance of experience of emotional exhaustion. This trait was also suggested as playing a mediator role, along with the trait of agreeableness, between staff's experience of challenging behaviour and their level of burnout.

## External Factors

### *Challenging Behaviour*

The impact of experiencing challenging behaviour while caring for an individual has been considered throughout the caring literature (e.g. family carers of adults with dementia; Pearlin, Mullan, Semple & Skaff, 1990, residential staff caring for those with LD & dementia; Kalsy, Heath, Adams & Oliver; 2007, and family carers of children with LD; McCallion & Toseland, 1993). This research indicates that challenging behaviour can have a negative impact on the experience of caring and is strongly related to carer stress.

For this reason it seems unsurprising that this review indicates that the effect of challenging behaviour is much the same for staff carers working with adults with LD. Suggesting that the levels of challenging behaviour staff experience can predict: their level of stress (Jenkins et al, 1997; Raczka, 2005), the extent staff

experienced fear of assault, and the reported level of burnout staff experienced (Mills & Rose, 2011; Chung & Harding, 2009).

### *Support and Relationships*

Social support has been considered as a factor that plays an important part in how individuals can cope with stress (Lees & Ellis, 1990). Research has indicated that this is because less support reduces the individuals confidence, collegiality and understanding of their own and others emotional reactions (Frost, et al, 1991). The papers that considered levels of support within this review reported that lower levels of support were associated with higher levels of stress (Rose et al, 2003) and increased the likelihood of experiencing depression (Jenkins et al, 1997). It was also suggested that support might act as a mediator between stressors and staff stress (Jenkins et al, 1997). With staff reporting that the level and type of support received was also an important consideration (Windley & Chapman, 2010)

The nature of relationships, and the impact of these relationships on perceived support, was also considered within this review. A link was suggested between burnout and a lack of perceived reciprocity in staff carer's relationships with; the service users, work colleagues and the employing organisation (Thomas & Rose, 2010). The strongest correlation between burnout and reciprocity was seen when considering the relationship staff carers have with the employing organisation (Thomas & Rose, 2010).

### *Organisational Factors*

The definition of burnout specifically links it to work related experiences (Schaufeli & Enzmann, 1998) and the findings of five of the 13 papers reported on



the impact of organisational factors. This review indicates that if organisational factors are considered demanding by staff carers, they are more likely to report high levels of stress (Rose et al, 2003). Role clarity and perception of the organisation, where two such factors considered within the review; the findings suggest that reduced role clarity is correlated with an increased level of burnout, and that there is an inverse relationship between the perception of the organisation and emotional exhaustion (Blumenthal et al, 1998). Number of staff on shift, lack of resources, risk management and training were also expressed by staff carers as impacting on both their experience of caring and the level of care they provided (Windley & Chapman, 2010; Rose, 1993). It was also suggested that job insecurity and poor pay, have more of an impact on the caring experience, as compared to other organisational factors such as the working environment (Robertson et al, 2005).

The final organisational factor considered within this review is job role. The findings are mixed as to whether or not there is an effect of job role on the caring experience of staff carers working with adults with LD. One study indicated that overall the managers' report low levels of stress (Elliot & Rose, 1997). While the another paper suggested that managers; felt under more pressure, experienced significantly higher levels of anxiety and reported significantly higher ratings on seven sources of work stress (as defined by Powell's Questionnaire- Powell, 1992) when compared to direct care staff (Rose et al, 2000).

### *Clinical Implications and Future Research*

Knowing the factors that impact on the caring experience of staff working with adults with LD is useful as it allows services to work towards bettering the caring experience of staff carers. Doing this would not only improve the carer's well-being, but may also reduce turnover and sick leave; hence reducing the

economic burden on services (Jacobson et al, 1996; Raiger, 2005). It could also improve care provision for service users, as staff carer's experience of caring has been found to impact on the care they provide (Jacobson et al, 1996; Raiger, 2005).

This review indicates the importance of continuing the provision of regular supervision for all staff carers. The importance placed on support as mediating the relationship between stressors and the experience of staff burnout and staff stress, also indicates that other forms of formalised support as well as supervision could be considered. For instance services could begin the introduction of formal peer support groups and begin to validate this type of intervention. In this way services can further mediate the impact of stressors such as those identified by this review; including challenging behaviour and organisational factors. Along with this training on coping strategies, also identified as a mediating factor by this review, could also begin to be implemented. This type of training may also help to reduce the impact of the stressors discussed in this review, as well as potentially going some way to influencing staff carer's appraisal of these stressors.

This review does indicate that the literature has gone some way in beginning to investigate the factors that may impact on the caring experience of staff carers working with adults with LD. Yet there are still some areas that would benefit from further research. To begin with, the 13 papers reported variable conclusions regarding the strength and consistency of the impact that the investigated factors had on the caring experience. With this in mind further research could begin to clarify this affect.

Another consideration is that all the quantitative papers that were considered by this review used a cross-sectional design and relied heavily on self-report measures, which can be biased. This affects how the results could be

interpreted. Future research, adapting a broader spectrum of methodologies would go some way in strengthening and broadening this research base.

When reviewing these papers it also became clear that much of the focus was on burnout, stress and the impact of stressors, all of which are negative experiences. Thus there is an argument for future research into the positive experiences of caring for adults with LD, and what positive factors help in maintaining this experience. This could begin to create a more holistic view of this caring experience, and contribute further to the development of ideas for enhancing the experience of caring for adults with LD.

A final consideration for any future research is that the papers considered by this review often indicated *variation within* the participant samples they had used. Despite this, most papers did not comprehensively report on the participant and service characteristics, in order to give full idea of the extent of the variation. This should be considered when conducting further research, and time should be taken to give a comprehensive context, as there are many potential considerations that could be gleaned from this information.

### *Limitations*

One of the limitations of this review is the variability in participant samples used by the 13 studies. Although all recruited staff from residential services supporting adults with LD, there was much variation between the papers participants; e.g. some researchers recruited both managers and direct-carers, while other recruited one or the other. This means that the participant sample considered by the review is not homogeneous, and as such it could be argued that the 13 papers considered are not comparable. Also as the researchers for each paper varied in what participant and service characteristics they reported, it is not

possible to comment on the extent of this variation. However the paucity of research does not offer the opportunity to consider multiple distinct participant groups in isolation.

Another limitation of this review is that there is also variation between the independent variables measured by the quantitative papers. Some papers used the concept of burnout, others: stress, anxiety, depression or psychological well-being. There was also some variation in the tools used to measure the dependant variables. For the purpose of this review the researcher chose to look at the caring experience as a whole and thus felt it was appropriate to include this variety of papers, but the variation means the findings of the review should be interpreted with caution.

A final limitation to consider is the variation in methodology, and although a rationale has been given for including both quantitative and qualitative methodologies, there are other arguments that should be considered. Firstly developing a technique for including and synthesizing qualitative research within a review is an under-developed area, especially when compared to the substantial literature base around the synthesis of quantitative evidence (Dixon-Woods, Fitzpatrick & Roberts, 2000). Thus inclusion of qualitative methodologies within a structured review process, such as a systematic review, could be deemed unwise (Dixon-Woods et al, 2005). Also due to this limitation it was necessary for the researcher to design a quality measure which could evaluate both methodologies and allow for some comparisons between the two. But it could be suggested that the methodologies are not truly comparable, given their fundamental ideological differences (Dixon-Woods et al, 2005). The same could be said for the inclusion of two forms of qualitative methodology, IPA and content analysis, as they both draw on different theory. These points should be remembered when considering the findings of this review.

## References

\* - Marks studies that are included within the review

- Allen, P., Pahl, J. & Quine, L. (1990). *Care Staff in Transition*. London: HMSO.
- Aman, M. G., Singh, N. N., Stewart, A. W. & Field, C. J. (1985). The Aberrant Behavioural Checklist: a behaviour rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency*, 89(1), pp. 485–491.
- Bersani, H. A. & Heifetz, L. J. (1985). Perceived stress and satisfaction of direct-care staff members in community residents for mentally retarded adults. *American Journal of Mental Deficiency*, 90(1), pp. 289–295.
- \*Blumenthal, S., Lavender, T. & Hewson, S. (1998). Role clarity, perception of the organisation and burnout amongst support workers in residential homes for people with intellectual disability: a comparison between a National Health Service trust and a charitable company. *Journal of Intellectual Disability Research*, 42(1), pp. 409–417.
- Borrill, C., Wall, T. D., West, M. A., Hardy, G. E., Shapiro, D. A., Carter, A.,.....Haynes, C. E. (1996). *Mental Health of the Workforce in NHS Trusts: Phase 1 Final Report*. Institute of Work Psychology, Sheffield.
- \* Chung, M. C. and Harding, C. (2009). Investigating burnout and psychological well-being of staff working with people with intellectual disabilities and challenging behaviour: The role of personality. *Journal of Applied Research in Intellectual Disabilities*, 22(1), pp. 549–560.
- Coon, D. W., Rubert, M., Solano, N., Mausbach, B., Kraemer, H., Arguëlles, T., .....Gallagher-Thompson, D. (2004). Well-being, appraisal, and coping in Latina and Caucasian female dementia caregivers: Findings from the REACH study. *Aging & Mental Health*, 8(4), pp.330-345.

- Cooper, C. L. & Marshall, J. (1976). Occupational sources of stress: a review of the literature relating to coronary heart disease and mental ill-health. *Journal of Occupational Psychology*, 49(1), pp. 11-28.
- Corrigan, P. W. (1993). Staff stressors at a developmental centre and state hospital. *Mental Retardation*, 31(1), pp. 234–238.
- Costa, P.T. & McCrae, R. R. (1992). *Revised NEO Personality Inventory (NEO-PI) and NEO Five-Factor Inventory (NEO-FFI) Professional Manuals*. Odessa: Psychological Assessment Resources.
- Courtenay, K., Jokinen, N. S. & Strydom, A. (2010). Care giving and Adults with Intellectual Disabilities Affected by Dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), pp. 26-33.
- Dagnan, D., Grant, F. & McDonnell, A. (2004). Understanding challenging behaviour in older people; the development of the Controllability Beliefs Scale. *Behavioural and Cognitive Psychotherapy*, 32(1), pp. 501–6.
- Dixon-Woods, M., Fitzpatrick, R., & Roberts, K. (2000). Including qualitative research in systematic reviews: opportunities and problems. *Journal of Evaluation in Clinical Practice*, 7(2), pp. 125–133.
- Downs, S. H. & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality of both randomised and non-randomised studies of health care interventions. *Journal of Epidemiol Community Health*, 52(1), pp. 377-384.
- Dyer, S. & Quine, L. (1998). Predictors of job satisfaction and burnout among the direct-care staff of a community learning disability service. *Journal of Applied Research in Intellectual Disabilities*, 11(1), pp. 320–332.

- \*Elliott, J. L. & Rose, J. (1997). An investigation of stress experienced by managers of community homes for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 10(1), pp. 48-53.
- Eysenck, M. (1988). Trait anxiety and stress. In Fisher, S. & Reason, J. (Eds.), *Handbook of Life Stress, Cognition and Health*, (pp. 476–482), Chichester: John Wiley & Sons Ltd.
- Felce, D. & Emerson, E. (2001). Living with support in a home in the community: predictors of behavioural development and household and community activity. *Mental Retardation and Developmental Disabilities Research Reviews*, 7(1), pp. 75–83.
- Fletcher, B. (1989). *The Cultural Audit: An Individual and Organisational Investigation*. Cambridge: PSI
- Forbat, L. (2006). Valuing people: Hopes and dreams for the future. *British Journal of Learning Disabilities*, 34(1), pp. 20-27.
- Freeman, M. (1994). The differential impact on carers dealing with clients with challenging behaviours. *Journal of Community and Applied Social Psychology*, 4(1), pp. 181–187
- Frost, J. C., Makadon, H. J., Judd, D., Lee, S., O'Neill, S.F. & Paulsen, R. (1991). Care for caregivers: a support group for staff caring for AIDS patients in a hospital-based primary care practice. *Journal of General Internal Medicine*, 6(2), pp. 162–7.
- Goldberg, D. P. (1978). *General Health Questionnaire (GHQ-12)*. Oxford: NFER Nelson.
- Goldberg, D. P. & Hillier, V. F. (1979). A scaled version of the general health questionnaire. *Psychological Medicine*, 9(1), pp. 139–145.

- Grant, G. (2001). Supporting the supporters – some reflections on family care giving. In Thompson, J. & Pickering, S. (Eds.), *Meeting the health needs of people who have a learning disability* (pp. 288–305). London: Bailliere Tindall, Harcourt Publications LTD.
- Hackman, J. R. & Oldham, G. R. (1975). Development of the Job Diagnostic Survey. *Journal of Applied Psychology*, 60(1), pp. 159– 170.
- Harris, P. (1993). The nature and extent of aggressive behaviour amongst people with learning disabilities (mental handicap) in a single health district. *Journal of Intellectual Disability Research*, 37(1), pp. 221-42.
- Harris, P., Humphreys, J. & Thomson, G. (1994). A Checklist of Challenging Behaviour: the development of a survey instrument. *Mental Handicap Research*, 7(1), pp. 118–33.
- Harris, P. & Thomson, G. (1993). The Staff Support Questionnaire: a means of measuring support among staff working with people with challenging behaviour. *Mental Handicap*, 21(1), pp. 122-7.
- Hastings, R. P. & Brown T, (2002). Behavioural knowledge, causal beliefs and self-efficacy as predictors of special educators' emotional reactions to challenging behaviours. *Journal of Intellectual Disability Research*, 46(1), pp. 144–150.
- Hatton, C. (1999). Staff stress. In Bouras, N. (Ed.), *Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation* (pp. 427–438), Cambridge: Cambridge University Press.
- \*Hatton, C., Brown, R., Caine, A. & Emerson, E. (1995). Stressors, coping strategies and stress-related outcomes among direct care staff in staffed houses for people with learning disabilities. *Mental Handicap Research*, 8(1), pp. 252–271.



- Hatton, C. & Emerson, E. (1993). Organisational predictors of staff stress and intended turnover in a service for persons with multiple disabilities. *Mental Retardation*, 31(1), pp. 388–395.
- Hatton, C. & Emmerson, E. (1995). The development of a shortened 'ways of coping' questionnaire for use with direct care staff in learning disabilities services. *Mental Handicap Research*, 8(1), pp. 237–251.
- Hatton, C., Emerson, E., Rivers, H., Mason, H., Mason, L.,.....Alborz, A. (1999a). Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research*, 43(4), pp. 253–267.
- Hatton, C., Rivers, H., Mason, H., Emerson, E., Kiernan, C., Reeves, D. & Alborz, A. (1999b). Organizational culture and staff outcomes in services for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 43(3), pp. 206–218.
- Jacobson, G. H., Aldana, S. G., Goetzel, R. Z., Vardell, K. D., Adams, T. B. & Pietras, R. J. (1996). The relationship between perceived stress and self-reported illness-related absenteeism. *American Journal of Health Promotion*, 11(1), pp. 54–61.
- Jeffcott, T. (2002). *Burnout Amongst Residential Care Staff for Looked After Children*. D. Clin. Psy Thesis, University of Birmingham, Birmingham.
- \*Jenkins, R., Rose, J. & Lovell, C. (1997). Psychological wellbeing of staff working with people who have challenging behaviour. *Journal of Intellectual Disabilities Research*, 41(1), pp. 502– 511.
- Kalsy, S., Heath, R., Adams, D. & Oliver, C. (2007). Effects of training on controllability attributions of behavioural excesses and deficits shown by

- adults with Down syndrome and dementia. *Journal of Applied Research in Intellectual Disabilities*, 20(1), pp. 64–68.
- Kane, R. A. (2001). Long term care and a good quality of life. *Gerontologist*, 41(1), pp. 293–304.
- Landis, J. R. & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, 33(1), pp. 159–174
- Lawrence, V., Murray, J., Samsi, K. & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. *British Journal of Psychiatry*, 193(3), pp. 240-246.
- Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lees, S. & Ellis, N. (1990). The design of a stress-management programme for nursing personnel. *Journal of Advanced Nursing*, 15(8), pp. 946–61.
- Maslach, C. & Jackson, S. E. (1986). *The Maslach Burnout Inventory Manual (Second Edition)*. Palo Alto: Consulting Psychologists Press.
- Maslach, C., Schaufeli, W. B. & Leiter, M. P. (2001). Job burnout. *Annual Review of Psychology*, 52(1), pp. 397–422.
- McCallion, P. & Toseland, R. (1993). Empowering families of adolescents and adults with developmental disabilities. *Families in Society*, 74(1), pp. 579-587.
- McCarron, M. & McCallion, P. (2005). A revised stress and coping framework for staff carers of persons with intellectual disabilities and dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 2(2), pp. 139-148.

McConkey, R., McAuley, P., Simpson, L. & Collins, S. (2007). The Male Workforce in Intellectual Disability Services. *Journal of Policy and Practise in Intellectual Disabilities*, 4(3), pp. 186-193.

\*Mills, S. & Rose, J. (2011). The relationship between challenging behaviour, burnout and cognitive variables in staff working with people who have intellectual disabilities. *Journal of Intellectual Disabilities Research*, 55(9), pp. 844-857.

National Health Service (2009), Carers Direct, Retrieved from

<http://www.nhs.uk/CarersDirect/guide/kinds/Pages/Overview.aspx?WT.srch=1&WT.NHScampaign=Carers%20-%20Only&WT.NHSadgroup=Carers%20-%20Only&WT.NHSkeyword=carers>, 09/11/010.

Newton, J. T. & Sturmey, P. (1988). The aberrant behaviour checklist: a British replication and extension of its psychometric properties. *Journal of Mental Deficiency Research*, 32(1), pp. 87–92.

National Institute for Clinical Excellence- NICE (2007). *The Guidelines Manual*, London: National Institute for Clinical Excellence.

Nihira, K., Leyland, H. & Lamben, N. (1994). AAMR Adaptive Behaviour Scale - Residential and Community (2nd Edition). *Examiner's Manual*, Texas: Pro-Ed 8700.

Pearlin, L. I., Mullan, J. T., Semple, S. J. & Skaff, M. M. (1990). Care giving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), pp. 583-594.

Powell, T. J. (1992). *Mental Health Handbook*. Bicester: Winslow Press.

- \*Raczka, R. (2005). A focus group enquiry into stress experienced by staff working with people with challenging behaviours. *Journal of Intellectual Disabilities*, 9(2), pp. 167-177.
- Raiger, J. (2005). Applying a Cultural Lens to the Concept of Burnout. *Journal of Transcultural Nursing*, 16(1), pp. 71–6.
- \*Robertson, J., Hatton, C., Felce, D., Meek, A., Carr, D., Knapp, M.,.....Lowe, K. (2005). Staff stress and morale in community-based settings for people with intellectual disabilities and challenging behaviour: A brief report. *Journal of applies research in intellectual disabilities*, 18(1), pp. 271-277.
- \*Rose, J. (1993). Stress and staff in residential settings: the move from hospital to the community. *Mental Handicap Research*, 6 (4), pp. 312–332.
- Rose, J. (1995). Stress and residential staff: towards an integration of existing research. *Mental Handicap Research*, 8(1), pp. 220–236.
- Rose, J. & Cleary, A. (2007). Care staff perceptions of challenging behaviour and fear of assault. *Journal of Intellectual & Developmental Disability*, 32(1), pp. 153–61.
- \*Rose, J., David, G. & Jones, C. (2003). Staff who work with people who have intellectual disabilities: the importance of personality. *Journal of Applied Research in Intellectual Disabilities*, 16(1), pp. 267–277.
- \*Rose, J., Jones, C. & Elliot, J. L. (2000). Differences in stress levels between managers and direct care staff in group homes. *Journal of Applied Research in Intellectual Disabilities*, 13(1), pp. 276-282.
- Rose, D. & Rose, J. (2005). Staff in services for people with intellectual disabilities: the impact of stress on attributions of challenging behaviour. *Journal of Intellectual Disability Research*, 49(1), pp. 827–838.

- Sharrard, H. (1992). Feeling the strain: Job stress and satisfaction of direct-care staff in the mental handicap service. *British Journal of Mental Subnormality*, 38(1), pp. 32–38.
- Schaufeli, W. & Buunk, B. (2003). Burnout: An Overview of 25 Years of Research and Theorizing. In Schabracq, M. J., Winnubst, J. A. M. & Cooper, C. L. (Eds.), *The handbook of Work and Health Psychology* (2nd Edition, pp. 383–424), UK: Wiley.
- Schaufeli, W. & Enzmann, D. (1998). *The burnout companion to study and practice*. London: Taylor and Francis.
- Skirrow, P. & Hatton, C. (2007). ‘Burnout’ amongst direct care workers in services for adults with intellectual disabilities: A systematic review of research findings and initial normative data. *Journal of Applied Research in Intellectual Disabilities*, 20(1), pp. 131–144.
- Stenfert-Kroese, B. & Fleming, I. (1992). Staff attitudes and working conditions in community based group homes for people with mental handicaps. *Mental Handicap Research*, 5(1), pp. 82–91.
- Suls, J. & Martin R., (2005). The daily life of the garden-variety neurotic: Reactivity, stressors exposure, mood spill over, and maladaptive coping. *Journal of Personality*, 73(1), pp. 1–25.
- \*Thomas, C. & Rose, J. (2010). The relationship between reciprocity and the emotional and behavioural responses of staff. *Journal of Applied Research in Intellectual Disabilities*, 23(1), pp. 167-178.
- Thompson, L. & Rose, J. (2011). Does organizational climate impact upon burnout in staff who work with people with intellectual disabilities? A systematic review of the literature. *Journal of Intellectual Disabilities*, 15 (3), pp. 177 – 193.

- Toseland, R., Smith, G. & McCallion, P. (2001). Helping family caregivers, In Gitterman A. (Ed.). *Handbook of social work practice with vulnerable populations* (pp. 548–581). New York: Columbia University Press.
- Van Horn, J. E., Schaufeli, W. B. & Enzmann, D. (1999). Teacher Burnout and Lack of Reciprocity. *Journal of Applied Social Psychology*, 29(1), pp. 91–108.
- Vlerick, P. (2001). Personality correlates of burnout: a cross-validation study. In De Jonge, J., Vlerick, P., Bussing, A. & Schaufeli, W. B. (Eds.), *Organizational Psychology and Health Care at the Start of a New Millennium* (pp. 139–155), Munich: Rainer Hampp Verlag.
- Vollrath, M. (Ed.) (2006). *Handbook of Personality and Health*. Chichester: John Wiley & Sons Ltd,
- Watson, D. & Clark, L. A. (1984). Negative affectivity: the disposition to experience aversive emotional states. *Psychological Bulletin*, 96(1), pp. 465–490.
- Whybrow, A. (1994). *Staff in a service for people with learning disabilities*. PhD Thesis, University of Liverpool, Liverpool
- Williams, R. & Rose, J. (2007). The development of a questionnaire to assess the perceptions of care staff towards people with intellectual disabilities who display challenging behaviour. *Journal of Intellectual Disabilities*, 11(1), pp. 197–211.
- \*Windley, D. & Chapman, M. (2010). Support workers within learning/intellectual disability services perception of their role, training and support needs. *British Journal of Learning Disabilities*, 38(1), pp. 310-318.
- Zellars, K. L., Hochwarter, W. A., Perrewe, P. L., Hoffman, N. & Ford, E. W. (2004). Experiencing job burnout: The roles of positive and negative traits and states. *Journal of Applied Social Psychology*, 34(1), pp. 887–911.

Zellars, K. L., Perrewe, P. L., Hochwarter, W. A. & Anderson. K. S. (2006). The interactive effects of positive affect and conscientiousness on strain. *Journal of Occupational Health Psychology*, 11(1), pp. 281–289.

**Part Two**  
**Empirical Research**



**The Caring Experience of Staff Carers Working With Adults with Learning  
Disability and Dementia**

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Research in Intellectual Disabilities. Please see Appendix G for the guidelines for  
authors.

## **Abstract**

### *Background*

There has been an increase in dementia within the learning disabilities (LD) population; however, there has been little research investigating the experience of care-staff working with this population. This study investigates the caring experience of care-staff working with individuals with LD and dementia (LDD).

### *Method*

A semi structured interview was conducted with nine participants. The transcripts were then analysed with Interpretative Phenomenological Analysis (IPA).

### *Results*

Four super-ordinate themes were identified: 1. Reciprocity and Relationships, 2. Culture of LD Services, 3. Emotional Impact, 4. Knowledge and Understanding.

### *Conclusions*

The findings indicate that staff carer relationships, and their level of knowledge and training impact on the experience of caring for an individual with LDD, and that the culture of LD services may impact on how care is provided for those with LDD. These findings are linked to previous studies and the clinical implications and future areas for research are discussed.

*Keywords: Learning Disability, Dementia, Staff Carers, Caring*

## **The Caring Experience of Staff Carers Working With Adults with Learning Disability and Dementia**

The life expectancy of the population as a whole is increasing and subsequently there is an increase in the conditions of older life, including dementia. The National Institute for Health and Clinical Excellence (NICE, 2006) describes dementia as a progressive syndrome which causes wide spread cognitive impairment including; memory loss, disorientation, impaired language, difficulty with daily activities and changes to personality (NICE, 2006). This increase in those with dementia has meant an increase in economic burden and more strain on services (Health Economics Research Centre & University of Oxford, 2010) and carers, including family members of individuals with dementia and health care staff (Department of Health, 2009).

This increase in the number of individuals with dementia is reflected within the learning disabled (LD) population (Forbat, 2006). The literature also indicates that in this population there is earlier onset and a higher prevalence of dementia (Millichap et al, 2003). It has also been reported that dementia progresses more quickly in individuals with LD (Forbat, 2006). It is for this reason that dementia has become important within LD research, and further studies are needed to guide the care of this population (Forbat, 2006).

Studies have begun to look into the behaviours of those individuals with LD who develop dementia (LDD). This appears to be attempting to spread awareness of the symptoms and how they are exhibited within those with LD so as to increase the likelihood that those who have dementia are recognised and receive treatment (Duggan, Lewis & Morgan, 1996). This type of research can also improve the awareness of what to expect with dementia in people with LD, so that their care can be adapted to adequately meet their new needs (Cooper, 1997).

The literature is also beginning to look at carer knowledge around aging and dementia within a learning disabled population (Whitehouse, Chamberlain & Tunna, 2000). There is also a growing literature that looks at carer experience of caring for various populations (Grant, 2001; Lawrence, Murray, Samsi & Banerjee, 2008; Chou, Pu, Lee, Lin & Kröger, 2009). However there is currently little quality research looking at the caring experience of carers working with an aging LD population (Courtenay, Jokinen & Strydom, 2010; Strydom et al, 2009).

### Carers

Carers are defined as individuals who look after a relative or friend who require support because of illness, including mental illness, age, and physical or learning disability (Wooff, Schnieder, Carpenter & Brandon; 2003). Although within the scientific literature the term carer can also include staff carers whose job is to care for those that require support for the aforementioned reasons. Carers play an important role in society and it is reported that the number of people caring for a loved one, has doubled in the last nine years (Carers UK, 2004). Along with this there has been an increase in the number of staff carers employed by the NHS and the private sector (National Health Services, 2009). The importance of their role means it is perhaps unsurprising that carers are an area of research interest within the scientific community. This research tends to consider two distinct carer groups- staff carers and family carers.

### *Family Carers*

Research investigating the experience of caring for a family member with dementia (without LD) indicates the following variables as being associated with family carer burden: supportiveness of the family unit, an individual's health status,

their relationship to the care recipient, the availability of external support and care recipient factors- such as aggression, an increase in behaviour problems and the rate and severity of cognitive and physical decline (Gwyther, 2000; Gaugler, Davey, Pearlin & Zarit, 2000).

A study recently completed by McLaughlin and Jones (2011) investigated the caring experience of both *family* carers and *staff* carers (no distinction made between the two groups) and reported similar findings. This qualitative study identified that a carers needs were different at pre-diagnosis, diagnosis and post-diagnosis of dementia, due to the change in needs and behaviour of the individual with LDD (McLaughlin & Jones, 2011). It was also suggested that carers felt health professional's key role was helping them manage these changes within the individual with LDD (McLaughlin & Jones, 2011). Other studies have investigated the significance of a family carer's stress for the individual with dementia, suggesting that levels of burden among family carers often predict institutionalization of the persons with dementia (McCallion, McCarron & Force, 2005).

One of the most well-known models within the family carer burden literature is proposed by Pearlin, Mullan, Semple and Skaff (1990). This model conceptualises the experience of caring for a family member with dementia (without LD), considering background and contextual factors, primary strains and secondary strains, mediating factors, as well as the outcomes or manifestations of stress (Pearlin et al, 1990). It also considers the positive factors of caring, including: self-esteem, mastery, competence and gain (Pearlin et al, 1990).

This interest in positive caring experience is echoed within the research around caring for a family member with LD (without dementia). Mothers looking after an adult child with an LD reported higher morale, better health, more social

support, less subjective burden, and more effective coping strategies- in contrast with those caring for an adult with a mental illness (Grant, 2001).

### *Staff Carers*

Initially there was speculation that staff carers may not be as susceptible to the negative impact of caring because it is their job, something they can leave at the end of their shift (McCarron & McCallion, 2005). Research now indicates however that this is not the case and factors such as absenteeism, staff turnover and burnout are most likely manifestations of the negative impact of caring (McCarron & McCallion, 2005). When discussing staff stress the literature will often refer to burnout. This term has been defined as 'a persistent, negative, work-related state of mind' (Schaufeli & Enzmann, 1998, pg. 36). It tends to include exhaustion, distress and even psychosomatic disease. This can lead to deterioration in quality of service provision, reduced quality of life for the carer and have a negative economic impact on the service due to absenteeism and turnover (Jacobson et al, 1996; Raiger, 2005).

Burnout is thought to be the result of prolonged exposure to stressors at work. Research has investigated the stressors thought to contribute to burnout for staff caring for those with LD (without dementia) (e.g. Rose, Jones & Fletcher, 1998; Rose & Schlewa-Davies, 1997). These factors were found to include organisational variables such as lack of autonomy in the job, high workloads, training level, lack of variety within the individuals work role, poor staff relations, and role conflict (Stenfert-Kroese & Fleming, 1992). Studies investigating the caring experience of healthcare workers also found that organisational factors can act as stressors, as well as an imbalance of demands, a perceived lack of skills and insufficient support at work (Weinberg & Creed, 2000).

Researchers have also looked into how these stressors can be mediated. It has been found that personal (Cooper, Dewe & O'Driscoll, 2001; Schaufeli & Buunk, 2003) and social support (Stenfert-Kroese & Fleming, 1992) can both play a part in mediating a staff carer's experience of burnout and stress. The literature also indicated that positive organisational factors can help mediate stress levels in staff carers (Kane, 2001).

This research into burnout in carers working with population other than an LDD population has been integrated, to create an adapted version of Pearlin et al's (1990) model (McCallion & McCarron, 2005). This model maps carer burden when caring for individuals with LDD, and offers a start point for developing a literature around the caring experience of staff carers working specifically with those with LDD.

The fact that carers in this area tend to be staff carers is the factor that contributed most to the differences between this new model and Pearlin et al's (1990) original model (McCallion & McCarron, 2005). Many of the original categories proposed in the Pearlin et al's model (1990) were retained; however, they added 'organisational support and resources' to the category of secondary strains (McCarron & McCallion, 2005). Also within the revised model fewer demographic variables are considered, along with the addition of stress caused by staff observing loss of skill in those they have worked with to develop new abilities (McCarron & McCallion, 2005). Along with this the model also takes consideration of the effect on staff of the challenge of assessing cognitive decline in the presence of a LD (McCarron & McCallion, 2005). This can mean decline occurs pre-diagnosis- meaning maladaptive behaviours can remain unexplained for long periods resulting in increased staff stress (McCarron & McCallion, 2005). Little research has been conducted to validate this new model- although inferences can be drawn from parallel literature- staff carers and dementia etc.

In regards to the developing literature surrounding positive experiences of caring, the focus on staff carers was offered as the explanation for not including the newer literature in this area within this adapted model (McCallion & McCarron, 2005). It is suggested that this is due to the fact staff carers do not often engage in life time care although McCallion and McCarron (2005) do recognise that the LD community fosters a family like environment, which indicates potential for prolonged caring or at least strong relationships.

### Rationale and Research Aims

Staff carer literature is as a whole only a small area, and there is an even smaller amount of research looking into staff carers working with LDD populations. Thus in order to improve the caring experience, and begin the process of developing effective support for staff carers working within services providing care for those with LDD, it important to begin with an increased understanding of their caring experience (Wooff et al, 2003).

Leading from the above, this research is a qualitative study which aims to explore how staff carers working with individuals with LDD understand their experience of caring.



## Method

### Design

The research used a qualitative semi-structured interview to generate data, about participant's experience of caring for individuals with LDD by considering questions under the headings of: perception of the caring experience, factors that affect the experience of caring and the outcomes of caring (Appendix O). This data was analysed using interpretative phenomenological analysis (IPA; Smith, Jarman & Osborn, 1999). A full rationale for the use of qualitative methodology and IPA can be found in Appendix H.

Demographic data (Appendix N) was collected to contextualise the qualitative data. Along with the Dementia Questionnaire for People with Learning Disabilities (DLD; Evenhuis, Kengen & Eurlings, 2007) and Part One of the Dementia Screening Questionnaire, for Individuals with Intellectual Disability (DSQIID; Deb, Hare, Prior & Bhaumik, 2007) (Appendix P and Q) which report previous and current level of functioning of the individual with LDD.

### Procedure

#### *Ethical Consideration*

Ethical approval was gained from the University of Hull's Postgraduate Medical Institute's Ethics Panel (Appendix I). The safety of participant and researcher were always considered, lone worker policies were followed and informed consent was sought from all participants. Willingness to participate was continually checked through discussion with participants. The recordings were securely stored on an encrypted and password protected USB drive and destroyed after transcription. Names and distinguishing features were removed and

pseudonyms along with an assigned number used to identify data; the master list was stored separately from the data.

### *Participant Identification*

Once ethical approval was given, the managers of private and local authority run residential homes supporting individuals with LD within the Yorkshire and Humber area were approached via telephone. The manager of the services confirmed to have LDD clients were then sent a letter along with an information sheet and poster, which detailed the purpose of the study (Appendix J, L and K). Those interested were contacted to arrange a convenient time for an interview, and to ensure that they met the criteria (Fig. 1).

<p>Inclusion Criteria:</p> <ul style="list-style-type: none"> <li>• Participants must have worked for a minimum of six months with at least one individual which has both: <ul style="list-style-type: none"> <li>▪ A recognised LD</li> <li>▪ A diagnosis of dementia</li> </ul> <p>This will allow for sufficient time working with a service-user with LDD to have experiences to discuss in the interview.</p> </li> <li>• Are able to give informed consent to participate so as to fulfil ethical requirements.</li> </ul> <p>Exclusion criteria:</p> <ul style="list-style-type: none"> <li>• Lack of sufficient fluency in English- so they are able to complete the interview.</li> <li>• Not wanting to participate</li> <li>• Unable to give informed consent</li> <li>• Working in the home for less than six months.</li> <li>• Voluntary or unpaid carer- as the focus of this research is staff carers, paid employment is necessary.</li> </ul>
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*Figure 1- Inclusion and Exclusion Criteria*

### *Data Collection*

At the start of the interview the researcher explained the process and supplied the participant with another copy of the information sheet. The participant then had the opportunity to read the information and ask any questions. If they were still willing to participate, the researcher undertook the process of obtaining written and informed consent (Appendix M), and requesting permission for audio recording of the interview. If consent was given the participant was asked to decide on a pseudonym, which was used to make the data and the interview transcripts anonymous.

Before beginning the interview participants were asked to fill in a demographic questionnaire, the DLD (Evenhuis et al, 2007) and the DSQIID (Deb et al, 2007) (no identifiable data about the individual with LDD was collected). Following completion of these measures the semi-structured interview began. This was recorded onto a digital audio device. After the interview there was another opportunity for participants to ask questions and discuss how they found the interview process.

### Participants

Nine participants were recruited from three residential homes within the Yorkshire and Humber area, details in Table 1. The number of participants fits with the recommended rule and convention for rigour within qualitative research (e.g. Elliot, Fischer & Rennies, 1999; Turpin et al, 1997).

<u>Residential Home</u>	<u>Number of Residents</u>	<u>Number of Residents with LDD</u>	<u>Age Range of Residents</u>	<u>Number of Staff</u>	<u>Type of Service</u>
<b>A</b>	8	1	45 – 91 years	16	Local Authority
<b>B</b>	19	2	19 – 87 years	16	Private
<b>C</b>	13	2	25 – 80 years	11	Local Authority

*Table 1: Residential Home Information*

The age of participants ranged from 25 to 58 years, with a mean age of 41.78 years. Eight of the nine participants were female and to ensure anonymity the gender of participant is not reported. The gender split of participants appears to not be ideal, however it appears to reflect the female dominated staff carer population (McConkey, McAuley, Simpson & Collins, 2007). The average time spent in the caring profession was 12.11 years (ranging from 2 to 24 years) with an average time in their current post of 5.22 years (ranging from 1 to 10 years), with the majority of participants working full time (six full-time and three-part time staff). Details can be seen in Table 2.

<u>Participant Number</u>	<u>Pseudonym</u>	<u>Age</u>	<u>Nationality</u>	<u>Full Time/ Part Time</u>	<u>Time Worked as Carer (to nearest year)</u>	<u>Time in Current Post (to nearest year)</u>	<u>Experience with LD and Dementia</u>
1	Titch	46	British	Part Time	6 years	3 years	18 months to 2 years
2	Smith	42	British	Part Time	17 years	2 years	1 year to 18 months
3	Adams	55	British	Full Time	10 years	8 years	3 years +
4	Bell	32	British	Full Time	15 years	3 years	18 months to 2 years
5	Ibsom	36	British	Full Time	11 years	5 years	3 years +
6	Loa	54	British	Full Time	18 years	10 years	3 years +
7	MB	25	British	Full Time	6 years	5 years	3 years +
8	CK	28	British	Part Time	2 years	1 year	1 year to 18 months
9	Tindle	58	British	Full Time	24 years	10 years	3 years +

*Table 2: Demographic Information*

### Data Analysis

Data from the interviews were analysed using IPA based on the guidelines by Smith et al (1999). Each transcript was read multiple times by the researcher, using the margin to note anything interesting or significant- during this process any emerging 'theme titles' were documented. The researcher then looked for connections between themes and identified the ones that re-occurred in the transcripts. (Appendix R)

The analysis itself was a process of interpretation and the theory behind IPA suggests the process can be strengthened through the use of multiple perspectives to validate the identified themes (Smith et al, 1999). To introduce this aspect the researcher was part of an IPA group consisting of trainee clinical psychologists, in which others also analysed the transcripts. The researcher also carried out respondent validation with one interested participant. (Appendix S)

The demographic data and the data collected from the DLD (Evenhuis et al, 2007) and the DSQIID (Deb et al, 2007) are presented in Table 3. These results indicate that all participants were reflecting on the experience of supporting someone with severe decline, both socially and cognitively, due to dementia.

<u>Servi- ce</u>	<u>Partic- ipant</u>	<u>Speech</u>		<u>Daily Living Skills</u>		<u>Accommodation</u>		<u>DLD Score</u>
		<u>Best</u>	<u>Current</u>	<u>Best</u>	<u>Current</u>	<u>Best</u>	<u>Current</u>	<u>Cogniti- ve (Social)</u>
<b>A</b>	3,5,6, 7 and 8	Fluen t	Only some Stereotyped words	Independent, minor help	Needs help with all daily living tasks	Shared House- Staffed	Nursing Home- Full time Care	42 (40)
<b>B</b>	4	Spea k a few words	Only some Stereotyped words	Not Independent, lots of help needed	Needs help with daily living skills sometimes	Group Home- Full time staff	Group Home- Full time staff	33 (40)
<b>B</b>	1	Short Sente -nces	Only some Stereotyped words	Not Independent, minor help needed	Needs help with daily living skills sometimes	Group Home- Full time staff	Group Home- Full time staff	26 (25)
<b>C</b>	2	Short Sente -nces	Only some Stereotyped words	Not Independent, minor help needed	Needs help with all daily living tasks	Group Home- Full time staff	Nursing Home- Full time Care	44 (51)
<b>C</b>	9	Fluen t	Only some Stereotyped words	Independent, minor help	Needs help with all daily living tasks	Group Home- Full time staff	Nursing Home- Full time Care	43 (43)

*Table 3- Characteristics of the individuals with LDD supported by participants*

## Results

Analysis of the transcripts was used to identify reoccurring themes in the interviews. Themes were organised into four super-ordinate themes, which split into nine sub-ordinate themes (Table 4). The themes are depicted through the use of verbatim quotes from the transcripts analysed.

<b>Super- Ordinate Themes</b>	<b>Sub-Ordinate Themes</b>
Reciprocity and the Relationship	Staff/Staff - Support
	Staff/Other Professionals – Respect
	Staff/Service user – Reciprocity
Culture of LD Services	‘From Empowering to Everything’
	Person Centred Care and Knowing the Individual
The Emotional Impact	Frustration
	‘Positive but Painful’
	Anxiety About Getting Older
Knowledge and Understanding	Training

*Table 4: The Super-Ordinate and Sub-Ordinate Themes*

### Reciprocity and the Relationship

Within the interviews participants discussed the importance of their relationships at work. Participants reflected on the nature of interactions that these relationships offered, while also discussing the effect these had on their experience of caring for those with LDD.

#### *The Staff/Staff Relationship- Support*

The importance of the staff team in order to provide care for the individuals with LDD was often stated within the interviews.

*'you can't do it alone; you can't care alone for anybody' (Titch)*

As with this quote from Titch, importance was placed on 'Team' and having others to draw on in order to provide care for the individual. Participants also appeared to value their team in the provision of emotional support.

*'we tend to natter away at each other if-if we need to do so I think that we get that (1) we get through us-us weeks that way sometimes if it's a bit (2) overpowering' (Loa)*

Loa is observing the importance of having people to talk and appears to suggest that this support and can be crucial in managing the emotional response to difficult situations at work. Along with this opportunity to share experiences and difficult feelings it was also observed that advice and the provision of practical assistance was valuable input from the staff team.

*'The team of people that I work with make it easier um because everybody can lean on everyone else, if you come up against something that you can't, you know that you're not sure you can deal with or you just emotionally can't cope with it um then someone else will pick up and say let's do it this way, or lets sort it that way' (Titch)*

#### *The Staff/Other Professionals Relationship Respect*

Along with the support of their staff team, participants reflected on the value of the support of other professionals; especially in regards to specialist knowledge and assistance in caring for the individuals with LDD that they support.

*'I think without that work (from other professionals) we wouldn't be able to go anywhere um because our job (1) sort of (1) ends, we can't say this is what's wrong with so and so, we can't diagnose something' (Bell)*



The opinion of other professionals on their work was an important part of how they experienced caring for people with LDD.

*'It's nice when professional people say things to us (1) what a lovely job you're doing, it's a loving home, the residents are happy, you know it's lovely, it blows us away to be fair' (Bell)*

*'I know sometimes like, yesterday I was talked to by a doctor like um (2) dirt basically over the phone um (2) if that was (2) that, so your looked down on straight away, he thinks he can talk to me like, like that really, which really it-it does put you down and it irritates ya, so I don't think it's appreciated what we do sometimes' (MB)*

The first quote by Bell indicates that positive feedback offered by a professional can be a valued experience. It appears that these comments generate a sense of pride and even happiness within the carer. The second quote from MB discusses the opposite situation, a negative interaction. This appeared to lead to feeling undervalued as well as causing MB to feel frustrated and angry.

#### *The Staff/Service users Relationship- Reciprocity*

This was a theme noted within the majority of transcripts; those interviewed reflected on the value of their relationship with service users. Particular importance was placed on the interactions they are able to have with them, which can be seen in the following quotation from MB. Within this quote it seems that much of the perceived gain of caring is dependent on receiving positive feedback on their provision of care.

*'I just find it real rewarding you get a good um when you (1) when you do something for someone you get some feedback it's nice to see people happy' (MB)*

Participants also reflected on the development of dementia and how their relationship with service users with LDD, or at least the reciprocity within the relationship, began to disappear. In the following quote Ibsom reflects that this is a very hard part in the experience of caring for an individual with LDD.

*'when she first came you could have a laugh and joke with her, she knew, that you know, that she could do that with you, but now sh-she just seems that she's in her own little world and it's so hard to penetrate though that and communicate with her as you could at first, ev-even to reassure her, it's really hard' (Ibsom)*

This sentiment was echoed throughout participant transcripts and it appears that this was often perceived by the carers interviewed as the hardest part of caring for an individual with LDD. As a result of this participants reported really valuing any interaction, any reciprocity, when caring for this individual.

*'When she smiles or she laughs or she'll make eye contact with you and smile, it seems to mean a bit more, not a bit more, but it seems to get, it just feels a bit different coming from her than it does form the other residents so th-that's nice' (CK)*

Within this quote CK seems unable to express why the small and infrequent interactions with the service users with LDD feel different from other interactions with service users. Despite this CK clearly describes how much these interactions mean. This theme of valuing the small and rare interaction with a service user with LDD was reflected throughout all participant transcripts.

## Culture of LD Services

Multiple factors that could be considered as part of the culture of LD services were discussed, along with the impact these factors had on the experience of caring for people with LDD.

### *'From Empowering to Everything'*

All participants reflected that in general the aim of the care they provided is to promote the independence of their service users, ensuring that they do everything that they are capable of doing without assistance of carers. This sentiment is clearly illustrated in the following extract from Tindle's transcript.

*'I think when people think you're a carer it means you do every single thing for a that person, but you don't, it's really you enabling people to do as much for themselves as possible' (Tindle)*

When reflecting on the onset of dementia participants often noted that the amount they had to do for their service users grew. As the dementia progressed the care required was reported to increase to the point that they had to do everything for an individual who had previously been relatively independent.

*'you think but that chap could do so and so a few weeks ago or few months ago (1) he doesn't seem to be able to manage that any more, you know it's just not the age part of it, that's the dementia.....their independence is very important, and we don't want to take their independence away from them'*  
*(Bell)*

Bell suggests that loss of independence is not something that fits with the ethos of the service, when saying 'we don't want to take their independence away from them'. Bell also describes this change and indicates how hard it is to watch someone lose their independence. In fact this experience was often reflected on as

a particularly difficult change for carers to observe in their service user as dementia progressed.

*'it's soul destroying, you watch them and you think, I've now got to do that for him, he still looks in the mirror before he come out of his room, but sometimes you wonder if he knows why he's looking there now (2) so yeah it's heart breaking' (Titch)*

### *Person Centred Care and Knowing the Individual*

Participants from each of the three residential services reflected that this was the ideology of their service. The following quote from Loa is an example of how this was discussed within the transcripts.

*'e-everyone's an individual where ever I've worked and I understand that 100%, that what you do for (1) caring for one person isn't how you ought to do for the next person cos they're all different um (1) we do work on a person centred approach to everyone' (Loa)*

When discussing the onset of dementia it was reflected that this ideology was invaluable. The quote below from Bell illustrates how some participants felt a person centred approach provided insight into the behaviour of their service users with LDD, and whether or not it was linked to the dementia.

*'y-you get to know the real person (1) you get to know something's what they've been through and sometimes you can (1) recognise how their behaviour is now, is, could it be something from early, you know' (Bell)*

Participants also valued the fact they knew the person prior to dementia onset and were able to continue to implement a person centred care approach. Still believing they were caring for service users in a way they would like, this is described in the following quote from Tindle.

*'you have to sort of remember what type of food, well we know what type of food she likes, and what she didn't like and-and things like that' (Tindle)*

## The Emotional Impact

### *Frustration*

The most common theme under the title of Emotional Impact was feeling frustrated. This feeling mostly appeared to be the result of the loss of communication and reciprocity within the relationship between them and the individual with LDD.

*'it's a bit frustrating, especially if I think back, sometimes it's like, I sit and read to this lady (1) which is nice, I can remember her, she use to sit at the side of me and put her hand on the book, or turn the page or (1) now does she even know I'm there' (Adams)*

Adams describes how reflecting on the way the relationship used to be in regards to reciprocity can cause feelings of frustration, if compared to the limited reciprocity available within the relationship now.

### *Positive but Painful*

Carers often used a phrase similar to this to encapsulate their feelings about their work. Loa expresses the sadness that the work with individuals with LDD can cause, something many of the participants discussed.

*'while he was really, really ill he was crying out and we didn't know why and it was awful, so that was a sad time' (Loa)*

Despite this sadness participants also reflected on the sense of pride they achieved from their work. Which they felt made also the experience a positive one.

*'Yeah positive but painful um (2) I enjoy it because I because I, every time I-I come to work I go away feeling as though I've achieved something, I've helped again, I've made a difference again, if I weren't here, ok there's thousands of people out there who would take my place, but if we weren't here, if the carers weren't here where would those people be, so yes I-I've achieved something, I feel good about it' (Titch)*

Titch sums up these feelings of sadness and pride in the phrase 'positive but painful', reflecting on the pride experienced from caring for an individual with LDD and how this pride generates a positive experience of the job role.

#### *Anxiety about Getting Older*

The other emotional response described by the majority of participants was that working with those with LDD appears to heighten anxiety about aging and possibly developing dementia themselves.

*'People who don't work with people like that (2) don't realise how awful it is, whereas because I work with people like this, it's my biggest dread [laughs] whereas someone who works in a bank all their life and they get to 60 and they're told they're getting (1) dementia (2) they don't really know first-hand, they haven't seen it (2) they don't really know how awful things can get' (Smith)*

Smith describes the dread of developing dementia and how it is only through working with this population that this feeling began. In response to this anxiety participants reported feeling lucky, having a greater value for life and wanting to do more with the time they've got. This is discussed in the following extract from Bell.

*'you start wanting to do more things, you appreciate your own life (1) you stop taking things for granted and you look at things differently, you don't know when, you know obviously, when your times up, so you kind of live your life a bit more' (Bell)*

### Knowledge and Understanding

The theme of knowledge and understanding could be seen across all the transcripts. The participants reflected on their knowledge of dementia, and value was placed on being able to understand its progression and how care should change with this. In the following extract Bell talks about how training and better knowledge would help develop the services provision of care for the residents they support with LDD.

*'understanding the changes of the different stages and how it could affect the individual, (1) so we could maybe think right, we haven't done that, maybe we could be doing that to help them or something, I mean maybe we are doing everything we could be doing but there's always that chance (1) you know' (Bell)*

### *Training*

Level of training was also discussed within the transcripts. Those that had not received any formal training tended to report feeling unequipped to provide the best possible care for those LDD. The quote below illustrates this and CK reflects on the fact that lack of training and consequent lack of understanding will impact on the care provided for the individual with LDD.

*'I'm not sure how many of us have actually had any training on dementia um I know I haven't so that effects my work with her because I don't understand*

*it and because I don't really know, know much about it umm I guess I'm probably not being as effective with her or-th-as I could be' (CK)*

## **Discussion**

The purpose of this research was to investigate the caring experience of staff caring for individuals with LDD. This was done via interviews in which participants reflected on: the value of knowledge and training, what affect the culture of LD services had on their caring for those with LDD, the emotional impact of working with individuals with LDD, and the value staff placed on the relationships they form as part of their work. The data collected about the individuals with LDD whom the participants supported indicated that they were all reflecting on their experience of caring someone with severe decline due to dementia, both cognitively and socially.

### **Relationships and Reciprocity**

Within the transcripts all participants reflected on the importance of their relationships at work when working with individuals with LDD. This included their relationships with other carers and other professionals. Support from colleagues and other professionals acting as mediating factors have been investigated by a multiple studies (McCallion & McCarron, 2005). Formalised support networks within a health care environment have been reported to reduce stress amongst the staff carers (Lee & Crockett, 1994). More informal support has also been linked to reduced stress and depression (Toseland, Smith & McCallion, 2001) along with greater confidence and understanding of others' emotional reactions (Frost et al, 1991). This research is reflected within McCarron and McCallion's framework (2005), where it is included as a mediating factor.



The participant's discussion around relationships also considered their relationships with their service users, and the impact of the perceived loss of interaction with dementia onset. This theme reflects the findings of research into reciprocity in caring relationships. Pritchard (1969) suggests that the carer in a caring relationship will have an internal standard for this type of relationship regarding the amount they should invest and the level of return they should receive. If the individual continuously perceives that this internal standard is not met, and they are investing more than they are receiving, research indicates that a perceived lack of reciprocity develops (Pritchard, 1969).

It has also been suggested that if there is a perceived lack of reciprocity within a caring relationship it is likely to decrease the carers' investment (Thomas & Rose, 2010). This can lead to carers interacting with service users in a depersonalized way, along with a reduction in amount of empathy the carer displays. As a result continuous perceived lack of reciprocity within a complementary caring relationship can lead to emotional exhaustion, burnout, a deterioration in the caring relationship and through this a reduction of perceived personal achievement (Buunk & Schaufeli, 1993; Firth-Cozens & Payne, 1990).

In this study staff carers were supporting those who had experience severe decline due to dementia; as a result the reciprocity possible in the caring relationship was limited. Participants clearly valued the rare and small moments of reciprocity they experienced with their service users with LDD, as well as describing the reduction in these moments as a source of sadness. Despite this there was no reflection on how, or if this impacted on how they delivered care.

### Culture of LD Services

Participants reflected on the culture of their residential services and how this dictated the provision of care. All the transcripts included discussion about the wider culture of LD services within the United Kingdom, particularly the aim of care being to empower the individuals they work with, promoting independence and community participation (McCallion & McCarron, 2005). As an individual develops dementia, staff noted that the type of care they had to provide changed, and the focus on empowering an individual became more and more difficult as the dementia progressed- from empowering to everything. Other research has also observed this and that it can be hard for a staff carer seeing an individual they have empowered and taught new skills, lose these skills and require more input (Marine, Ruotsalainen, Serra & Verbeek, 2006).

This was reflected within the transcripts of this research with participants observing how hard it was to watch the individual with LDD lose their skills and consequently their independence, meaning care became less about empowering and more about meeting basic needs. With this in mind it could be suggested that perhaps aging in place for an individual with LD who develops dementia may not be appropriate, as the care required goes against the culture instilled in care staff, and as such can cause staff stress, which may negatively impact on care provision.

Despite this there are pros to aging in place. For instance participants from the three residential services reflected on the importance of person centred care within their service, stating that with the onset of dementia this ethos was invaluable in providing what they perceived to be the most appropriate care. Participants also valued the fact they knew the person prior to dementia onset, as they were able to continue to care for the service user with LDD in a way they believed the service user would like to be treated. Other researchers have commented on this culture within LD service and how it does act as an incentive for

creating opportunities to age in place (Courtenay et al, 2010; McCarron & McCallion, 2005; Watchman, 2003).

Interestingly despite this focus on the culture of person centred care and knowing the person they care for (Courtenay et al, 2010), there was no explicit mention of grief in reference to the onset of dementia. This may be because of their role as staff carers, and perhaps a belief that grief should only be for family. Yet closer inspection of the themes suggests that participants do reflect on some of the concepts of grief despite not directly referencing it. In particular participants discussed an increased appreciation for their own life and health (Kübler-Ross & Kessler, 2005). Participants also appeared to discuss mourning the losses of the multiple roles the person had in their lives, when referencing the loss of reciprocity within the relationship and the individual's loss of skills they had previously helped facilitate (Kübler-Ross & Kessler, 2005). As a result it is clear that the experience of grief in staff carers perhaps due to the person centred culture of LD services needs to be considered when deciding on appropriate service provision for those with LDD.

### The Emotional Impact

The negative emotional impact of caring is a common focus of staff carer literature (Skirrow & Hatton, 2007). McCarron and McCallion (2005) considered negative emotional impact as the potential outcome of caring within their revised Stress and Coping Framework; they included anxiety, burnout and depression. This was reflected in the themes of this research's transcripts with feelings of frustration and sadness reported as the emotional impact of working with individuals with LDD. This appeared to be mostly linked to the changes that occur with the progression of dementia, specifically the individual's loss of communication and previously held skills.

The other emotional response reflected on within the transcripts was an increase in anxiety, which again reflects previous research. However, this anxiety was mostly linked to the individual fearing growing old and about developing dementia themselves. As yet it appears that little research has explored this idea within staff carers working with an aging population, although the concept of death anxiety and how it may be stimulated by proximity to aging and death is discussed as a theory within existential therapy literature (Yalom, 2008).

Within the transcripts it was also observed that participants discussed the positive emotional impact of caring, describing a sense of pride they achieved from their work. The more recent development of research into the positive experiences of caring also indicates that staff carers are not wholly driven by the fact that caring is their job, and that they do also experience positive emotional responses to their work (Kane, 2001; Cooper et al, 2001; Schaufeli & Buunk, 2003). It is felt that these positive emotional responses are important in mediating the negative emotional impact of the caring role, which appears to encapsulate the concept of 'positive but painful' that was discussed by the participants in this research.

### Knowledge and Training

Few of the participants interviewed for this research had received any formal dementia training. This reflects the findings of previous studies on staff carer knowledge, which indicated that most staff carers within residential services for people with LD only had a basic knowledge of aging and dementia (Whitehouse et al, 2000). Which creates a reactive response to dementia, rather than having pre-planned changes to implement when required (Wilkinson, Kerr, Cunningham & Rae, 2004).

Participants appeared to place value on understanding the progression of dementia and how to adapt the care they provided accordingly. Linked to this they reflected on any training they had received; with those that had not received any formal training on dementia often reporting that they felt ill-equipped to provide the best possible care for their residents with LDD. This is perhaps unsurprising as the literature indicates that training and knowledge are important background and contextual factors when considering the development of stress in staff carers (McCallion & Kolomer, 2003; Toseland et al., 2001). This contribution to stress is thought to be due to a lack of training which results in staff carers experiencing more uncertainty about unexplained behaviours (McCarron & McCallion, 2005).

#### Clinical Implications and Further Research

This study suggests some areas for consideration in regards to clinical practise as well as indicating areas that may benefit from future research. One key finding was the emotional impact of caring, particularly participants reflection on experiences of sadness and frustration due to the loss of reciprocity within their relationship with service users with LDD. This highlights the importance of support being available for staff carers.

The value placed on support, the support of colleagues and of other professionals. This highlights the importance of provisions such as supervision for staff carers in this setting and as a result services should ensure that their structured policy for regular supervision is adhered to. The value of support also indicates that staff support groups may be another possible intervention. Despite the fact that the literature indicates the importance of support in mediating staff stress, as yet no research has begun to investigate the use of support groups, and again validating this may be an area for further research (Van Wyk & Pillay-Van Wyk, 2010; McCallion & McCarron, 2005).

Studies within healthcare have begun to assess the effects of teaching staff carer's skills to reduce their experience of job stress. This has included training to increase awareness of situations that may cause stress and how to respond in order to reduce it (Reynolds, Taylor & Shapiro, 1993; Rowe, 1999) as well as training in specific stress management techniques such as relaxation (Tsai & Crockett, 1993), assertiveness (Lee & Crockett, 1994), mindfulness (Mackenzie, Poulin & Seidman-Carlson, 2006) and career goal management (Yamagishi, 2008). Widespread implementation of such interventions within LDD residential settings should be the next step in this process. In order to allow for validation of these approaches, as well as leading to possible improvement in the experience of staff carers caring for those with LDD and mitigating the staff carer difficulties caused by aging in place.

Other forms of training are also an important consideration, this study and other research in the area has suggested that the level of knowledge a carer feels they have about dementia can greatly influence their experience of job stress. The literature has indicated that care-staff knowledge can be significantly improved by training on dementia, especially training focused on the behavioural changes that dementia may cause (Kalsy, Heath, Adams & Oliver, 2007). LD services appear to already understand the value of training for staff especially if services are to pursue an emphasis on aging in place for individuals with LD (Janicki et al, 2002). Yet despite this, guidelines within national policy to ensure this training is implemented are not currently in place. It appears that further investigation into the best type of training and the more long term influence of training is still an area in which future research could develop (Marine et al, 2006). Although it is already clear that training should be provided on LDD for staff cares involved in the provision of care. This training should provide practical information about dementia; its onset, course, possible behavioural changes and what can be done to help (Kalsy et al, 2007). As

well as this information about what can be emotional challenging when caring for those with LDD should be provided so staff carers are better prepared to provide aging in place.

Finally the sample used for this study should be considered, it consisted of mostly middle aged women and all were white British. If a social constructivist stance is taken then this is an important consideration, as all experience is seen through the lens of the individual's historical, cultural and linguistic context (Willig, 1999). However, this study uses IPA, and as such it only attempts investigate the in-depth experience of the participants of the research, as opposed to attempt to uncover a definitive truth, that is transferable to the population as a whole (Smith et al, 1999). For this reason the homogenous nature of the sample is not necessarily a limitation of the current research, however future research should be conducted to look at the experience of male staff carers, or staff carers from different cultural backgrounds.

### Limitations and Challenges

Within the design of the interview schedule and when conducting the interviews it became apparent that it would be difficult to look at the experience of caring for an individual with LDD completely separately from the participants other caring experience. This was especially difficult as all participants were currently caring for people with LD as well as an individual with LDD, and consequently this had to be considered throughout the analysis process.

Another consideration that needs to be made is how able participants felt to voice negative views and experiences within the interviews. Caring for vulnerable adults is a loaded topic within our society, with major news stories recently reporting abuse by staff carers. Thus carers may have been guarded in reporting

difficult experiences in fear of what judgements and inferences may have been made by the researcher.



## References

- Buunk, B. P., & Schaufeli, W. B. (1993). Professional burnout: a perspective from social comparison theory. In Schaufeli, W. B., Maslach, C. & Marek, T. (Eds.) *Professional Burnout: Recent Developments in Theory and Research* (pp. 53–69), UK: Hemisphere.
- Carers UK (2004). Carers UK- The Voice of Carers, Retrieved from <http://www.carersuk.org/Newsandcampaigns/News/Familiesatriskasfull-timecarersnumbersdouble>, 09/11/010.
- Chou, Y. C., Pu, C. Y., Lee, Y. C., Lin, L.C. & Kröger, T. (2009). Effect of perceived stigmatization on the quality of life among ageing female family carers: a comparison of carers of adults with intellectual disability and carers of adults with mental illness. *Journal Of Intellectual Disability Research: JIDR*, 53 (7), pp. 654-64.
- Coon, D. W., Rubert, M., Solano, N., Mausbach, B., Kraemer, H., Arguëlles, T., .....Gallagher-Thompson, D. (2004). Well-being, appraisal, and coping in Latina and Caucasian female dementia caregivers: Findings from the REACH study. *Aging & Mental Health*, 8(4), pp.330-345.
- Cooper, S. A. (1997). A population-based health survey of maladaptive behaviours associated with dementia in elderly people with learning disabilities. *Journal of Intellectual Disability Research*, 41(6), pp. 481-487.
- Cooper, L., Dewe, P. J. & O'Driscoll, M. P. (2001). *Organizational stress*. London: SAGE.
- Courtenay, K., Jokinen, N. S. & Strydom, A. (2010). Care giving and Adults with Intellectual Disabilities Affected by Dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), pp. 26-33.

- Deb, S., Hare, M., Prior, L. & Bhaumik, S. (2007). Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID). *British Journal of Psychiatry*, 190(1), pp. 440-444.
- Department of Health (2009). *Living well with dementia: a National Dementia Strategy implementation plan*. UK: Department of health.
- Duggan, L., Lewis, M. & Morgan, I. (1996). Behavioural changes in people with learning disability and dementia: A descriptive study. *Journal of Intellectual Disability Research*, 40(4), pp. 311-321.
- Elliot, R., Fischer, C. T. & Rennies, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38(1), pp. 215-229.
- Evenhuis, H. M., Kengen, M. M. F. & Eurlings, H. A. L. (2007). *Dementia Questionnaire for People with Learning Disability (DLD): UK adaptation*. San Antonio: Harcourt Assessment.
- Firth-Cozens, J. & Payne, R. (1990). *Stress in health professionals*. U.K.: Wiley.
- Forbat, L. (2006). Valuing people: Hopes and dreams for the future. *British Journal of Learning Disabilities*, 34(1), pp. 20-27.
- Frost, J. C., Makadon, H. J., Judd, D., Lee, S., O'Neill, S.F. & Paulsen, R. (1991). Care for caregivers: a support group for staff caring for AIDS patients in a hospital-based primary care practice. *Journal of General Internal Medicine*, 6(2), pp. 162-7.
- Gaugler, J. E., Davey, A., Pearlin, L. I., & Zarit, S. H. (2000). Modelling caregiver adaptation over time: The longitudinal impact of behaviour problems. *Psychology and Aging*, 15(3), pp. 437-450.
- Grant, G. (2001). Supporting the supporters – some reflections on family care giving. In Thompson, J. & Pickering, S. (Eds.), *Meeting the health needs of*

*people who have a learning disability* (pp. 288–305), London: Bailliere Tindall, Harcourt Publications LTD.

Gwyther, L. P. (2000). Family issues in dementia: Finding a new normal.

*Neurologic-Clinics*, 18(1), pp. 993–1010.

Health Economics Research Centre & University of Oxford (2010). *Dementia 2010:*

*The economic burden of Dementia and associated research funding in the United Kingdom*. UK: Alzheimer's Research Trust.

Jacobson, G. H., Aldana, S. G., Goetzel, R. Z., Vardell, K. D., Adams, T. B. &

Pietras, R. J. (1996). The relationship between perceived stress and self-reported illness-related absenteeism. *American Journal of Health Promotion*, 11(1), pp. 54–61.

Janicki, M.P., Henderson, C. M., Davidson, P. W., McCallion, P., Taets, J. D.,

Force, L.T.,.....Ladrigan, P. M. (2002). Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research*, 46(4), pp. 287-298.

Kalsy, S., Heath, R., Adams, D. & Oliver, C. (2007). Effects of training on

controllability attributions of behavioural excesses and deficits shown by adults with Down syndrome and dementia. *Journal of Applied Research in Intellectual Disabilities*, 20(1), pp. 64–68.

Kane, R. A. (2001). Long term care and a good quality of life. *Gerontologist*, 41(1),

pp. 293–304.

Kübler-Ross, E. & Kessler D. (2005). *On Grief and Grieving: Finding the Meaning*

*of Grief through the Five Stages of Loss*. New York: Scribner

- Lawrence, V., Murray, J., Samsi, K. & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. *British Journal of Psychiatry*, 193(3), pp. 240-246.
- Lee, S. & Crockett, M. S. (1994). Effect of assertiveness training on levels of stress and assertiveness experienced by nurses in Taiwan, Republic of China. *Issues in Mental Health Nursing*, 15(4), pp. 419–32.
- Mackenzie, C. S., Poulin, P. A. & Seidman-Carlson, R. (2006). A brief mindfulness-based stress reduction intervention. *Applied Nursing Research*, 19(2), pp. 105–9.
- Marine, A., Ruotsalainen, J. H., Serra, C. & Verbeek, J. H. (2006). Preventing occupational stress in healthcare workers, Cochrane Database of Systematic Reviews. Issue 4, Art. No.: CD002892., DOI: 10.1002/14651858.CD002892.pub2.
- McCallion, P. & Kolomer, S. R. (2003). Understanding and addressing psychosocial concerns among aging family caregivers of persons with intellectual disabilities. In Davidson, P. W. , Prasher, V. & Janicki, M. P. (Eds.), *Mental health, intellectual disabilities and the aging process* (pp. 179–196), London: Blackwell.
- McCallion, P., McCarron, M. & Force, L. T. (2005). A measure of subjective burden for dementia care: The Caregiving Difficulty Scale - Intellectual Disability. *Journal of Intellectual Disability Research*, 49(5), pp. 365-371.
- McCarron, M. & McCallion, P. (2005). A revised stress and coping framework for staff carers of persons with intellectual disabilities and dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 2(2), pp. 139-148.

- McLaughlin, K. & Jones, A. (2011). 'It's all changed:' Carers' experience of caring for adults who have Down's syndrome and dementia. *British Journal of Learning Disabilities*, 39(1), pp. 57-63.
- McConkey, R., McAuley, P., Simpson, L. & Collins, S. (2007). The Male Workforce in Intellectual Disability Services. *Journal of Policy and Practice in Intellectual Disabilities*, 4(3), pp. 186 – 193.
- Millichap, D., Oliver, C., McQuillan, S., Kalsy, S., Lloyd, V. & Hall, S. (2003). Descriptive functional analysis of behavioural excesses shown by adults with Down's syndrome and dementia. *International Journal of Geriatric Psychiatry*, 18(9), pp. 844-854.
- National Health Service (2009), Carers Direct,  
<http://www.nhs.uk/CarersDirect/guide/kinds/Pages/Overview.aspx?WT.src=h=1&WT.NHScampaign=Carers%20-%20Only&WT.NHSadgroup=Carers%20-%20Only&WT.NHSkeyword=carers>, 09/11/010.
- Nation Institute for Health and Clinical Excellence- NICE (2006). Dementia: Supporting People with Dementia and their Carers in Health and Social Care. UK: NICE.
- Pearlin, L. I., Mullan, J. T., Semple, S. J. & Skaff, M. M. (1990). Care giving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), pp. 583-594.
- Pritchard, R. D. (1969). Equity theory: a review and critique. *Organizational Behaviour and Human Performance*, 4(1), pp. 176–211.
- Raiger, J. (2005). Applying a Cultural Lens to the Concept of Burnout. *Journal of Transcultural Nursing*, 16(1), pp. 71–6.

- Reynolds, S., Taylor, E. & Shapiro, D. (1993). Session impact and outcome in stress management training. *Journal of Community and Applied Social Psychology*, 3(1), pp. 325–37.
- Rose, J., Jones, F. & Fletcher, B. (1998). Investigating the relationship between stress and worker behaviour. *Journal of Intellectual Disability Research*, 42(1), pp. 163–172.
- Rose, J. & Schlewa-Davies, D. (1997). Staff stress and team climate. *Journal of Learning Disabilities*, 1(1), pp. 19–24.
- Rowe, M. M. (1999). Teaching health-care providers coping: results of a two-year study. *Journal of Behavioural Medicine*, 22(5), pp. 511–27.
- Schaufeli, W. & Buunk, B. (2003). Burnout: An Overview of 25 Years of Research and Theorizing. In Schabracq, M. J., Winnubst, J. A. M. & Cooper, C. L. (Eds.), *The handbook of Work and Health Psychology* (2nd Edition, pp. 383–424), UK: Wiley.
- Schaufeli, W. & Enzmann, D. (1998). *The burnout companion to study and practice*. London: Taylor and Francis.
- Skirrow, P. & Hatton, C. (2007). 'Burnout' amongst direct care workers in services for adults with intellectual disabilities: A systematic review of research findings and initial normative data. *Journal of Applied Research in Intellectual Disabilities*, 20(1), pp. 131–144.
- Smith, J. A., Jarman, M. & Osborn, M. (1999). Doing Interpretative Phenomenological Analysis. In Murry, M. & Chamberlain, K. (Eds.), *Qualitative Health Psychology* (pp. 218-240), London: Sage.
- Stenfert-Kroese, B. & Fleming, I. (1992). Staff attitudes and working conditions in community based group homes for people with mental handicaps. *Mental Handicap Research*, 5(1), pp. 82–91.

- Strydom, A., Lee, L. A., Jokinen, N., Shoshtari, S., Raykar, V., Torr, J.,.....Maaskant, M. A. (2009). *Report on the State of Science on Dementia in People with Intellectual Disabilities*. UK: IASSID Special Interest Research Group on Ageing and Intellectual Disabilities.
- Thomas, C. & Rose, J. (2010). The relationship between reciprocity and the emotional and behavioural responses of staff. *Journal of Applied Research in Intellectual Disabilities*, 23(1), pp. 167-178.
- Toseland, R., Smith, G. & McCallion, P. (2001). Helping family caregivers. In Gitterman A. (Ed.), *Handbook of social work practice with vulnerable populations* (pp. 548–581). New York: Columbia University Press.
- Tsai, S. L. & Crockett, M .S. (1993). Effects of relaxation training, combining imagery, and meditation on the stress level of Chinese nurses working in modern hospitals in Taiwan. *Issues in Mental Health Nursing*,14(1), pp. 51–66.
- Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J. A. & Walsh, S. (1997). Standards for research projects and theses involving qualitative research methods: Suggested guidelines for trainees and courses. *Clinical Psychology Forum*, 108(1), pp. 3-7.
- Van Wyk, B. E. & Pillay-Van Wyk, V. (2010). Preventive staff-support intervention for health workers (Review). *The Cochrane Database of Systematic Reviews*, Issue 3, Art. No.: CD003541, DOI: 10.1002/14651858.CD003541.pub2.
- Watchman, K. (2003). Critical issues for service planners and providers of care for people with Down's syndrome and dementia. *British Journal of Learning Disabilities*, 31(2), pp. 81-84.

- Weinberg, A. & Creed, F. (2000). Stress and psychiatric disorder in healthcare professionals and hospital staff. *Lancet 2000*, 355 (9203), pp. 533–7.
- Whitehouse, R., Chamberlain, P. & Tunna, K. (2000). Dementia in people with learning disabilities: A preliminary study into care staff knowledge and attributions. *British Journal of Learning Disabilities*, 28(4), pp. 148-153.
- Wilkinson, H., Kerr, D., Cunningham, C. & Rae, C. (2004). *Home for good? Preparing to support people with learning difficulties in residential settings when they develop dementia*. UK: Pavilion Press.
- Willig, C. (1999). Beyond appearances: A critical realist approach to social constructionism. In Nightingale, D. J. and Cromby, J. (Eds.), *Social constructionist psychology: A critical analysis of theory and practice* (pp. 37-51), UK: Open University Press
- Wooff, D., Schnieder, J., Carpenter, J. & Brandon, T. (2003). Correlates of stress in carers. *Journal of Mental Health*, 12(1), pp. 29-40.
- Yalom, I. (2008). *Staring at the Sun: Overcoming the Terror of Death*. U.K.: Piatkus Books.
- Yamagishi, M., Kobayashi, T. & Nakamura, Y. (2008). Effects of web based career identity training of stress management among Japanese nurses: a randomised control trial. *Journal of Occupational Health*, 50(1), pp. 191–3.



## Appendices

**Appendix A:**  
**Reflective Statement**

## Reflective Statement

### Systematic Literature Review

I'd had no previous experience of conducting a systematic literature review and begun the process of learning this new methodology with enthusiasm. Advice from colleagues who had previously completed a systematic review was to begin the process as soon as possible, and given the length of time the review took this input was invaluable.

During the process of completing scoping searches and defining a question the enthusiasm soon turned to anxiety. The attempts to set limiters and lay out the inclusion and exclusion criteria was at times overwhelming, and the entire process was conducted numerous times before I was satisfied that I had conducted the steps in a systematic and replicable manner. Even then I still had concerns that I may have missed something important.

This desire to ensure the process was entirely correct and nothing important was missed meant I was thorough when reading the abstracts and full texts. As a result this process was far longer than I had previously anticipated. I often had to re-read papers to fully understand them and sometimes it was only on reading a paper multiple times that I discovered it did not meet the criteria for the review I was conducting. This was a frustrating and monotonous process.

While conduct the review I was simultaneously working on the empirical research and at times I felt so disheartened by the review process that the empirical paper received more input. The support of my research supervisor at this time was invaluable. It helped to reflect on the fact I was avoiding the review paper as it felt overwhelming, however avoidance did nothing to reduce this feeling. Several days of intensive work on the paper eventually yielded some progress which was sufficient to reduce the anxiety that the review had been causing.

I feel I learnt from these challenges and would adapt my approach to future research in order to avoid these complications. For instance before beginning I would ensure I had a clear and coherent question set out, as well as a clear process for searching and extracting papers, and I would now set aside more time.

Towards the end of the write up process some of the enthusiasm felt at the beginning of the process returned. Especially when I was able to use the knowledge gained from reading the numerous papers within the interpretation of the findings of my empirical paper. The realisation of the link between the two papers was a real pleasure, and it was clear that the process, albeit difficult at times, had greatly enhanced my knowledge of the literature in this area. For this reason I can appreciate the value of systematic reviews and feel that I now am better placed to conduct this type of review in the future.

### Empirical Paper

The empirical research element of the compendium thesis went through many incarnations in the initial stages of the development process. This included a lengthy consideration of a quantitative design, which was to be based on validating some of the factors considered in McCallion and McCarron's (2005) stress framework for the experience of carers working with individuals with LDD. During the peer review stage it became clear that this idea was unfeasible, especially given the constraints of thesis research. At this point the concept was reconsidered and the current methodology and approach was decided on (see the epistemological statement for a detailed explanation of why IPA was chosen).

### *Conducting Interviews*

After months of multiple reports, preparation, peer reviews and ethics approval I was keen to start the interview process and truly begin the research I had set out to do. Conducting the interviews was an enjoyable process, and the staff I had the privilege of interviewing were incredibly open and honest in discussing their experiences. Within this process the interview questions underwent some alteration, with areas that appeared to yield more relevant information being incorporated. I also had not anticipated how foreign the interview process would initially feel. As I conducted more interviews my technique developed and became more appropriate for research interviews.

It was also during the process of conducting interviews that I began to appreciate the purpose of my research. Although I had a well-defined idea based on the literature it was not until I was able to talk with staff carers working with this population that I began to see the value of my research on a clinical level. Carers appeared to see my research as important in giving them a voice, and were enthusiastic at the idea that there was potential for it to be published. It is this feedback that will push me forward in attempting to get the empirical paper published.

### *Transcribing and Analysis*

The experience of completing the empirical paper was overall a positive one, with the interviews and analysis stage being particularly enjoyable and interesting. I did struggle at times with the transcribing process. Yet when beginning the analysis phase, I realised I already knew the transcripts quite well as a result of the transcribing process. As a result, I would recommend completing transcribing

yourself and not, as tempting as it is, getting someone else to complete this process for you.

As a result of using an IPA approach I had to ensure my own opinions and beliefs was kept in mind during the analysis process, in order to minimise the impact they had on the research findings. During the initial process of surveying the literature I developed an interest in the research surrounding the positive experience of caring. So much of the research focused on the negative experiences of caring and little seemed to look at why people choose to continue caring despite the obvious stressors. For this reason I was keen to ensure that the research I undertook would not focus on the negative aspects of caring for people with LDD, and this opinion could have influenced my results. The validation methods implemented should have helped mediate this, especially the reflective log and IPA group. Although despite this, it is inevitable that my own beliefs and areas of interest will have affected the analysis stage to some degree, and as such the results reported should be considered with this in mind.

### Overall

Overall the completion of the compendium thesis was a positive one. There were some areas of difficulty, particularly with the SLR, however I feel I learnt from these and would be better placed to conduct similar research in future. The interest I had in the experience of care staff has developed throughout this process and I would be interested in conducting further research in this area in the future. Perhaps beginning to validate the interventions and preventative strategies which may help mediate the negative impact of caring.

**Appendix B:**

**Author Guidelines for Clinical Psychology Review**



ELSEVIER CLINICAL PSYCHOLOGY REVIEW

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*Clinical Psychology Review* publishes substantive reviews of topics germane to clinical psychology. Papers cover diverse issues including: psychopathology, psychotherapy, behaviour therapy, cognition and cognitive therapies, behavioural medicine, community mental health, assessment, and child development. Papers should be cutting edge and advance the science and/or practice of clinical psychology.

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Psychologists and Clinicians in Psychopathy

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**Appendix C:****Reference for SLR Papers Excluded (after full reading)**



## References

- Devereux, J. M., Hastings, R. P., Noone, S. J., Firth, A. & Totsika, V. (2009). Social Support and Coping as Mediators or Moderators of the Impact of Work Stressors on Burnout in Intellectual Disability Support Staff. *Research in Developmental Disabilities*, 30(1), pp. 367 – 377.
- Dyer, S. & Quine, L. (1998). Predictors of Job Satisfaction and Burnout Among the Direct Care Staff of a Community Learning Disability Service. *Journal of Applied Research in Intellectual Disabilities*, 11(4), pp. 320 – 332.
- Hatton, C., Emerson, E., Rivers, H., Mason, H., Mason, L.,.....Alborz, A. (1999a). Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research*, 43(4), pp. 253–267.
- Hatton, C., Rivers, H., Mason, H., Emerson, E., Kiernan, C., Reeves, D. & Alborz, A. (1999b). Organizational culture and staff outcomes in services for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 43(3), pp. 206–218.
- Howard, R., Rose, J. & Levenson, V. (2009). The Psychological Impact of Violence on Staff Working with Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22(1), pp. 538 – 548.
- McConkey, R., McAuley, P., Simpson, L. & Collins, S. (2007). The Male Workforce in Intellectual Disability Services. *Journal of Policy and Practice in Intellectual Disabilities*, 4(3), pp. 186 – 193.
- Rose, D., Horne, S., Rose, J. & Hastings, R. P. (2004). Negative Emotional Reactions to Challenging Behaviour and Staff Burnout: Two Replication

Studies. *Journal of Applied Research in Intellectual Disabilities*, 17(1), pp. 219 – 223.

Rose, J., Madurai, T., Thomas, K., Duffy, B. & Oyeboode, J. (2010). Reciprocity and Burnout in Direct Care Staff. *Clinical Psychology and Psychotherapy*, 17(1), pp. 455 – 462.

Sharp, K., Murray, G. C. & McKenzie, K. (2002). Stress Busters. *Learning Disability Practise*, 5(6), pp. 12 – 16.

**Appendix D:**

**Rationale for SLR's Inclusion and Exclusion Criteria**

Rationale for Systematic Literature Review Inclusion and Exclusion Criteria

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>	<b>Rationale</b>
Participants are caring for an adult aged 18 years+ with a recognised Learning Disability		As this review is focused on the experience of caring for adults (18+ years) with a Learning Disability.
Papers which focus on the carer's experience of caring and/or what may impact on the carers experience		As this is the desired area of focus for this review,
Participants are employed within a residential home with the job title Carer or Support Worker and receive pay for their work.		As the focus of this research is on the experience of staff carers, thus the job title and receiving pay for their work is necessary.
	Literature reviews and book reviews	Literature reviews, book reviews and other non-empirical papers would not present any evidence for what this review aims to investigate and the report of previous studies

		by reviews may be incomplete or biased.
	Focus on participants caring for an adult aged 18 years+ with a recognised Learning Disability and additional diagnosis such as Mental Health problems and Substance Abuse	The experiences of caring for an individual with Learning Disability and additional difficulties were not included due to potential confounding factors.
	Papers not written in English	The articles could not be translated into English due to time constraints and financial limitations.
	Research conducted outside of the United Kingdom	Each country has a different set up for services involved in the provision of care for individuals with Learning Disability; this may cause variation in the experience of carers. As such this review focused on the United Kingdom.
	Papers which are not peer	To ensure a similar base

	reviewed	line standard for all papers to be included within the review.
	Participants who work in a forensic or non-residential setting.	The culture of these services and the nature of the role can be very different in forensic and non-residential settings. Thus these settings were considered distinct from the chosen area of focus for this review- staff carers.

**Appendix E:**  
**Data Extraction Form**

**Data Extraction**

<b>General Information</b>	<i>Title</i>		
	<i>Author</i>		
	<i>Year</i>		
<b>Study Characteristics</b>	<i>Research Aims</i>		
	<i>Hypothesis</i>		
	<i>Study Design</i>		
	<i>Participants</i>	<u>Number</u>	
		<u>Age</u>	
		<u>Gender</u>	
		<u>Other</u>	
	<i>Participant Recruitment</i>	<u>Method</u>	
		<u>Inclusion Criteria</u>	
		<u>Exclusion Criteria</u>	
		<u>Drop-out</u>	
	<i>Quality</i>		
<i>Measures used</i>			
<b>Results</b>	<i>Analysis used</i>		
	<i>Main Findings</i>		
<b>Conclusions</b>	<i>Interpretation of Results</i>		
	<i>Limitations</i>		
	<i>Further Research Suggested</i>		



**Appendix F:**  
**Quality Measure**

Title of Study:

Year Published:

Authors:

Journal:

Questions	Yes = 2 Partly = 1 No = 0
<p><b>1. Is the Qualitative/Quantitative approach appropriate?</b></p> <p>➤ Could another approach have better addressed the research question?</p>	
<p><b>2. Is the study clear in what it seeks to do?</b></p> <p><u>Qualitative:</u></p> <p>➤ Is the purpose of the study discussed?</p> <p>➤ Are the research question(s) presented?</p> <p>➤ Is there adequate/appropriate reference to the literature?</p> <p>➤ Are underpinning values/assumptions/theory discussed?</p> <p><u>Quantitative:</u></p> <p>➤ Is the purpose of the study discussed?</p> <p>➤ Are the hypothesis presented?</p> <p>➤ Are the Outcomes to be measured clearly stated?</p>	
<p><b>3. How defensible/rigorous is the research design/methodology?</b></p> <p>➤ Is the design appropriate to the research question?</p> <p>➤ Is a rationale given for using the approach?</p>	
<p><b>4. How well was the data collection carried out?</b></p> <p>➤ Are the data collection methods clearly described?</p> <p>➤ Were the appropriate data collected to address the research question?</p>	
<p><b>5. Is the context clearly described?</b></p> <p><u>Both:</u></p>	

<ul style="list-style-type: none"> <li>➤ Are the characteristics of the participants and settings clearly defined?</li> <li>➤ Was context bias considered?</li> </ul> <p><u>Qualitative:</u></p> <ul style="list-style-type: none"> <li>➤ Has the relationship between the researcher and the participants been adequately considered?</li> <li>➤ Does the paper describe how the research was explained and presented to the participants?</li> </ul>	
<p><b>6. <u>Qualitative:</u> Was the analysis sufficiently rigorous?</b></p> <ul style="list-style-type: none"> <li>➤ Is the procedure explicit – is it clear how the data were analysed to arrive at the results?</li> <li>➤ How systematic is the analysis – is the procedure reliable/dependable?</li> <li>➤ Is it clear how the themes and concepts were derived from the data?</li> </ul> <p><b><u>Quantitative:</u> Were the measures used valid and reliable?</b></p>	
<p><b>7. Is the analysis reliable?</b></p> <p><u>Qualitative:</u></p> <ul style="list-style-type: none"> <li>➤ Did more than one researcher theme and code transcripts/data?</li> <li>➤ Did participants feedback on the transcripts/data? (if possible and relevant)</li> </ul> <p><u>Quantitative:</u></p> <ul style="list-style-type: none"> <li>➤ Were the statistical tests used to assess the main outcomes appropriate?</li> </ul>	
<p><b>8. Are the findings convincing?</b></p> <p><u>Both:</u></p> <ul style="list-style-type: none"> <li>➤ Are the findings clearly presented?</li> <li>➤ Are the findings internally coherent?</li> <li>➤ Are the data appropriately referenced?</li> <li>➤ Is the reporting clear and coherent?</li> </ul> <p><u>Qualitative:</u></p> <ul style="list-style-type: none"> <li>➤ Are extracts from the original data included?</li> </ul> <p><u>Quantitative:</u></p>	

<ul style="list-style-type: none"> <li>➤ Have actual probability values been reported?</li> </ul>	
<p><b>9. Are the findings relevant to the aims of the study?</b></p>	
<p><b>10. Are the conclusions adequate?</b></p> <ul style="list-style-type: none"> <li>➤ How clear are the links between data, interpretation and conclusions?</li> <li>➤ Are the conclusions plausible and coherent?</li> <li>➤ Have alternative explanations been explored and discounted?</li> <li>➤ Does this study enhance understanding of the research subject?</li> <li>➤ Are the implications of the research clearly defined?</li> <li>➤ Is there adequate discussion of any limitations encountered?</li> </ul>	
<p><b>11. How clear and coherent is the reporting of ethical considerations?</b></p> <ul style="list-style-type: none"> <li>➤ Have ethical issues been taken into consideration?</li> <li>➤ Are ethical issues discussed adequately – do they address consent and anonymity?</li> <li>➤ Have the consequences of the research been considered; for example, raising expectations, changing behaviour?</li> </ul>	

Based on:

National Institute for Clinical Excellence (2007), The Guidelines Manual, London, National Institute for Clinical Excellence

Downs and Black, The feasibility of creating a checklist for the assessment of the methodological quality of both randomised and non-randomised studies of health care interventions, J Epidemiol Community Health, 1998, 52(1), pp. 377-384.

**Appendix G:**

**Author Guidelines for Journal of Applied Research in Intellectual Disabilities**

# Journal of Applied Research in Intellectual Disabilities

[Published on behalf of](#)

**Edited by:**

Chris Hatton and Glynis Murphy

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[Top](#) **Author Guidelines**



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version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

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- Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning*

*Disabilities*. Cambridge University Press, Cambridge.

-McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.

-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

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**Appendix H:**  
**Epistemological Statement**

### **Epistemological Statement**

During the process of developing the research for the empirical paper of this compendium thesis, much time was spent considering which methodology would be most effective. It was encouraged to consider which methodology would best meet the aims of the research as well as what would fit with the ideological perspective of the researcher. To begin with a quantitative approach was considered as it appeared to fit with the aim of the research and offered the researcher an opportunity to use this methodology, as all previous research experience had used a qualitative approach. This changed during the peer review process, where it was pointed out that there is a limited amount of research which focuses on staff carers working with those with LDD. For this reason it is extremely difficult to reliably define the carer experience for staff carers, working with the LDD population, so as to look at any particular area of this experience in a quantifiable manner. Thus a quantitative approach could not effectively capture what the research set out to achieve.

It was also noted that my own ideological perspective meant that a qualitative approach would better fit with what I wanted to contribute to this area of research. This perspective could be considered as social constructivist, in that I believe that reality is not composed of truths which can be discovered (a positivists stance; Cohen, Manion, & Morrison, 2007). Instead reality is unique and personal to the individual, it is a product of our culture, our ethnicity, our place in society, our age, the time we live in and our past experiences (Willig, 1999). Qualitative research aims to explore individual experience (Willig, 2001) and allows this research to look at the unique experiences of staff cares working with those with LDD so that we can begin to give meaning to this experience of caring. It does not aim to create an evidence base that can be generalised. So it was decided to

pursue a qualitative approach, and the multiple methods within this for collecting and analysing data were then considered.

*Interpretive Phenomenological Analysis (IPA):* IPA is both phenomenological and idiographic. It is phenomenological in that it explores an individual's perception of an event as opposed to attempting to produce an objective record of it (Smith, Jarman & Osborn, 1999). It is also idiographic as it is concerned with just the detailed analysis of the case perhaps before moving further case analysis (Smith et al, 1999). In short IPA is a technique which attempts to understand lived experience and how an individual makes sense of an experience- the meaning of them (Smith et al, 1999). As a result this methodology lends itself to an exploratory study of the lived experience (the experience and meaning) of staff carers working with individuals with both LDD.

*Discourse Analysis:* Discourse analysis was actually the first method of analysis considered, as it emerged from the Social Constructionist movement and the researcher had previous experience with its use (Willig, 2001). This approach examines how language is used by an individual in a social context, to construct meaning for their experiences. It involves interviews, often via focus groups, which are then transcribed, and analysed with particular focus on the linguistics (Willig, 2001). The difficulty with Discourse Analysis for this research is that it assumes that what is said is what the individual means- i.e. language is taken at face value (Willig, 2001). Staff carers who may feel unable to express difficult feelings to another professional may not always be articulating exactly what they mean (Willig, 2001). IPA methodology allows for a more interpretative stance (Smith et al, 1999).

*Grounded Theory:* When conducting Grounded Theory the researcher begins by drawing themes based on theoretical ideas from initial interviews or another data source, such as written extracts, or magazines and newspapers (Willig, 2001). Following this stage, further interviews are conducted and analysed (Willig, 2001). In this process the researcher compares new data with the previous data, checking for similar or conflicting themes (Willig, 2001). This process continues until a point of data saturation; at this point the data contains no more new themes or concepts (Willig, 2001). This approach allows Grounded Theory to aid the development of theory (Willig, 2001) and it is for this reason that this methodology was not chosen. This research does not aim to produce new theoretical ideas, and is instead interested in the lived experience of participants, so it was felt that Grounded Theory was not appropriate.

*Content Analysis:* This approach allows for quantitative analysis of qualitative data (Willig, 2001). The number of times a particular word or theoretical idea occurs within a data source (e.g. an interview transcript) is recorded and quantified, the researcher then uses statistics to analyse this new data (Willig, 2001). In order to use this approach the researcher must define the words and concepts to be quantified. Not only does this create a bias towards the researchers' viewpoint, i.e. investigating the researcher's reality and not the participant, it also requires the researcher to have some concepts in mind that they wish to investigate. As there is a limited amount of research in the area of staff carers working with those with LDD, it is extremely difficult to define any particular area in a quantifiable manner. For this reason Content Analysis was not chosen for this research.

## References

- Cohen, L., Manion, L. & Morrison, K. (2007). *Research Methods in Education: Sixth Edition*. Oxon: Routledge.
- Smith, J. A., Jarman, M. & Osborn, M. (1999). Doing Interpretative Phenomenological Analysis. In Murry, M. and Chamberlain, K. (Eds.), *Qualitative Health Psychology* (pp. 218-240), London: Sage.
- Willig, C. (1999). Beyond appearances: A critical realist approach to social constructionism. In Nightingale, D. J. and Cromby, J. (Eds.), *Social constructionist psychology: A critical analysis of theory and practice* (pp. 37-51), UK: Open University Press
- Willig, C. (2001). *Introducing Qualitative Research in Psychology: Adventures in Theory and Practice*. USA: Open University Press.



**Appendix I:**  
**Ethics Approval**



SRK/JBK

23 May 2011

Ms C Moore  
Department of Clinical Psychology  
The University of Hull  
Cottingham Road  
HULL  
HU6 7RX

Dear Charlotte

**Re: CARE STAFF EXPERIENCE OF SUPPORTING PEOPLE WITH LEARNING  
DISABILITY AND DEMENTIA**

Thank you for sending me the revised documentation for your research project. I can confirm that these changes are appropriate and I am now able to fully approve your research proposal.

May I once again take this opportunity of wishing you every success with your research.

Yours sincerely

A handwritten signature in black ink, appearing to read "S. R. Killick".

STEPHEN R KILLICK  
Chair - PGMI Ethics Committee

Professor Nicholas D Stafford MB FRCS  
Director - Postgraduate Medical Institute  
Postgraduate Medical Institute, Hartford Building (Room 203)  
The University of Hull  
Hull, HU6 7RX, UK  
T: +44 (0) 1482 465348/464213  
F: +44 (0) 1482 469421  
N.D.Stafford@hull.ac.uk

**Appendix J:**  
**Information Sheet**



## **Care Staff Experience of Supporting People with Learning Disability and Dementia Participant Information Sheet**

*We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. **The researcher will go through the information sheet with you and answer any questions you have.** We'd suggest this should take about 5 minutes. Please ask if anything is not clear.*

### ***What is the purpose of the study?***

Due to the general increase in life expectancy of the population as a whole, there has been an increase in the illnesses of older life, such as dementia, within those with learning disabilities (Forbat, 2006).

Caring for people with learning disabilities and dementia can at times be difficult and challenging and research shows it is important to support carers so as to reduce any distress caused by the prolonged strain of caring.

There has not been very much research looking at what it is like for staff carers working with those with both a learning disability and dementia. More research in this area is needed. The purpose of this study is to gain an understanding of the experience of staff carers working with individuals with LD and dementia.

### ***Why have I been invited?***

You have been invited to take part because you are a staff carer currently working with an individual with both a Learning Disability and Dementia- and have done so for at least six months. We are hoping to recruit around 12 staff carers in total.

### ***Do I have to take part?***

No, it is up to you to decide to take part. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. Whether or not you take part will have no effect on your work.

### ***What will happen if I decide to take part?***

We will arrange a time convenient to you for you to participate in the study. Initially you will be asked to sign the consent form and then you will be given two questionnaires to fill in. The questionnaire will ask some general questions about you, the individual(s) you care for and some information about your experience as carer. The questionnaires should take about 10 minutes to complete.

After this we will begin the interview, this will last approximately an hour and will consist of a series of questions about your experience working with people with both

a learning disability and dementia. The interview will be recorded and at a later point transcribed by the primary researcher.

***What are the possible disadvantages and risks of taking part?***

Taking part in this study requires some of your time, which may be inconvenient for you. It is possible that you may find some of the questions difficult. This is because you will be asked to think about your experience of caring and how these have affected you.

At the end of the Interview there will be an opportunity to ask questions and talk about how you found the interview. If you do become upset during or after answering any of the questions you should talk to your line manager or supervisor.

After completing the interview if you have any questions regarding the research you can contact the researcher.

***What are the possible benefits of taking part?***

We hope that the information we gain from this study will help improve the understanding of staff carers experience in this area and perhaps lead to changes in support and service procedure.

Taking part will also give you an opportunity to think about your experience of caring and some people find that helpful.

***What will happen if I decide I no longer wish to take part?***

You can decide not to take part in the study at any point in the process, including after signing the consent form. Even if you have already completed the questionnaire and interview, if you have kept a note of your pseudonym, you can contact us at any time and we will remove and destroy any information you have provided.

***What if there is a problem?***

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [Primary Researcher's research mobile number to be inserted].

***Will my taking part in this study be kept confidential?***

All data will be handled according to ethical and legal practice and any information collected about you during the course of the research will be anonymous. Your completed questionnaires and interview transcript will be labelled with your pseudonym. This will be used throughout the analysis of the results. All audio recordings, questionnaires and transcripts will be stored securely and will only be accessible by the researcher and the research supervisor. They will be destroyed after use.

***What will happen to the results of the study?***

The findings will be written up as part of a doctoral degree in clinical psychology. The final write up may also be published in an academic journal so other people

can read about the findings of the study. You will not be personally identified in any parts of the final write up.

***Who is organising the research?***

This research is being undertaken as part of a doctoral research project in Clinical Psychology at the University of Hull.

***Who has reviewed the study?***

All research conducted by the University of Hull is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by a Research Ethics Committee. This means the study has been checked to make sure it is appropriate and ethical.

***Further information and contact details***

If you have any further questions or queries, please contact Charlotte Moore on 07504492156 between the hours of 9:30am and 4:30pm.

**Appendix K:**  
**Information Poster**

Primary Researcher: Charlotte Moore

Supervisor: Dr Nick Hutchinson;

### **INTRODUCTION**

Due to the general increase in life expectancy of the population as a whole, there has been an increase in the illnesses of older life, such as dementia, within those with learning disabilities (Forbat, 2006).

Caring for people with learning disabilities and dementia can at times be difficult and challenging and research shows it is important to support carers so as to reduce any distress caused by the prolonged strain of caring.

There has not been very much research looking at what it is like for staff carers working with those with both a learning disability and dementia. More research in this area is needed. The purpose of this study is to gain an understanding of the experience of staff carers working with individuals with LD and dementia.

#### ***Who can take part?***

Any paid staff carer, who speaks English and is currently working with an individual with both a Learning Disability and dementia; and has done so for at least 6 months, can take part in the study.

#### ***Will my taking part in this study be kept confidential?***

All data will be handled according to ethical and legal practice and any information collected about you during the course of the research will be anonymous. All audio recordings, questionnaires and transcripts will be stored securely and will only be accessible by the researcher and the research supervisor.

You are free to withdraw at any time, without giving a reason. Whether or not you take part will have no effect on your work.

#### ***What will happen if I decide to take part?***

We will arrange a time convenient to you to participate in the research. You will be initially asked to sign a consent form and then you will be given two questionnaires to fill in. The questionnaires will ask some general questions about you, the individual(s) you care for and some information about your experience as carer. This will take about 10 minutes to complete. Following this there will be an interview which will last approximately an hour and will consist of a series of questions about your experience working with people with both a learning disability and dementia. The interview will be recorded and at a later point transcribed by the researcher.

#### ***What will happen to the results of the study?***

The findings will be written up as part of a doctoral degree in clinical psychology. The final write up may also be published in an academic journal so other people can read about the findings of the study. You will not be personally identified in any parts of the final write up.

The research has been organised by the University of Hull and has been looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by a Research Ethics Committee. This means the study has been checked to make sure it is appropriate and ethical. If you would like to participate or have any further questions or queries, please talk to your manager.



**Appendix L:**

**Template for Letters to Residential Service Managers**



[Address of residential home to be inserted]

To [Managers name inserted],

Following from our telephone conversation please find enclosed a copy of the information sheet discussed. Within it there is further information on the research I am conducting on the experience of staff carers working with individuals with both a learning disability and dementia. More detailed information about what participation within this research will involve is laid out and hopefully this document will answer any questions you have. However please feel free to contact myself if any further questions come up.

I have also enclosed a poster version of the information sheet in the hope that it can be put up in some appropriate place, so as to help recruit participants and to communicate the purpose of the research to your staff team. If required I am happy to come in and talk further about the research to all staff.

If anyone is interested in taking part and/or would like further information please put in them in touch with me. I can be reached Monday to Friday between 9.30 and 4.30pm on 07504492156.

Yours Sincerely,

Charlotte Moore  
Trainee Clinical Psychologist

**Appendix M:**  
**Consent Form**



Pseudonym chosen by participant for this study:

## CONSENT FORM

**Title of project:** Care Staff Experience of Supporting People with Learning Disability and Dementia

**Name of Researcher:** Charlotte Moore (Trainee Clinical Psychologist)

**Please initial  
the box**

1. I confirm that I have read and understand the information sheet dated 25 <sup>th</sup> of March 2011 (version 1.3), for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	<input type="checkbox"/>
3. I am aware of the potential risks and benefits of taking part.	<input type="checkbox"/>
4. I agree to take part in the above study	<input type="checkbox"/>

Name of participant \_\_\_\_\_ Date \_\_\_\_\_ Signature \_\_\_\_\_

Name of person \_\_\_\_\_ Date \_\_\_\_\_ Signature \_\_\_\_\_

Taking consent

**Appendix N:**  
**Questionnaire**

## Background Information

Female:   
 Male:

Age \_\_\_\_\_

Pseudonym \_\_\_\_\_

### Job information

#### Place of work (Please tick one box)

Residential private

Residential Local authority

Residential voluntary/ charity organisation

Other (please specify)

### Experience

How many months or years have you worked as a carer?

How many months or years have you worked in your current job?

### Experience in Learning Disabilities:

How much experience have you had working with people with learning disabilities? (Please circle)

<b>Less than 6 months</b>	<b>1 year to 18</b>	<b>18 months to 2</b>	<b>3 year +</b>
<b>months</b>		<b>years</b>	<b>+</b>

How much experience have you had working with people with learning disabilities and Dementia? (Please circle)

<b>Less than 6 months</b>	<b>1 year to 18</b>	<b>18 months to 2</b>	<b>3 year +</b>
<b>months</b>		<b>years</b>	

Do you have past experience (6 months or more) with other client groups (for example, older adults)?

Yes

---

No

---

If yes, please specify

---

Hours of work

Full time

Part time

---

**Information about the residential setting in which you work**

How many people live here?

---

How many of the people living here have both a learning disability and dementia?

---

At approximately what stage of dementia is each person at? (Please put how many people are at each stage of dementia in the corresponding box).

Early Stage

Mid Stage

Late Stage

---

What is the age range of the people who live there?

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How many staff work there (approximately)

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**Appendix O:**  
**Interview Schedule**



Interview Schedule- Care Staff Experience of Supporting People with Learning Disability and Dementia

*A- Perception of the Caring Experience*

1. Can you tell me a bit about why you became a Carer?
2. Tell me a bit about your experience of being a Carer

**Prompt:** How long have you been working as a Carer? Where have you worked? With who have you worked? Has it been a good experience over all?

3. How do you understand the meaning of the term 'Carer'?

**Prompt:** How would you explain it to someone else?

4. What does being a Carer mean to you?

**Prompt:** How does it affect how you see yourself?

5. Can you describe to me what your role is as Carer?

**Prompt:** what's your job role? What do you do in day? What are you responsible for?

6. Is that role any different when working with those with learning disability and dementia?

**Prompt:** Is it a more positive or negative experience?

*B- Factors that affect the experience of Caring*

7. What factors impact on your work? How do they impact?

**Prompt:** Family? Friends? Colleagues? Management? Service structure?

**Prompt:** Negatively? Positively?

8. Are the factors different when working with clients with both dementia and a learning disability?

**Prompt:** would you add any factors? Would you take any factors away?

9. What do you do when / what would you do if these factors have a negative impact?

**Prompt:** How do you/would you deal with stress at work? What are you coping strategies?

*C- Outcomes of Caring*

10. How do you feel about being a Carer?

**Prompt:** Is it a good job? - Why?; Is it what you want to do?- why?

11. How do you feel about your work with people with learning disability and dementia?

**Prompt:** any positives? Any negatives?

12. Would this be any different from working with another population? - If so how?

13. How dose being a carer affect other areas of your life?

**Prompt:** Family? Friends? Hobbies?

14. Has being a carer for people with learning disabilities and dementia changed this? – If so how?

**Prompt:** How would you describe yourself? Would you have described yourself differently before you became a carer for those with dementia and a learning disability?

15. Would this be any different working with another population? – If so how?

16. How do you think others see you?

**Prompt:** Family? Friends? Colleagues?

17. Do you think this has changed since becoming a carer for people with learning disability and dementia? – If so how?

19. Do you think your experience of caring affects the clients' experience of being cared for? - If so how?

**Prompt:** If you're having a positive experience how does that affect clients? Would it be different if you were having a negative experience of caring?

*Ending*

20. Is there anything else you would like to add?

21. Is there any questions you would add in that you think are important and I didn't ask?

22. What has it been like completing this interview? Has it been what you expected?

23. Do you have any questions?

**Appendix P:**

**Measures- DSQUID Part One**

## **INDIVIDUALS WITH INTELLECTUAL DISABILITIES (DSQIID)**

**Professor Shoumitro Deb, MBBS, FRCPsych, MD  
Clinical Professor of Neuropsychiatry & Intellectual Disability,  
University of Birmingham, Division of Neuroscience,  
Queen Elizabeth Psychiatric Hospital,  
Mindelsohn Way,  
Birmingham B15 2QZ, U.K.**

**E-mail: [s.deb@bham.ac.uk](mailto:s.deb@bham.ac.uk)**

**URL: [www.bham.ac.uk/psychiatry](http://www.bham.ac.uk/psychiatry)**

**August 2007**

### **References**

Deb S., Hare M., Prior L. & Bhaumik S. (2007) Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID). *British Journal of Psychiatry*, 190, 440-444.

Deb S., Hare M. & Prior L. (2007) Symptoms of dementia among adults with Down's syndrome: a qualitative study. *Journal of Intellectual Disability Research*, 51, 9, 726-739.

**PART 1: LEVEL OF 'BEST' ABILITY**

Please indicate the level of 'best' ability the person has, or has had, by \_ the appropriate boxes.

**SPEECH:**

- \_ Could speak fluently and understandably
- \_ Could make short sentences
- \_ Could speak only a few words
- \_ Could not speak much but used sign language
- \_ Could not speak and did not use sign language

**DAILY LIVING SKILLS (e.g. Dressing, washing, eating etc.):**

- \_ Could live independently with minor help
- \_ Could live independently but needed a lot of help with self help skills
- \_ Could not live independently and needed minor help with self help skills
- \_ Could not live independently and needed a lot of help with self help skills

**CURRENT ACCOMMODATION:**

- \_ On his/her own
- \_ With relatives
- \_ In a shared, staffed house
- \_ In a group home with full time staff
- \_ In a nursing home with full nursing care
- \_ Other \_\_\_\_\_

**OTHER RELEVANT INFORMATION:**


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**Appendix Q:**

**Measures- DLD**

*(Removed For Hard binding)*





























**Appendix R:**

**Example work through of Analysis**

### Example work through of Analysis

#### *Stage 1: Reading*

The transcript were typed up and then read through for the first time. An example section of Tindle's transcript can be seen below:

Researcher: Ok, so if you think about the individual that you're currently supporting, you know with dementia as well as a learning disability, is your role any different when you're with her compared to your other residents?

Mrs. Tindle: Well it is because I have to do everything (1) for her yeah (2) um and- and sometimes um (1) when your chatting to her and if you, if you feel that she's recognised ya, it's really quite nice, or if she smiles, because she doesn't always smile a lot, but sometimes she will, and it's quite an effort for her you can tell by the way she does it, it's sort of a bit jerky um (1) and she does give eye contact, every now, every now and then (1) and then you sort of see a bit of (1) her old self, by some of the words, odd words that she just comes out with um (1) but ya um, and I think you tend to sort of have to choose her clothes for her and buy her clothes for her, and (1) and it's like, her food, you have to sort of remember what type of food, well we know what type of food she likes, and what she didn't like, and-and things like that, but you have to sort of do everything for her, so yeah it is different, although while you are helping her, you are sort of telling her what you're doing, explain stuff like that um (1) and sort of chatting to her really (1) but that's the difference is that you're doing everything for her (2)

Researcher: umm so (2) what factors do you think impact on, on how well you do your job, or how well you can do your job in a day? (2)

Mrs. Tindle: um (2) I suppose it's how I'm feeling on that day when I come to work (1) yeah (1) the weather, sunny or-or dull um (1) and I say in general, how-how the,

the place is as well (1) and as I say we've had some just lately, who's been quite challenging just lately, and that, it-it-it's made a big difference on all of it, it's just completely changed (2) the whole, the whole place, because you still on edge that, that person can um (3) just become abusive or, tend to sort of still have that in the back of your mind (1) and it all depends, as well, is whether I'm duty officer or not, if I'm not duty officer (1) I' everything, I-I don't have that responsibility of-of running the shift, so that makes a difference to how I am, cos then I can (1) just freely run around and do or, you know, without having to worry about what everybody else is (1) you know making sure everybody else is doing, well everybody else does what they're supposed to do, but there's like little odd jobs that you have to do that, that's different (1) so there's the responsibility, but that, that's (1) that makes a difference, and in general how people are feeling (1) the residents are feeling, if their (1) if their happy it makes a difference, if somebody's not very well that makes a difference so (2) yeah and maybe how the other staff are feeling as well [laughs]

Researcher: [laughs] I can imagine

Mrs. Tindle: But usually we're quite a good group that (1) people will sort of come in and uh, and you know, you think, you sort of know peoples a bit (1) tense or not feeling too well or, or something and once you've, once you've chatted about it you're ok, sort of have a chat and you're ok (1) but even sometimes if I come in and you've sort of had a row or something like that, you come in and you've just sort of said to somebody you've had a row, it's, it's, its halved it and it's just sort of levelled it off a bit (3)

Researcher: Ok (1) how about if you think about, again the individual you work with, with dementia as well as learning disability, are the factors that affect working with her any different? (1)

Mrs. Tindle: I think, it's only if she's, if she's feeling a bit, um (2) if she's not feeling too well, or if it seems like she's not too well or sometimes she gets in theses like

um (2) these little, it's like a um (1) an angry mood, although (1) and you also get the feeling that she knows what she wants to say or wants to do, but she can't express it verbally, she's trying to (1) express it by sound um just making the noises and (1) she clenches her fists and things like that, and it's not knowing what she wants, I think that's-that's the hardest thing, and you sort of try different, maybe a drink, maybe a, something to eat, maybe just needs to move position, the usual things (1) and that, or maybe just having a chat, maybe (1) putting some music on, put some (1) she has some (1) funny light things um you know to put on (1) but sometimes you just can't get, no matter how hard you try you just can't find out what, what it is that's, that's worrying her, so really that can sort of, she makes these loud noises and it's, and you tell her don't shout, but (1) she don't always know what's happening

### *Stage 2: Notes*

The transcript was read a second time and initial notes were made in the left hand margin. An example section of this can be seen below:

<p>The little things, in the interaction-recognition</p> <p>Knowing People- Person Centred</p>	<p>Researcher: Ok, so if you think about the individual that you're currently supporting, you know with dementia as well as a learning disability, is your role any different when you're with her compared to your other residents?</p> <p>Mrs. Tindle: Well it is because I have to do everything (1) for her yeah (2) um and-and sometimes um (1) when your chatting to her and if you, if you feel that she's recognised ya, it's really quite nice, or if she smiles, because she doesn't always smile a lot, but sometimes she will, and it's quite an effort for her you can tell by the way she does it, it's sort of a</p>
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<p>Care</p> <p>Tailoring the level of support to the person needs, enabling them to do as much as they can.</p>	<p>bit jerky um (1) and she does give eye contact, every now, every now and then (1) and then you sort of see a bit of (1) her old self , by some of the words, odd words that she just comes out with um (1) but ya um, and I think you tend to sort of have to choose her clothes for her and buy her clothes for her, and (1) and it's like, her food, you have to sort of remember what type of food, well we know what type of food she likes, and what she didn't like, and-and things like that, but you have to sort of do everything for her, so yeah it is different, although while you are helping her, you are sort of telling her what you're doing, explain stuff like that um (1) and sort of chatting to her really (1) but that's the difference is that you're doing everything for her (2)</p>
<p>Many things can affect how they cope on a given day</p>	<p>Researcher: umm so (2) what factors do you think impact on, on how well you do your job, or how well you can do your job in a day? (2)</p>
<p>Feeling of anxiety</p>	<p>Mrs. Tindle: um (2) I suppose it's how I'm feeling on that day when I come to work (1) yeah (1) the weather, sunny or-or dull um (1) and I say in general, how-how the, the place is as well (1) and as I say we've had some just lately, who's been quite challenging just lately, and that, it-it-it's made a big difference on all of it, it's just completely changed (2) the whole, the whole place, because you still on edge that, that person can um (3) just become abusive or, tend to sort of still have that in the back of your mind (1) and it all depends, as well, is whether I'm duty officer or not, if I'm not duty officer (1) I' everything, I-I don't have that responsibility of-of</p>

<p>Support from colleagues helps with coping</p>	<p>running the shift, so that makes a difference to how I am, cos then I can (1) just freely run around and do or, you know, without having to worry about what everybody else is (1) you know making sure everybody else is doing, well everybody else does what they're supposed to do, but there's like little odd jobs that you have to do that, that's different (1) so there's the responsibility, but that, that's (1) that makes a difference, and in general how people are feeling (1) the residents are feeling, if their (1) if their happy it makes a difference, if somebody's not very well that makes a difference so (2) yeah and maybe how the other staff are feeling as well [laughs]</p> <p>Researcher: [laughs] I can imagine</p>
<p>Feelings of frustration losing the ability to communicate</p> <p>Loosing independence and difficulty understanding the changes</p>	<p>Mrs. Tindle: But usually we're quite a good group that (1) people will sort of come in and uh, and you know, you think, you sort of know peoples a bit (1) tense or not feeling too well or, or something and once you've, once you've chatted about it you're ok, sort of have a chat and you're ok (1) but even sometimes if I come in and you've sort of had a row or something like that, you come in and you've just sort of said to somebody you've had a row, it's, it's, its halved it and it's just sort of levelled it off a bit (3)</p> <p>Researcher: Ok (1) how about if you think about, again the individual you work with, with dementia as well as learning disability, are the factors that affect working with her any different? (1)</p>



<p>Person Centred Care, knowing the person</p>	<p>Mrs. Tindle: I think, it's only if she's, if she's feeling a bit, um (2) if she's not feeling too well, or if it seems like she's not too well or sometimes she gets in theses like um (2) these little, it's like a um (1) an angry mood, although (1) and you also get the feeling that she knows what she wants to say or wants to do, but she can't express it verbally, she's trying to (1) express it by sound um just making the noises and (1) she clenches her fists and things like that, and it's not knowing what she wants, I think that's-that's the hardest thing, and you sort of try different, maybe a drink, maybe a, something to eat, maybe just needs to move position, the usual things (1) and that, or maybe just having a chat, maybe (1) putting some music on, put some (1) she has some (1) funny light things um you know to put on (1) but sometimes you just can't get, no matter how hard you try you just can't find out what, what it is that's, that's worrying her, so really that can sort of, she makes these loud noises and it's, and you tell her don't shout, but (1) she don't always know what's happening</p>
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*Stage 3: Themes*

Emerging themes were noted in the right hand margin. Example below:

<p>Care provides everything</p> <p>The little things, in the interaction-recognition</p> <p>Knowing People-Person Centred Care</p> <p>Tailoring the level of support to the person needs, enabling them to do as much as they can.</p>	<p>Researcher: Ok, so if you think about the individual that you're currently supporting, you know with dementia as well as a learning disability, is your role any different when you're with her compared to your other residents?</p> <p>Mrs. Tindle: Well it is because I have to do everything (1) for her yeah (2) um and-and sometimes um (1) when your chatting to her and if you, if you feel that she's recognised ya, it's really quite nice, or if she smiles, because she doesn't always smile a lot, but sometimes she will, and it's quite an effort for her you can tell by the way she does it, it's sort of a bit jerky um (1) and she does give eye contact, every now, every now and then (1) and then you sort of see a bit of (1) her old self , by some of the words, odd words that she just comes out with um (1) but ya um, and I think you tend to sort of have to choose her clothes for her and buy her clothes for her, and (1) and it's like, her food, you have to sort of remember what type of food, well we know what type of food she</p>	<p>Culture of LD</p> <p>Services:</p> <p>'Empowering to Everything'</p> <p>Relationship-Client (Reciprocity)</p> <p>Culture of LD</p> <p>Services: Person Centred Care</p> <p>Culture of LD</p> <p>Services:</p> <p>'Empowering to Everything'</p>
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<p>Many things can affect how they cope on a given day</p>	<p>likes, and what she didn't like, and-and things like that, but you have to sort of do everything for her, so yeah it is different, although while you are helping her, you are sort of telling her what you're doing, explain stuff like that um (1) and sort of chatting to her really (1) but that's the difference is that you're doing everything for her (2)</p>	<p>Emotional Impact</p>
<p>Feeling of anxiety</p>	<p>Researcher: umm so (2) what factors do you think impact on, on how well you do your job, or how well you can do your job in a day? (2)</p> <p>Mrs. Tindle: um (2) I suppose it's how I'm feeling on that day when I come to work (1) yeah (1) the weather, sunny or-or dull um (1) and I say in general, how-how the, the place is as well (1) and as I say we've had some just lately, who's been quite challenging just lately, and that, it-it-it's made a big difference on all of it, it's just completely changed (2) the whole, the whole place, because you still on edge that, that person can um (3) just</p>	<p>Emotional Impact</p>
<p>Support from colleagues helps with coping</p>	<p>become abusive or, tend to sort of still have that in the back of your mind (1) and it all depends, as well, is whether I'm duty officer or not, if I'm not duty officer (1) I' everything, I-I don't have that responsibility of-of running the shift, so that makes a difference to how I</p>	<p>Relationship- Colleagues (Support)</p>

<p>Feelings of frustration: losing the ability to communicate</p> <p>Losing independence and difficulty understanding the changes</p> <p>Person Centred Care, knowing the person</p>	<p>am, cos then I can (1) just freely run around and do or, you know, without having to worry about what everybody else is (1) you know making sure everybody else is doing, well everybody else does what they're supposed to do, but there's like little odd jobs that you have to do that, that's different (1) so there's the responsibility, but that, that's (1) that makes a difference, and in general how people are feeling (1) the residents are feeling, if they're (1) if they're happy it makes a difference, if somebody's not very well that makes a difference so (2) yeah and maybe how the other staff are feeling as well [laughs]</p> <p>Researcher: [laughs] I can imagine</p> <p>Mrs. Tindle: But usually we're quite a good group that (1) people will sort of come in and uh, and you know, you think, you sort of know peoples a bit (1) tense or not feeling too well or, or something and once you've, once you've chatted about it you're ok, sort of have a chat and you're ok (1) but even sometimes if I come in and you've sort of had a row or something like that, you come in and you've just sort of said to somebody you've had a row, it's, it's, its halved it and</p>	<p>Emotional Impact</p> <p>Relationship (Client)- Loss of Reciprocity in the Relationship</p> <p>Culture of LD</p> <p>Services: 'Empowering to Everything'</p> <p>Knowledge and Understanding</p> <p>Culture of LD</p> <p>Services: Person Centred Care</p>
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it's just sort of levelled it off a bit

Researcher: Ok (1) how about if you think about, again the individual you work with, with dementia as well as learning disability, are the factors that affect working with her any different? (1)

Mrs. Tindle: I think, it's only if she's, if she's feeling a bit, um (2) if she's not feeling too well, or if it seems like she's not too well or sometimes she gets in theses like um (2) these little, it's like a um (1) an angry mood, although (1) and you also get the feeling that she knows what she wants to say or wants to do, but she can't express it verbally, she's trying to (1) express it by sound um just making the noises and (1) she clenches her fists and things like that, and it's not knowing what she wants, I think that's-that's the hardest thing, and you sort of try different, maybe a drink, maybe a, something to eat, maybe just needs to move position, the usual things (1) and that, or maybe just having a chat, maybe (1) putting some music on, put some (1) she has some (1) funny light things um you know to put on (1) but sometimes you just can't get, no matter how hard you try you just can't find out what, what it is that's,

	that's worrying her, so really that can sort of, she makes these loud noises and it's, and you tell her don't shout, but (1) she don't always know what's happening	
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#### *Stage 4 and 5: Organising Themes*

The emerging themes were then reviewed, and a note made of those that re-occurred throughout transcripts. Similar ideas were grouped together, organising the themes into super-ordinate and sub-ordinate themes. A note of any verbatim quotes from the transcripts that particularly demonstrated these themes were made.

<b>Super- Ordinate Themes</b>	<b>Sub-Ordinate Themes</b>
Reciprocity and the Relationship	Staff/Staff - Support
	Staff/Client – Reciprocity
Culture of LD Services	'From Empowering to Everything'
	Person Centred Care and Knowing the Individual
The Emotional Impact	Frustration
Knowledge and Understanding	

**Appendix S:**  
**Theme Validation**

### **Theme Validation**

When using Interpretative Phenomenological Analysis (IPA) methodology consideration must be given to the transparency and reflexivity of the researcher (Smith, Jarman & Osborn, 1999). To aid this process the researcher kept a reflective log. This process allowed for the opinions and attitudes of the researcher to be tracked in a transparent manner, throughout the research process. Another measure taken was to participate in an IPA group, and have the transcripts read over by group members. This process allowed for the validation of themes, and ensured the analysis was not confined to only one interpretative perspective.

To further validate the analysis process, the researcher also attempted to utilise respondent validation, by inviting all participants to comment on the emergent themes found by the researcher in relation to their own experiences. It should be noted that there is some discussion about whether or not respondent validation is useful within IPA analysis. Particularly considering the already inherent double hermeneutic within IPA (Smith & Osborn, 2003), and the fact that it assumes there is a truth to be found by the researcher and confirmed by the participant, which is a theoretical idea inconsistent with the social constructivist roots of IPA. For this reason it is thought best to not see it as a validation tool, in its pure sense, and instead use it as an error minimising step within analysis, this was the approach taken by the researcher. Unfortunately only one participant was able to engage in this process, but this still was a useful experience and provided further rigour to the analysis process of this research.

Despite all of the above, it is still inevitable that; areas of interest, characteristics, beliefs and assumption off the researcher, will have affected the analysis stage to some degree. As such the results reported should be considered with this in mind.



## References

- Smith, J. A., Jarman, M. & Osborn, M. (1999). Doing Interpretative Phenomenological Analysis. In Murry, M. and Chamberlain, K. (Eds.), *Qualitative Health Psychology* (pp. 218-240), London: Sage.
- Smith, J. A. & Osborn, M. (2003). Interpretative phenomenological analysis. In Smith, J. A. (Ed), *Qualitative Psychology*, London: Sage.