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KIRSTEN L. MELLOWS BA Hons

EMPLOYED CARERS' EMPATHY TOWARDS PEOPLE  
WITH LEARNING DISABILITIES

Section A: AN ATTACHMENT THEORY PERSPECTIVE ON  
EMPLOYED CARERS' EMPATHY TOWARDS PEOPLE WITH  
LEARNING DISABILITIES AND THE PROVISION OF QUALITY  
CARE

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CARERS' EMPATHY TOWARDS PEOPLE WITH LEARNING  
DISABILITIES

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Section C: CRITICAL APPRAISAL

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## Summary of portfolio

**Section A** presents the hypothesis that attachment representations determine individuals' capacities for empathy, which is necessary for sensitive and responsive caregiving. It reviews the evidence pertaining to whether this hypothesis applies within the context of employed caregivers caring for adults with learning disabilities. The evidence is considered in a stepwise fashion, based on four literature searches. The paper concludes by considering the implications of this literature for clinical practice and future research.

**Section B** is an empirical research paper which describes the development of a new questionnaire aiming to measure employed carers' empathy towards people with learning disabilities. It describes how investigation of the questionnaire's factor structure illuminated the salient processes that may influence empathy in this specific relational context. It presents evidence of the questionnaire's construct validity, internal reliability and test-retest reliability. The results are linked to existing literature and recommendations for clinical practice are made. Limitations of the study and directions for future research are considered.

**Section C** offers a critical appraisal of the research undertaken and reflections on the process of conducting the research. It discusses how this research will influence the author's own clinical practice and describes how further research could build on the current project.

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## SECTION A

An attachment theory perspective on employed carers' empathy towards people with learning disabilities and the provision of quality care

Word count: 5500 (plus 466 additional words)

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### SECTION A: Literature Review

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### Abstract

Empathy from professional caregivers may be particularly important for people with learning disabilities, who may lack wider social networks. Contemporary advancements to attachment theory suggest that adults' attachment representations influence their empathy, determining whether they can be sensitive and responsive caregivers. Literature and evidence pertaining to whether this applies to professional carers supporting adults with learning disabilities are reviewed.

Research suggests that attachment dynamics may be prominent within services for people with learning disabilities. Although there is some evidence that carers' attachments influence their empathy and caregiving behaviour, methodological difficulties with the measurement of empathy make this evidence weak.

Future research should explore the nature of carers' empathy towards people with learning disabilities and establish valid and reliable ways to measure this. Clinicians should consider the impact of carers' attachments on their empathy. Services should adopt organisational policies that support carers to feel as psychologically secure as possible at work.

## Introduction

### Empathy and Prosocial Behaviour

The concept of empathy eludes a singularly accepted definition (Davis, 1980). Empathy has been described as an emotional reaction congruent with another person's affective experience, which might involve a vicarious experience of the other's state (Eisenberg & Miller, 1987; Merhabian & Epstein, 1972; Stotland, 1969, as cited in Davis, 1983). Empathy has also been conceptualised as perspective taking or the ability to intellectually put oneself in the other's place and recognise and understand their position (Dymond, 1949). Davis (1980) acknowledges both aspects, terming the former affective and the later cognitive empathy. This paper will adopt Davis' position and consider empathy as an individual difference factor which varies between people (Davis, 1983; Mehrabian, Young, & Sato, 1988).

Research robustly supports a link between empathy and helping behaviour (see Batson, 2011 or Eisenberg, 2010 for reviews). Batson (2010) defined *empathic concern* as "an other-orientated emotional response elicited by and congruent with the perceived welfare of someone in need" (p. 20). He provides substantial evidence that empathic concern produces an altruistic motivation to care and relieve the other's distress, a claim termed the empathy-altruism hypothesis (Batson, 1991; 2010).

In the health and social care sector, staff empathy is critical to quality service provision. To exemplify, greater staff empathy has been related to (a) improved psychotherapy outcomes (Elliot, Bohard, Watson, & Greenberg, 2011); (b) decreased patient distress (Olson & Hanchett, 1997); (c) the improved mental health and satisfaction with care of cancer patients (La Monica, Wolf, Madea, & Oberst, 1987); (d) improved results on diabetic patients' blood tests, an outcome attributable to increased compliance with advice

(Hojat et al., 2011). Unfortunately, reviews claim professionals show little empathy (Reynolds & Scott, 2000) or report varying levels of empathy across studies (Yu & Kirk, 2008). Differences in empathy measurement methods may explain inconsistencies.

### **Relationships In The Lives Of People With Learning Disabilities**

The White Papers Valuing People (Department of Health [DoH], 2001) and Valuing People Now (DoH, 2009) have been criticised for pursuing values such as rights and autonomy (Cumella, 2008) whilst placing little emphasis on supporting people with learning disabilities to form and maintain meaningful interpersonal relationships (Clegg & Lansdall-Welfare, 2010; Hall, 2010). Many people with learning disabilities lack relationships with friends or family (Emerson, 2005; Robertson et al., 2001). Employed caregivers, such as support workers, are frequently their greatest source of practical and emotional support (Forrester-Jones et al., 2006). In this paper such employed caregivers will be called *carers*. Unsurprisingly, people with learning disabilities value empathy and understanding from carers (Clarkson, Murphy, Coldwell, & Dawson, 2009; Roeden, Maaskant, & Curfs, 2011). However, carers' empathy and its relationship to care provision remains barely researched.

### **Aim Of The Review**

Contemporary developments of Bowlby's (1982) attachment theory proposed that individuals' attachment representations influence their dispositional empathy and ability to provide quality care (Mikulincer & Shaver, 2007; Mikulincer, Shaver, & Gillath, 2008). This paper explores whether this *attachment hypothesis* has the potential to explain individual differences in carers' empathy and caring behaviour towards people with learning disabilities. It begins by reviewing the theoretical basis for this proposal. Evidence that the

attachment hypothesis applies to caring for adult strangers and professional caregivers caring for adults is reviewed. The paper then explores whether attachment dynamics exist in relationships between people with learning disabilities and their carers. Finally, literature pertaining to carers' attachments and their empathy towards people with learning disabilities is considered. Appendix 1 contains the literature search strategy used for the review.

### **An Attachment-empathy Model Of Caregiving**

#### **Attachment**

Bowlby (1982) proposed that humans are born with an attachment behavioural system, whereby infants become emotionally attached to their primary caregiver and thus maintain proximity to someone who can provide protection and support at times of danger or anxiety. He suggested that early experiences with caregivers shape behavioural systems and thus influence adults' mental representations of relationships. Such *attachment representations* are considered unconscious, only accessible by examining behaviours and thoughts occurring when the system is activated. This principle has been used to develop infant (Ainsworth, Blehar, Waters, & Wall, 1978) and adult attachment status categories (Main & Goldwyn, 1985/1990/1994 as cited by George & West, 1999; Main, Kaplan, & Cassidy, 1985). In brief, receiving quality care typically results in a *secure* attachment status (de Wolff & van IJzendoorn, 1997), characterised by mental integration of attachment related experiences and confidence that close others will care. Poor caregiving may leave individuals unconfident that others will care, resulting in preoccupation with close others (*preoccupied* status) or minimisation of their importance (*dismissing* status) (Dykas & Cassidy, 2011).

Attachment theory has been applied to adult romantic relationships (e.g. Hazan & Shaver, 1987) and termed the *social orientation* of the theory to distinguish it from the original *developmental orientation* (described above). Self-report questionnaires were designed to assess how attachment style varies on two dimensions, anxiety and avoidance (Brennan, Clark, & Shaver, 1998), or falls into four attachment patterns (*secure, anxious, avoidant* and *disorganised*) created by high and low scores on the dimensions (Griffin & Bartholomew, 1994). Some argue that such measures make valid assessments of attachment representations such that anxious and avoidant styles relate to preoccupied and dismissing status' respectively (see George & West, 1999, for a review of these claims). However, evidence suggests developmental and social measures assess different aspects of attachment representations and may not provide equivocal findings (Roisman et al., 2007). Nonetheless, attachment styles are associated with characteristic patterns of information processing and interpersonal behaviour (see Mikulincer & Shaver, 2007, for a review).

### **Caregiving**

Bowlby (1982) postulated a reciprocal innate caregiving behavioural system, which functions to support others who are chronically dependent or temporarily in need. This involves providing a *safe haven* to distressed dependents or a *secure base* to facilitate the dependent's development (Bowlby, 1982). Although Bowlby focussed on parent-child relationships, he claimed that humans will care for people other than their own offspring. Drawing on Hamilton's (1964) Inclusive Fitness Theory, he suggested the caregiving behavioural system evolved because it increased the likelihood that genetically-related individuals would survive to reproductive age. In fact, for most of evolutionary history people lived in groups where many people were biologically related (Foley, 1992, as cited by

Simpson & Beckes, 2010) making it probable that humans evolved to care for everyone in their tribe. Additionally, many societies socialise children to treating all humans well (Mikulincer & Shaver, 2007). This provides a solid underpinning for the claim that the caregiving system influences behaviour in all caregiving relationships.

Bowlby (1982) defined quality caregiving as sensitive and responsive to the careseeker. Empathy is a necessary ingredient for providing such care (Collins, Ford, Guichard, Kane, & Feeney, 2010; Collins, Guichard, Ford, & Feeney, 2006). The importance of empathy is readily apparent within Mikulincer et al.'s (2008) definition of sensitivity as "attunement to and accurate interpretation of another person's signals of distress, worry or need and responding in synchrony with the person's support-seeking behaviour" (p. 231). Reis and Patrick (1996) define responsive care as that in which the recipient feels understood and validated. Empathy is clearly crucial to understanding others.

### **Individual Differences**

Evidence strongly suggests that securely attached caregivers are more likely to provide sensitive and responsive care than insecure caregivers (e.g. Haft & Slade, 1989; Kunce & Shaver, 1994). Research indicates that secure caregivers have patterns of beliefs, feelings and motivations about caregiving (called *mental representations of caregiving*) likely to facilitate such quality care (Reizer & Mikulincer, 2007; Shaver, Mikulincer, & Shemesh-Iron, 2010).

Attachment representations may influence caregiving representations and behaviours in several ways (Collins et al., 2010). Mikulincer & Shaver (2007) suggested that attachment security provides a psychological foundation for empathy. In support of this, they cited evidence that securely attached individuals are comfortable with intimacy and

interdependence, so can acknowledge others' needs for support, whilst perceiving others as deserving care. Furthermore, seeing someone in distress may evoke both other-orientated empathy and self-orientated feelings of discomfort termed *personal distress* (Batson, 1991). Secure individuals have the necessary emotion regulation skills to manage personal distress, leaving them free to empathise with others. In contrast, avoidant individuals may prefer to remain distanced from needy others, who may be perceived as a drain on resources or reminder of one's own weaknesses. Such individuals may be unmotivated to attend to other people's minds and needs.

Anxious individuals may be motivated to care and are comfortable with interdependence but have insufficient intrapersonal and interpersonal emotion regulation skills to manage personal distress (Mikulincer & Shaver, 2007). When adults feel distressed, their own attachment systems are activated, which may inhibit caregiving (Kunze & Shaver, 1994). Anxious individuals' personal distress may thus interfere with providing empathic care. Additionally, anxious individuals may care in order to meet their own needs for interpersonal closeness rather than in an empathic manner attuned to careseekers' needs (Collins et al., 2006). Their desire for closeness may mean they differentiate less between the self and others (e.g. Mikulincer & Horesh, 1999). This might further heighten personal distress, interfering with empathising.

Abundant research from various relational contexts (e.g. parent-child relationships, romantic relationships) demonstrates systematic differences in the empathy and caregiving behaviour of individuals with different attachment patterns (see Mikulincer & Shaver, 2007, for a review). Before examining relevant subsets of this literature, a discrepancy between the theory being proposed and the supporting research is addressed.

In applying attachment theory to empathy and care for people with learning disabilities, this paper explores whether unconscious attachment representations underlie empathy and caregiving for adults. However, most evidence pertaining to helping/caring for adults has utilised self-report attachment measures. As discussed above, questionnaires may not measure unconscious attachment representations. Evidence based on such measures might have low validity as support for the current claims. However, a few studies have used a measure of unconscious attachment representations, the Adult Attachment Interview (AAI; Main et al., 1985), to study caring for adults (Dozier, Cue, & Barnett, 1994; Steele, Phibbs, & Woods, 2004; Tyrell, Dozier, Teague, & Fallot, 1999) although none also measured empathy. Such evidence suggests that there is no underlying theoretical difference between the mechanisms governing care for adults and children.

With this validity issue acknowledged, studies investigating whether attachment representations influence empathy and caring towards unrelated adults will be reviewed. This literature is pertinent because employed carers are unrelated to people with learning disabilities in their care.

### **Attachment and Empathy For Unrelated Adults**

In a sample of students, security of attachment and empathy were significant predictors of prosocial behaviour (Thompson & Gullone, 2008). Similarly, Carlo, McGinley, Hayes, and Martinez (2012) found that students' attachment security was related to empathy, which in turn correlated with tendency to perform prosocial behaviours. In both studies empathy partially mediated relationships between attachment and prosocial behaviour, supporting the claim that attachment security influences helping behaviour both directly and indirectly, through empathy. Consistent with this, Wayment (2006) found that

students with more avoidant attachment styles were less empathic to the bereaved following terrorist attacks. Less empathic students offered less actual help. Avoidant attachment was therefore indirectly related to helping via empathy. However, attachment anxiety was related to neither empathy nor helping, perhaps because of a possible curvilinear relationship between anxiety and empathy. Some attachment anxiety might make individuals more empathic but too much might interfere with empathy. However, these studies are unable to demonstrate causality. The small to moderate effects found indicate that any causal influence of attachment on empathy is modest. The studies used student participants, so require replication in broader populations.

Mikulincer, Shaver, Gillath, and Nitzberg (2005) compared adults primed to feel momentary attachment security with those primed in ways unrelated to security. The former group felt more empathic and displayed more helping behaviour towards strangers. This provides some evidence that attachment influences empathy and helping rather than simply being related to them. Priming security enhanced empathy regardless of dispositional attachment style. Consistent with theory, dispositional avoidance was associated with less empathy and helping. Dispositional attachment anxiety was associated with greater personal distress but did not influence empathy or helping. Together with Wayment's (2006) findings, this suggests the relationship between anxiety and empathy is complex and may be mediated or moderated by anxiety's effect on personal distress. Even *subliminal* priming enhanced empathy, providing early evidence that the attachment-empathy link is preconscious, even when caring for adults. Whilst the use of experimental controls and the replication of results make these studies robust, the findings come from one set of experimental protocols; their wider application requires demonstration.

In summary, there is some evidence that secure attachment may be associated with empathy and care, even when caregivers and care-seekers have no prior relationship. Direct support for this claim has been obtained in specific contexts: Further research is needed to establish whether the attachment-hypothesis applies for a range of people and within a broad range of settings or protocols. However, a substantial body of robust evidence drawn from wider contexts (e.g. parent-child relationships, romantic relationships, see Mikulincer & Shaver, 2007) can be extrapolated to suggest a link between attachment representations and empathy towards unrelated adults is likely. Since there is some evidence that the attachment hypothesis may apply when adults have no prior relationship, the following section examines whether it may apply when carers are employed to care for adults.

### **Attachment and Empathy In Professional Caregiving Relationships**

Three studies have examined whether the attachments of staff without therapeutic training impact on their approach to clients.

Dozier et al. (1994) studied case managers working in mental health services. More secure clinicians were more sensitive to clients' actual needs rather than presentations of need. Presentations of need are typically greater for preoccupied than dismissing clients (see Mikulincer & Shaver, 2007, for a review). Compared to dismissing clinicians, more preoccupied clinicians provided interventions at a more emotional level and perceived clients as having greater needs. In a follow up study, secure clinicians formed stronger working alliances with clients when their secondary attachment strategy (either anxious or avoidant) was dissimilar to the client's attachment strategy (Tyrell et al., 1999).

Berry et al. (2008) found an association whereby staff with lower attachment anxiety had more positive relationships with mental health service users. Greater attachment

avoidance was associated with lower psychological mindedness and greater discrepancy between staff and patient ratings of the patient's difficulties. To the extent these dependent variables indicate empathy, avoidant staff may be less empathic.

Unfortunately, these studies utilised small samples of predominantly female staff: the use of parametric analysis may invalidate their conclusions and findings may not be valid for male staff. Furthermore, dependent variables were measured by rating how staff spoke about clients and described interactions with them. High inter-rater reliabilities were obtained but these dependent variables may be invalid indicators of actual interactions.

Two studies have examined the association between attachment and empathy in interactions. Rubino, Barker, Roth, and Fearon (2000) assessed trainee psychologists' attachment styles using the Relationships Style Questionnaire (Griffin & Bartholomew, 1994). Since "therapists did not fall into unique attachment groups" (p. 412), factor analysis was used to produce scores on anxiety and avoidance dimensions. Three raters used Likert scales to judge empathy in response to a therapeutic alliance rupture. Greater attachment anxiety was associated with less empathic responses. Avoidant attachment was not associated with empathy but, given participants did not fall into discrete attachment groups, this might be attributable to insufficient variance in avoidance. Additionally, an alliance rupture might activate the attachment representations of anxious trainees, who fear rejection, but not those of avoidant trainees unperturbed by interpersonal distance. These confounding explanations reduce the validity of this null finding.

McCluskey (2005) studied student social workers' empathy whilst engaging with actors playing clients. Students completed attachment questionnaires, which were combined to provide scores on "insecure" and "compulsive caregiving" (p. 173) dimensions. The validity and reliability of these dimensions is unknown. Empathy was rated by students,

actors and independent observers. However, the former two groups were not trained to recognise and measure empathy. Anxious and avoidant individuals use cognitive biases to respectively increase and decrease their perceived closeness to others (Mikulincer, Orbach, & Iavnieli, 1998). Students' attachment representations may therefore have influenced their empathy ratings. Based on the independent ratings, made by trained raters achieving inter-rater reliability of 0.8, there were no significant Spearman correlations between the attachment variables and empathy. However, a chi-square test demonstrated that greater insecurity was associated with lower empathy.

In summary, initial evidence suggests that secure attachment may facilitate positive interactions with clients and the provision of sensitive care. However, studies' methodological limitations decrease their validity as support for this claim. Some weak evidence indicates that attachment representations may relate to professional carers' empathy. Although this evidence is inconclusive, studies are too methodologically poor for null findings, such as the lack of relationship between avoidance and empathy, to actively threaten the validity of the attachment hypothesis. Furthermore, the inconclusive evidence exists in the context of stronger literature demonstrating an attachment-empathy link in wider contexts (see Mikulincer & Shaver, 2007) and the slightly stronger, albeit still somewhat inconclusive, evidence of an attachment-empathy link when adults care for an unrelated adult (as reviewed above). Overall, firm conclusions about whether professional carers' attachment representations are associated with their empathy cannot be drawn. However, since it remains plausible that the attachment hypothesis may apply when people are employed to care, let us examine whether it might apply within services for people with learning disabilities.

## **Applying The Attachment Hypothesis To Care For People With Learning Disabilities**

### **Relevance To Services For People With Learning Disabilities**

Activation of the caregiving system is most likely when (a) someone has to cope with danger or discomfort and is seeking or would clearly benefit from help; b) a person requires help to gain from a learning opportunity (Collins et al., 2006). These circumstances arise frequently for people with learning disabilities, implying that carers' caregiving representations would be very active.

If the attachment hypothesis is applicable, one might expect to see evidence of attachment dynamics between carers and people with learning disabilities. The attachment styles of the carer and the person with a learning disability will mesh to form the dynamics of the caregiving relationship.

### **People With Learning Disabilities' Attachments**

Like all adults, people with learning disabilities' attachment styles will guide their interactions with others, especially caregivers. Attachment representations are therefore particularly likely to influence people with learning disabilities' behaviour towards care staff.

Janssen, Schuengel and Stolk (2002) reviewed evidence that a greater proportion of people with learning disabilities have insecure attachments compared to the general population. However, other research (Larsen, Alim, & Tsakanikos, 2011) indicates that secure and insecure attachment rates may be similar, at least for those with mild disabilities. Regardless of whether the rates of insecure attachment are similar to or higher than those in the wider population, those people with learning disabilities who are also insecure may contribute some harder-to-manage interpersonal behaviour to relationships with staff. To exemplify, anxiously attached people with learning disabilities may be

hypervigilant to rejection (Baldwin & Kay, 2003), so become upset when preferred carers support someone else. Avoidant people with learning disabilities may be adverse to intimacy (Doi & Thelen, 1993), including physical proximity (Kaitz, Bar-Haim, Lehrer, & Grossman, 2004) so might become distressed by care.

Clegg and Lansdall-Welfare (1995) exemplify how insecure attachment representations may lead to interpersonal behaviours considered challenging. Janssen et al. (2002) suggest security increases resilience to stress thus should be associated with less challenging behaviour. Clegg and Sheard (2002) found that overinvestment in a few relationships was associated with challenging behaviour but Larsen et al. (2011) found that insecure attachment was unrelated to most forms of challenging behaviour. However, neither overinvestment nor Larsen et al.'s (2011) measure are demonstrably adequate attachment measures. Consequently, these studies do not provide robust evidence about the relationship between insecure attachment and challenging behaviour.

Preferred attachment figures change as people mature (Hazan & Zeifman, 1994). Adults without spouses often rely on friends to fulfil this role (Schachner, 2006 as cited in Mikulincer & Shaver, 2007). It is therefore unsurprising that some studies suggest that people with learning disabilities may form attachments to carers, especially given evidence that some clients use therapists in this way (e.g. Parish & Eagle, 2003).

Mattison and Pistrang (2000) found that some people with learning disabilities' accounts of their keyworkers indicated dependency and a child-like position of "looking for an idealised parent figure" (p. 54). Keyworkers were sometimes described as meeting people with learning disabilities' primary care needs or caring for their emotional welfare. People with learning disabilities described seeking out and sticking with keyworkers when upset because they provide comfort. Keyworkers held a special significance, with people

with learning disabilities experiencing pain when keyworkers left or emotions were unreciprocated. The intensity of affect and use of keyworkers as a secure base supports the suggestion that people with learning disabilities may form attachments to staff. This claim is supported by Smith and McCarthy (1996), who asked people with learning disabilities what they would do if feeling worried, down or fearful. Those who said they would tell someone frequently nominated paid carers.

Similarly, De Schipper and Schuengel (2010) found that secure attachment behaviour towards staff was related to wellbeing and behavioural adaptation, possibly because staff became attachment figures, providing a secure base to facilitate emotion regulation. Alternatively, people with learning disabilities with secure early attachments may have been both better adjusted in their relationships to staff and have had greater wellbeing/behavioural adaptation. However, this is unlikely because each person with a learning disability treated different staff members as a secure base to different extents. Furthermore, each relationship with staff contributed independently to explaining differences in behaviour.

### **Carers' Attachments**

Little research addresses how paid carers' attachment representations influence their care for people with learning disabilities.

Mattison and Pistrang (2000) interviewed keyworkers, some of whom described their relationships with people with learning disabilities as having parent and child transferences. Decisions about how to leave jobs were sometimes explicitly related to carers' own needs in managing separations. Carers described experiencing a dilemma about how close their relationships with people with learning disabilities should become, with

individuals taking different positions on this. Evidence suggests that attachment representations influence how close individuals like being to others and how they manage separations (see Mikulincer & Shaver, 2007 for a review). Indeed, Clegg and Lansdall-Welfare (1995) suggest attachment representations influence whether carers respond to challenging behaviour by becoming enmeshed, fearful of being overwhelmed by the people with learning disabilities' needs or by avoiding them altogether. Plausibly, anxious caregivers would engage in close relationships, possibly enmeshment, whereas avoidant carers might distance themselves from people with learning disabilities' needs. Similarly, Watt and Brittle (2008) suggest that caring for people with learning disabilities may fulfil a compulsion to care. Such caregiving is insensitive to the recipient's needs (Bowlby, 1979) and is associated with anxious attachment (Collins et al., 2006).

Some people with learning disabilities struggle to communicate, necessitating that carers attune to subtle cues and interpret them to facilitate sensitive care (Schuengel, Damen, Kef, & Worm, 2010). This parallels the sensitive care required from parents in order to notice cues from children with learning disabilities (Atkinson et al., 1999; Schuengel & Janssen 2006). Like parents, secure carers may be better equipped to provide sensitive care than insecure carers (Schuengel et al., 2010). In support of this, Schuengel, Damen, Kef and Worm (2012) found that secure and preoccupied carers give more communications confirming they have noticed people with learning disabilities' attempts to connect than dismissing carers. Initially, attachment representations had no significant influence on other behaviours indicative of quality care, such as amount of shared emotion. However, securely attached carers improved these behaviours once their attention had been drawn to them, suggesting they had the caregiving skills. In contrast, insecure carers only improved during training, indicating they initially lacked the skills.

Carers were predominantly female whilst people with learning disabilities mainly had severe and profound disabilities: the findings may not apply to male carers or more able care recipients. Furthermore, the inconsistent results make unconvincing evidence that attachments influence carers' capacities to provide sensitive and responsive care. However, the research utilised the AAI thus supports the assertion that care for people with learning disabilities is influenced by unconscious attachment representations.

Carers' attachment representations may interact with people with learning disabilities' attachment representations, such that even secure carers can take part in insecure relationships (Schuengel et al., 2012). Organisational constraints may also interact with attachment representations to influence care. Frequent changes in staffing, poor recognition of the value of attuned caregiving or organisational values that prioritise independence over facilitating relationships may promote insecure attachment (Clegg & Lansdall-Welfare, 2010; Schuengel et al., 2010). Even secure carers may struggle to provide quality care in such environments.

### **Carers' Empathy**

There is some preliminary evidence that people with learning disabilities' and carers' attachment representations influence their relationships. Notably, the little research pertaining to this topic sometimes presents inconsistent evidence, leaving the exact nature of the influence of attachment representations unclear. Since evidence suggests the attachment hypothesis may even apply in relationships between adult strangers with no ongoing care relationship, it is likely to apply in this relational context, which may be rich in attachment dynamics. As such, this paper will now consider literature pertaining to carers' empathy.

Two studies suggest that carers can find it difficult to recognise people with learning disabilities' emotions correctly, a phenomenon called empathic accuracy. Clark, Read and Sturmey (1991) found low reliability between carers' perceptions of people with learning disabilities' sadness and their clients' self-reports of sadness. Antonsson, Graneheim, Lundstrom, and Astrom (2008) interviewed carers about interacting with people with learning disabilities, summarising that "it was often a mystery why residents were angry, and guesses and misunderstandings occurred frequently" (p. 487). Carers described how being unable to understand evoked feelings of indifference or made them stop listening.

Two studies have measured carers' empathy using the Interpersonal Reactivity Index (IRI, Davis, 1980). This 28-item questionnaire measures both cognitive and affective dispositional empathy with considerable validity and reliability (Davis, 1983). Ireland and Clarkson (2007) studied 100 carers working in an inpatient unit whilst Giesbrecht (2008) studied 594 carers from two community support organisations. Both studies produced high mean cognitive and affective empathy scores, suggesting carers view themselves as empathic individuals.

However, dispositional empathy may not necessarily predict carers' empathy towards people with learning disabilities. Regardless of whether carers are altruistically motivated, their obligation to care even at personal cost may modify empathy. Empathy may be incompatible with some emotions (Bromley & Emerson, 1995) or cognitions (Jahoda & Wanless, 2005) evoked by challenging behaviours. People are less empathic when the subject is less similar to themselves (Barnett, Tetreault, & Masbad, 1987; Hodges, Kiel, Kramer, Veach, & Villanueva, 2010). Whether carers perceive people with learning disabilities as similar to themselves may modify their empathy. People are also less empathic to members of outgroups (Dovidio et al., 2010; Sturmer, Snyder, & Omoto, 2005):

people with learning disabilities are often an outgroup. Additionally, it may be harder to empathise with people with learning disabilities who struggle to communicate their perspectives clearly (Barrett-Lennard, 1981; Zaki, Bolger, & Ochsner, 2008) or if exchanging emotional cues is difficult. This might explain the discrepancy between carers' reports of being empathic by disposition and indications that carers struggle to be empathically accurate with people with learning disabilities (Antonsson et al., 2008; Clark et al., 1991). However, the well established differences between self-reported empathy and empathic accuracy (Ickes, Stinson, Bissonnette, & Garcia, 1990) could also explain the discrepancy. Finally, people with learning disabilities have high levels of need and are sometimes viewed as childlike. Batson, Lishnet, Cook, and Sawyer (2005) demonstrated that individuals who bring out people's *nurturance tendencies* are afforded greater empathy. People with learning disabilities might therefore evoke empathy even from carers who score lowly on dispositional empathy measures.

One study (Bell & Espie, 2002) investigated carers' empathy more specifically towards people with learning disabilities. Carers used 10-point Likert scales to rate the extent they experienced several emotions, including empathy. Although a single self-report question may have poor validity as an empathy measure, the mean empathy score was higher than most other scores, again suggesting carers perceive themselves as relatively empathic. Interestingly, there was a large range in carers' scores, perhaps because the question was specifically about empathy towards people with learning disabilities. Carers might be more empathic than the general population but still vary in their empathy towards people with learning disabilities at work, a suggestion consistent with evidence that people who choose caring roles have high dispositional empathy (Davis et al., 1999).

Reinders (2010) asserts that quality care for people with learning disabilities arises from carers' tacit skills, such as empathic attunement. He suggests attachment theory may explain individual differences in such skills. Giesbrecht (2008) investigated the relationships between attachment, empathy and caregiving by administering attachment and caregiving questionnaires alongside the IRI. Overall, anxiety and avoidance were negative predictors of affective and cognitive empathy and of quality caregiving. Cognitive and affective empathy positively predicted quality caregiving. However, the exact relationships between attachment and empathy varied. Carers working for an organisation with an interdependent ethos had higher anxiety and affective empathy scores. Avoidance was the more salient negative predictor of empathy. In contrast, carers working for an organisation which valued independence had higher avoidance and cognitive empathy scores. Anxiety was the stronger negative predictor of empathy. In summary, organisational values were associated with carers' attachment styles, such that different attachment styles became stronger predictors of empathy in different organisations.

This well powered path analysis study found highly significant low to moderate correlations, suggesting weak relationships between aspects of the model. Although the study cannot prove causal effects, it suggests that an indirect path whereby attachment influences empathy which influences caregiving is viable albeit weak. However, like the IRI, the attachment and caregiving questionnaires were not specific or appropriate to the professional caregiving context; they referred to romantic relationships. Consequently, whether attachment influences empathy and caregiving towards people with learning disabilities remains untested.

### **Summary**

A small body of research suggests that secure attachment representations may be associated with empathy and the provision of quality care towards unrelated adults. Two methodologically weak studies provide early evidence that attachment representations may be related to employed caregivers' empathy. Most studies' designs rendered them unable to investigate whether attachment representations causally influence empathy, although Mikulincer et al. (2005) provide initial evidence that felt security enhances empathy.

At least some relationships between people with learning disabilities and carers may be characterised by attachment dynamics, with very early indications that carers' attachment representations may be associated with caregiving behaviour. Dispositional empathy measures may be invalid indicators of carers' empathy towards people with learning disabilities. Consequently, little is known about empathy in this relational context or how it might be associated with attachment representations and caregiving.

### **Implications**

#### **Clinical Practice Implications**

Services should facilitate their staff forming quality caring relationships with people with learning disabilities. This is paramount for client wellbeing, bringing additional benefits such as decreased costs from specialist interventions. Given that the relationship between attachment and quality caregiving is complex, attempting to employ securely attached carers may not necessarily result in positive outcomes. Although there is some evidence that secure attachment facilitates empathy and quality caregiving, evidence of this within services for people with learning disabilities is insufficient to support policy or service level change where the cost-benefit analysis of such change is unclear. However, services should

consider moderate changes, such as introducing organisational strategies that support carers to feel secure in their workplace, e.g. small, stable teams working in one location and receiving regular, reflective supervision from a consistent manager. Psychologists could provide relevant training and support to managers and consult with organisations about the promotion and achievement of psychological security. Services struggling to provide high quality care may benefit from planned regular consultations with a consistent psychologist.

Psychologists could optimise interventions by incorporating information about people with learning disabilities' and carers' attachments, and carers' empathy, into formulations. Staff attachments may contribute to problems typically described as belonging to people with learning disabilities. Attachment representations may determine how easily carers can modify their caregiving (Schuengel et al., 2012): Guidance about behaving differently may be insufficient without reflection on carers' emotional experiences.

Empathy might be developed through training, reflective practice or staff team consultations. Zijlmans, Embregts, Gerits, Bosman, and Derksen (2011) found that training increases carers' emotional intelligence, a concept including empathy. Many psychologists may already see enhancing empathy as key to their work. An attachment perspective adds theoretical vigour to this practice and may indicate how to proceed when interventions are not effective. The relationship between attachment and empathy has been explicitly realised within Mentalization approaches, which could be integrated with systemic practice with staff teams in a similar way to families (Asen & Fonagy, 2011).

## **Research Implications**

Future research should not adopt existing dispositional empathy measures without first establishing they are (a) valid within the context of paid carers' empathy towards people with learning disabilities; (b) sufficiently sensitive, with a high enough 'ceiling', to detect variance in carers' empathy. A new, context-specific measure would be highly valuable. Research should then determine whether and how self-reported empathy is related to carers' attachments and caregiving towards people with learning disabilities. Ideally, to clarify causality, research would measure the effect of manipulating momentary attachment security on empathy and caregiving. Such research could assess carers before and after organisational changes designed to increase felt security. Studies should also explore how people with learning disabilities' and carers' attachments might interact to influence the caring relationship.

Although this paper focussed on the relationship between attachment and empathy, other mechanisms by which attachment representations might influence professional caregiving are worthy of research. Research expanding our understanding of how empathy operates in this context and can be increased would also be valuable. Finally, research should attempt to integrate an understanding of carers' attachment representations and empathy with existing literature in the learning disability field, for example by investigating whether these factors influence carers' attributions.

## **Conclusion**

The link between secure unconscious attachment representations and the ability to provide sensitive, responsive care to children is well established. Contemporary advancements to attachment theory suggest that securely attached adults possess

psychological resources, including empathy, that facilitate sensitive and responsive caregiving to a range of recipients. Such claims are consistent with evolutionary theory. This paper explored evidence pertaining to whether attachment representations influence employed carers' empathy and caregiving towards adults with learning disabilities.

Evidence suggests that attachment representations may influence people's empathy and caregiving towards unrelated adults. Limited and sometimes methodologically weak evidence indicates that this effect may be maintained when caregivers are employed: securely attached professional caregivers *may* be more empathic than their insecure counterparts but further evidence is needed to clarify the validity of this assertion.

Within the context of learning disability services, there is increasing recognition that both carers' and people with learning disabilities' attachment representations may influence the caring relationship. Some early evidence indicates that people with learning disabilities may develop attachments to carers. Several authors suggest that carers' attachments might influence their caregiving. Recently, Schuengel et al. (2012) provided the first evidence that secure attachment may facilitate quality caregiving for people with learning disabilities, although results were inconsistent and their wider applicability needs establishing. However, research investigating carers' empathy has utilised measures that may be invalid indicators of empathy towards people with learning disabilities. As such, little is known about carers' empathy towards people with learning disabilities or how attachment representations might influence this.

These findings imply that psychologists should support staff teams and consult with service managers to facilitate organisational change such that carers feel maximally secure in their workplaces. Research priorities include developing a measure of carer empathy towards people with learning disabilities. The factors that influence empathy towards

people with learning disabilities, including attachment representations, psychological interventions and organisational changes, could then be investigated.

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## SECTION B

The EMP-LD: A new measure of employed carers' empathy towards  
people with learning disabilities

Word count: 8000 (plus 204 additional words)

For the Journal of Applied Research in Intellectual Disabilities

(Appendix 2 contains guidelines for authors)

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**Keywords:** EMPATHY, INTELLECTUAL DISABILITIES, STAFF, QUESTIONNAIRE, ATTACHMENT

## Abstract

### **Background**

Little is known about paid caregivers' empathy towards people with intellectual disabilities. This study aimed to develop a self-report measure of carers' empathy and explore the nature of empathy in this relational context.

### **Materials and Methods**

Following questionnaire development, 194 staff working in services for people with intellectual disabilities completed self-report questionnaires, including the new empathy measure. The measure's factor structure and psychometric properties were investigated.

### **Results**

A three factor solution suggested two key processes in empathising: experiencing commonality between one's own and people with intellectual disabilities' psychological experiences and efforts to attune to their internal worlds. The final factor represented whether carers find it challenging to empathise. Validity was evidenced by correlations with beliefs about caregiving.

### **Conclusions**

The salient processes in empathising with people with intellectual disabilities may be different from other contexts. Empathy is related to beliefs about the self and others in caregiving relationships. Establishing determinants of carer empathy may facilitate interventions.

## Introduction

The concept of empathy has been present in literature for approaching 300 years. Smith (1759, as cited in Davis, 1980) differentiated between an instinctive emotional response to others' experiences and an intellectualised ability to recognise the state of others without experiencing any emotion oneself. Twentieth Century definitions followed similar groupings. Some suggested that empathy involves the observer experiencing the same emotional state as another person or a state appropriate and related, but not necessarily identical to, the other (e.g. de Vignemont & Singer, 2006; Eisenberg & Miller, 1987). Others suggested that the observer's affective state must involve compassion (Batson, 1991). The emergence of cognitive theories (e.g. Mead, 1934; Piaget, 1932) led to an understanding of empathy as a process of trying to understand another's perspective (e.g. Dymond, 1949). Davis (1980) integrated these positions, proposing that empathy consists of affective and cognitive components.

Seeing someone in need can evoke two emotional responses (Batson, Fultz, & Schoenrade, 1987). *Empathic concern* produces an altruistic motivation to help and predicts prosocial behaviour whilst *personal distress* (self-orientated feelings of disturbance) does not (see Batson, 2010 for a review of supporting evidence). In health and social care, empathy is considered key to therapeutic relationships (e.g. Alligood, 2005; Rogers, 1961). Staff empathy is associated with decreased patient distress (Olson & Hanchett, 1997; Reid-Ponte, 1992) and better physical (Hojat et al., 2011) and psychotherapy outcomes (Elliot, Board, Watson, & Greenberg, 2011).

Evidence suggests that empathy is dispositional (Marangoni, Garcia, Ickes, & Teng, 1995; Penner & Orom, 2010), with women being more empathic than men (see Baron-

Cohen, 2002 for a review). However, people may seek situations that allow expression of their characteristic traits (Snyder, 1983). Greater dispositional empathy is associated with greater willingness to volunteer to help needy others (Davis et al., 1999). Consequently, empathic individuals may be more likely to choose caring professions.

People with learning disabilities value empathy and understanding from professional caregivers (Clarkson, Murphy, Coldwell, & Dawson, 2009; Dinsmore & Higgins, 2011; Roeden, Maaskant, & Curfs, 2011). Such carers are often their greatest source of emotional support (Forrester-Jones et al., 2006) given their sometimes small networks of family and friends (Emerson, 2005; Robertson et al., 2001). Relationships with staff therefore become important (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006) and carers require empathy to navigate such relationships sensitively. Furthermore, some people with learning disabilities have less ability to communicate feelings clearly, or may do so through challenging behaviours. They rely on empathic carers to interpret their needs and respond accordingly.

Few studies have investigated the extent of carers' empathy in this particular context. Giesbrecht (2008) and Ireland and Clarkson (2007) utilised the Interpersonal Reactivity Index (IRI; Davis, 1980), a self-report measure of dispositional empathy, to suggest carers have high cognitive and affective empathy. However, carers' dispositional empathy may not validly predict their empathy towards people with learning disabilities. Carers' obligation to care and responsibility to prevent things going wrong may modify their empathy. Certain challenging behaviours may evoke emotions (Bromley & Emerson, 1995) or cognitions (Jahoda & Wanless, 2005) incompatible with empathy. It may be harder to empathise if people cannot communicate their internal worlds easily (Barrett-Lennard,

1981; Zaki, Bolger, & Ochsner, 2008). Carers might avoid empathising because connecting with the emotional pain frequently experienced by people with learning disabilities (Arthur, 2003) is distressing. Carers may experience burnout (Lawson & O'Brien, 1994) that decreases their empathy at work. Alternatively, carers might be more empathic when in role at work or because people with learning disabilities have high levels of need.

Bell and Espie (2002) asked carers to rate their empathy towards people with learning disabilities using a Likert scale. Carers perceived themselves as relatively empathic but scores were wide ranging. Consistent with the suggestion that empathic individuals might choose care work, carers might have generally high dispositional empathy compared to the general population but still vary in their empathy towards people with learning disabilities. Dispositional measures might have *ceilings* too low for sensitivity to variation in carers' empathy: in the aforementioned IRI data two standard deviations from the mean went beyond the upper limit of some subscales.

Two approaches discuss how empathic emotions influence care towards people with learning disabilities. Sympathy has sometimes been considered an empathic emotion (Baron-Cohen & Wheelwright, 2004; Batson, 2010). Research based on Weiner's (1980) attribution model has consistently found that sympathy correlates with intention to help people with learning disabilities showing challenging behaviour (Dagnan, 2012; Hill & Dagnan, 2002; McGuinness & Dagnan, 2001; Wanless & Jahoda, 2002). Dagnan & Cairns (2005) found that various attributions predicted sympathy, which predicted intention to help. However, the model accounted for low amounts of variance in sympathy and helping, suggesting other predictors exist. Betancourt (1990) found that an empathic stance increases sympathy, the attributions that pre-empt sympathy, and helping behaviour.

Incorporating dispositional empathy into attribution models might enhance predictive ability.

Other research draws on Bowlby's (1973) premise that early experiences of care shape *attachment representations*. These templates about interpersonal relationships influence people's working models about caregiving and their capacity to provide care (George & Solomon, 1996). People who receive sensitive and responsive care in childhood may develop a *secure* attachment status (Ainsworth, Blehar, Waters, & Wall, 1978). They are likely to become sensitive and responsive caregivers whilst those with insecure attachments (*anxious* or *avoidant*) may be less able to provide quality care (e.g. Haft & Slade, 1989; Kunce & Shaver, 1994; Shaver, Mikulincer, & Shemesh-Iron, 2010). Authors have suggested (e.g. Clegg & Landsdall-Welfare, 1995; Schuengel, Kef, Damen, & Worm, 2010; Watt & Brittle, 2008) or demonstrated (Schuengel, Kef, Damen, & Worm, 2012) that attachment representations influence carers' interactions with service users.

Carers' attachments may explain differences in tacit abilities, including capacity to empathise (Reinders, 2010). Indeed, evidence suggests (see Mikulincer & Shaver, 2007 for a review) that securely attached adults have the psychological resources for empathising. People with avoidant attachment styles may be unmotivated to empathise. Anxiously attached individuals may lack emotion regulation skills: their attention becoming self-focussed, leaving limited resources for empathising. In a sample of carers for people with learning disabilities, Giesbrecht (2008) found that attachment anxiety and avoidance negatively predicted self-reported beliefs and behaviours indicative of quality caregiving, both directly and indirectly through empathy. However, the research utilised the IRI and a measure about caregiving in romantic relationships (Kunce & Shaver, 1994). Consequently it

does not demonstrate that attachment representations predict empathy and professional caregiving towards service users. Notably, the Mental Representations of Caregiving Scale (Reizer & Mikulincer, 2007), which measures generalised motivations for and beliefs about caregiving, has theoretically predictable relationships with attachment style and empathy.

In summary, dispositional empathy measures may be invalid indicators of carers' empathy towards people with learning disabilities. Consequently, we aimed to develop a new questionnaire, measuring empathy in this specific relational context. Adopting the starting premise that empathy towards people with learning disabilities might be similar in nature to empathy more generally, the questionnaire was designed to follow Davis' (1980) conceptualisation and measure both cognitive and affective empathy. Since these components may be difficult to disentangle (Baron-Cohen & Wheelwright, 2004), we aimed to determine the questionnaire's factor structure and whether it measures cognitive and affective processes. This would illuminate the nature of empathy towards people with learning disabilities. Construct validity would be investigated through the hypotheses that factor scores would:

- 1) Positively correlate with indices of empathy but negatively correlate with an index of personal distress.
- 2) Positively correlate with mental representations about caregiving that are indicative of quality caregiving and altruistic motivation to care, but negatively correlate with an index of egoistic motivation to care.
- 3) Not correlate with tendency to give socially desirable responses.
- 4) Be higher for females than males.

5) Be higher for participants who knew a person with a learning disability outside their work context than those without such a relationship.

To determine test-retest reliability a sixth hypothesis, that factors scores would correlate with scores obtained four to six weeks later, was explored.

## **Materials and Methods**

### **Design**

The study followed Rattray and Jones' (2005) steps for questionnaire development. This included; development of the construct to be measured, determination of the measurement format, item generation, item reduction, piloting of a draft questionnaire, and investigation of the questionnaire's psychometric properties.

### **Ethics**

Ethics approval was granted by an ethics board at Canterbury Christ Church University (see Appendix 3). At the end of the study, a report of findings was sent to the ethics board and those participants and organisations who wished to receive feedback (see Appendix 4).

### **Procedure**

**Development of the empathy construct.** DeVellis (1991) suggested that scale development should utilise "at least a tentative theoretical model" (p. 52). We adopted Davis' (1980) definition of empathy as a multidimensional construct. Given the limited literature about carers' empathy towards people with learning disabilities, experts' views were also sought. Members of the British Psychological Society's Faculty for Learning

Disabilities were emailed via a mailing list (see Appendix 5) and asked “what comes to mind when you think of the empathy of paid carers towards people with a learning disability?” Thirty-one members responded. Appendix 6 contains a sample of responses.

Responses were subjected to the first three stages of thematic analysis described by Braun and Clarke (2006). Analysis was conducted from an inductive realist position, although we were aware of the cognitive-affective distinction. Since this area had not previously been researched, the initial stages of thematic analysis were completed on the entire data corpus rather than focussing on a single specific aspect. Extracts were defined as a word, phrase or paragraph. Analysis focussed on extracts’ semantic meanings.

Phase one entailed collating the data items and reading them three times, whilst noting potential codes. In phase two, the first researcher (KM) went systematically through the data generating initial codes. Guided by these codes, a second researcher (CH) re-coded the data, adding additional codes. In phase three, coded extracts were arranged into initial themes. Appendices 7 and 8 contain a list of codes, with examples, and a thematic map of initial themes. Full thematic analysis of the entire data corpus may, with the experts’ consent, form a separate paper.

The current requirement was for themes to guide item development. We identified prevalent subthemes relevant to the measurement of dispositional empathy towards people with learning disabilities. As Braun and Clarke (2006) recommended, prevalence was determined by both frequency across and salience within data items. Relevance was determined by whether subthemes pertained to empathy and described constructs that might vary between carers i.e. subthemes were not about situational influences on empathy. Subthemes used to develop items are described and exemplified in Table 1.

Table 1

*Subthemes Used to Develop Questionnaire Items*

| Subtheme                                   | Description   | Example  |
|--|---|--|
| Understanding level of learning disability | 13 experts described how empathic carers gauge people with learning disabilities' strengths and weaknesses in order to understand them.             | <i>Understanding the client's... ..cognitive strengths and weaknesses and how these relate to the behaviours displayed (E28).</i>        |
| Interpretation                             | 6 experts suggested empathic carers interpret people with learning disabilities' behaviour and/or consider whether they have interpreted correctly. | <i>You can almost see the processing gap or interpretative moment as they hold back before speaking themselves (E4).</i>                 |
| Perspective taking                         | 12 experts said imagining people with learning disabilities' perspectives contributes to empathy.   | <i>The ability to put yourself in someone else's shoes... ..and imagine yourself experiencing the world from their perspective (E1).</i> |
| Emotional                                  | 11 experts described how  | <i>Staff mirror and reflect the body language</i>  |

|                               |   |  |
|-------------------------------|---|--|
| connection                    | some carers demonstrate empathy at an emotional, non-verbal level.  | <i>of the person being supported in a compassionate manner. There is a dialogue at a pre-verbal level between a carer and the client (E20).</i>  |
| Listening to lived experience | 8 experts suggested empathic carers understand people with learning disabilities' presentations in the context of their life histories and accounts of their experiences.   | <i>Making sense of it in the context of the client's developmental history (E2).</i>   |
| Pleasure in company           | 2 experts described empathic carers as sharing in mutually enjoyable exchanges with people with learning disabilities. Although mentioned less frequently, this subtheme captured an alternative aspect of empathy. | <i>Not being afraid to gently tease the person with LD and not being so concerned to be politically correct to the point of being a robot. A sense of taking genuine pleasure in the company of people with LD (E4).</i> |
| Making sense                  | 12 experts described how empathy manifests as   | <i>I can see empathy go wrong at times when carers make wrong assumptions about a</i>  |

|                               |   |  |
|-------------------------------|---|--|
| of behaviour                  | whether carers find it difficult to understand why people with learning disabilities perform behaviours.                                      | <i>person's motives (E3).</i>  |
| Parent-child relationship     | 7 experts said viewing people with learning disabilities as children or acting like a parent indicates low empathy.                           | <i>There are many attitudes about the 'poor' person with LD and the 'childlike mind' which goes some way to dictating how the carer works with that client (E31).</i>  |
| Experiences requiring empathy | 8 experts suggested people with learning disabilities suffer disadvantages or painful experiences requiring empathy.                          | <i>...if paid carers understand the power their clients have, that there is a cumulative impact of having little power to effect change on others or an environment (E18).</i>   |
| Similarities and differences  | 10 experts suggested empathy is influenced by whether carers perceive people with learning disabilities as being similar to or different from | <i>...the range of empathy implicit in the statements 'they are the same as me' (and have my feelings and reactions and will like what I like - over empathic) to 'they are different to me' (they cannot be understood and won't appreciate what I value in life - potentially no empathy at all)</i> |

|                          |  |   |
|--------------------------|--|---|
|                          | themselves.  | (E23).  |
| Managing strong emotions | 10 experts suggested carers' ways of managing strong emotions make empathising easier or more difficult. | <i>Carers may withdraw from empathic relationships (focusing on the physical care aspects) as being in touch with clients' difficult emotions can be overwhelming (E9).</i>   |
| Personal experiences     | 6 experts said personal experiences may influence carers' empathy.                                       | <i>Empathy comes out of our own experiences of a situation / role that allow us to feel some of what the other person feels. What is it about LD work that produces our empathy? Is it our own sense of our experiences of being stupid / not getting what is going on, through no fault of our own, of being rejected from mainstream 'society'... (E7).</i> |

Note. E is used to denote which expert made each comment.

**Determination of measurement format.** Oppenheim (1996) suggested Likert scales are preferred by participants and provide more information than dichotomous systems. Additionally, they are simple to construct and often have high reliability (Oppenheim, 1996). We chose to utilise a 1 (*strongly disagree*) to 6 (*strongly agree*) Likert scale. This allowed for inclusion of items of varied natures and prevented participants selecting a middle option, which can be hard to interpret (Clark & Watson, 1995). Six response options allowed

participants to indicate very moderate opinions, hopefully decreasing any objections to having to choose a side of the fence (Clark & Watson, 1995).

**Item generation.** Based on the subthemes, we developed items pertaining to cognitive and affective empathy and phrased in both positive and negative terms. Items from one author's (DD) draft of an empathy measure were adapted and mapped onto the themes. We reviewed the items, adapting wording and removing those with low face validity. This produced 60 items (see Appendix 9).

**Item reduction.** We invited respondents to the empathy question to join an expert panel to review items. Five experts responded. We also requested the views of a psychologist who had conducted empathy research. Experts used a one (*not at all*) to five (*very much*) scale to rate the extent they thought each item measured empathy. We selected the 19 items which all raters gave at least three and the nine items where the median and modal rating was at least four. Two items, which experts considered likely to evoke socially desirable responses, were replaced by items with a median score of at least three and a mode of four. We distributed positively and negatively phrased items, and those focussing on cognitive and affective empathy, to produce a 28-item draft measure. We planned to remove items during the psychometric study to make the questionnaire practical for routine use.

**Pilot study.** We asked six carers at a residential home to complete the questionnaire and provide feedback. Overall, they reported that the instructions and items were easy to understand. Based on their feedback we adjusted the wording of the instructions and some items; for example item three was simplified and an example was added to item seven.

**Study of psychometric properties.** We recruited 194 participants using convenience sampling. Convenience sampling was appropriate because, following Kass and Tingley's (1979, as cited in Field, 2009) advice that factor analysis requires a minimum variable to participant ratio of 1:5, at least 140 participants were needed. Furthermore, previous similar research (Giesbrecht, 2008; Reizer & Mikulincer, 2007) suggested that correlations with other measures might be small. At a power of 0.8, 154 participants were needed to detect correlations of 0.2. To ensure an adequate sample, all staff employed to work specifically with people with learning disabilities were eligible for inclusion.

Managers or chief executives of 13 different services or service providers were asked whether they would be willing for their staff to participate. This included independent, charitable, local government and NHS providers. Managers gave verbal consent. Written approval was granted from the Research and Development department of a Trust in which a few of the participants worked for the NHS (Appendix 10). We followed managers' preferences about approaching staff to participate. Staff were given questionnaire packs at training events, in team meetings, via the post or via their work post trays. Staff were not paid but were eligible to participate in a draw to win a £100 voucher. Staff returned the consent form and questionnaires in freepost envelopes or gave them to a member of the research team. The overall response rate was 24.25%.

Participants from one employer were asked to complete the new questionnaire a second time, four to six weeks after the first administration. Twenty-one participants returned this questionnaire.

Data were analysed using Statistical Package for the Social Sciences- Version 17.0.

## Materials

The psychometric study utilised written packs containing information sheets for participants (Appendix 11), a consent form (Appendix 12), and the following five questionnaires (Appendix 13):

- A questionnaire requesting details about the participant, their work and the people with learning disabilities they support. We designed this questionnaire to facilitate determination of whether our findings might apply to the wider population of staff working with people with learning disabilities. To facilitate testing of hypothesis five, participants were asked whether they knew a person with a learning disability outside their work context.
- The new empathy measure, henceforth called the EMP-LD.
- The Marlowe-Crowne Social Desirability Questionnaire (MCSDS; Crowne & Marlowe, 1960). Participants respond true or false to indicate whether they perform 33 highly socially desirable but unlikely behaviours. A total score is calculated by summing socially desirable responses. Based on students, the MCSDS has good internal consistency ( $\alpha = 0.88$ ) and test-retest reliability ( $r = 0.89$ ) (Crowne & Marlowe, 1960). Its construct validity is evidenced (Crowne & Marlowe, 1960) through correlations with Minnesota Multiphasic Personality Inventory scores (MMPI; Dahlstrom & Walsh, 1960). The MCSDS was selected because it is brief to complete and has established psychometric properties.
- The Interpersonal Reactivity Index (IRI; Davis, 1980). This dispositional empathy measure requires participants to use a 1 (*does not describe me well*) to 5 (*describes me very well*) Likert scale to rate how well 28 items about emotions describe them personally. Four seven-item subscales are measured. Perspective taking (PT) and fantasy (F) pertain to

cognitive empathy. Empathic concern (EC) and personal distress (PD) assess affective experiences. Item scores are added to give subscale scores. Higher PT, EC and F scores indicate higher ability on these empathy skills. Higher PD scores suggest an emotional response that may disrupt empathy. Based on over 500 students, subscales have adequate internal reliability ( $0.70 < \alpha < 0.78$ ) and test-retest reliability ( $0.61 < r < 0.81$ ) (Davis, 1980). Factor structure remains constant across both sexes, although females score more highly on all subscales (Davis, 1980). Construct validity has been demonstrated through correlations with interpersonal functioning, self-esteem, emotionality, sensitivity to others and several other empathy scales (Davis, 1983; Lawrence, Shaw, Baker, Baron-Cohen, & David, 2004). The IRI was used because it is brief to complete and measures both cognitive and affective empathy.

- The Mental Representations of Caregiving Scale (MRC; Reizer & Mikulincer, 2007). This questionnaire measures motivations for caregiving and beliefs about the self as a caregiver and others as care recipients. Respondents use a 1 (*strongly disagree*) to 7 (*strongly agree*) Likert Scale to rate the extent that 27 items are descriptive of them in caring interactions with close others. Four subscales (perceived ability to recognise others' needs, appraisal of others as worthy of help, perceived ability to provide effective help, and altruistic motivations for helping) measure qualities needed for effective caregiving. The remaining subscale measures egoistic motivations for caregiving. The mean score on items in each subscale is calculated. Higher scores indicate greater endorsement of each belief or value. Based on 841 Israeli adults, the MRC subscales have acceptable internal consistency ( $0.75 < \alpha < 0.80$ ; Reizer & Mikulincer, 2007). The authors demonstrated construct validity through correlations with empathy, attachment style,

prosocial values and attitudes towards parenting. Women scored significantly more highly than men on three subscales and men more highly than women on one subscale.

The MRC was used because it was the only measure of caregiving representations not specific to romantic relationships. It is theoretically and demonstrably related to empathy, as measured by the IRI (Davis, 1980). The MRC has not been validated for professional carers. However, no measures are both valid for professional carers and demonstrably related to empathy. Additionally mental representations of caregiving are more relevant to the study of professional caregiving than other constructs. Using the MRC, which was developed from attachment theory, also builds on previous research.

The MCSDS is freely available for use. Consent to use the MRC and IRI was obtained (see Appendices 14 and 15).

## Results

### Sample Characteristics

Most (95%) participants responded to each question on the first questionnaire. The sample was 74% female with a mean average age of 43 years ( $SD = 11.50$ ), ranging from 18 to 67 years. Staff worked for 13 different employers including statutory, charitable and independent providers. Most (95%) participants had worked with people with learning disabilities for over a year and many (48%) for 10 years or more. A high proportion (69%) reported knowing a person with a learning disability outside their work context. Most (75%) were employed on a full-time basis, the remainder being employed part-time or as bank staff. Nineteen percent reported working in residential homes, 26% in day services, 21% in people with learning disabilities' own homes and 10% in inpatient units. An additional 24%

worked in two or more of these settings. The sample consisted of 67% support workers, 15% nurses, 7% managers, 7% allied health professionals, 3% higher managers and 1% administrators.

Participants specified whether they work with people with learning disabilities who (a) speak fluently; (b) use phrases; (c) say single words; (d) do not use words to communicate; (e) are independent with personal care; (f) need some support with personal care; (g) need full assistance with personal care. Each descriptor was endorsed by over 60% of participants. Most participants (84%) managed challenging behaviour, with 22% managing it daily.

### **Data Screening**

The distributions of responses for all items were screened. Item 19 was removed because most (77%) participants scored six, indicating the item was insensitive. Item 20 was removed because, with hindsight, we thought it ambiguous whether high scores indicated high or low empathy. The univariate and multivariate normality of the remaining items was explored. Two univariate outliers, which were greater than three standard deviations from the mean and discontinuous with the distribution, were removed. Mahalanobis distances were calculated and compared to the critical value of the  $\chi^2$  distribution ( $\chi^2(26) = 38.88, p = 0.05$ ), which resulted in removal of 13 cases. Factor analysis requires normally distributed variables but is considered robust when skew is below two and kurtosis is below seven (Curran, West, & Finch, 1996). These criteria were met by all items except item 15, which was removed. Missing EMP-LD data were excluded from further analysis in a pairwise fashion.

Single missing items on MRC or IRI subscales were replaced with the mean of the other items on the subscale. Where a MCSDS item was missing, a score of one was added to the total score i.e. the participant was assumed to have made a socially desirable response. No score was calculated if two or more items were missing from any scale or subscale.

### Factor Analysis

Parallel analysis is one of the most robust methods for determining how many factors to extract (Fabrigar, Wegener, MacCallum, & Strahan, 1999). Syntax for parallel analysis (O'Connor, 2000) was imported to SPSS. Following recommendations from How2Stats (2011), a parallel analysis based on 1000 random permutations of the raw data was conducted. As shown in Table 2, three factors obtained eigenvalues above the eigenvalue at the 95th percentile of those obtained from the random permutations. Since parallel analysis can overestimate the number of meaningful factors (Buja & Eyuboglu, 1992), two and three factor solutions were attempted. We chose a three factor solution because it was more robust, theoretically meaningful and accounted for more variance.

Table 2

*Eigenvalues of Extracted Factors v. Eigenvalues From Random Data Permutations*

|          | Eigenvalues of extracted factors | Eigenvalues from random data permutations |
|----------|----------------------------------|---|
| Factor 1 | 4.77                             | 1.15                                      |
| Factor 2 | 2.63                             | 0.99                                      |
| Factor 3 | 1.08                             | 0.86                                      |

Items 12, 25 and 28 were removed because they had communalities below 0.2 thus shared little common variance with other items. Principle Axis Factor analysis with Direct Oblimin oblique rotation was then performed. The Kaiser-Meyer-Olkin measure ( $KMO = 0.79$ ) indicated good sampling adequacy (Hutcheson & Sofroniou, 1999). Bartlett's Test of Sphericity indicated that the correlations between the items were adequate for factor analysis ( $\chi^2 = 1000.26, p \leq 0.001$ ).

Tabachnick and Fidell (2007) recommend interpretation of the pattern matrix following oblique rotation because structure matrix loadings can be inflated by overlap between factors. The pattern matrix presents the unique relationships between factors and variables once overlapping variance amongst factors has been taken into account (Tabachnick & Fidell, 2007). The rotated pattern matrix revealed that many items had substantial relationships to a single factor.

Since items had already been removed, only item two was removed to shorten the scale. Item two's highest factor loading was weaker than most others and it had a second substantial loading on another factor. Furthermore, most (68%) participants scored six on this item, indicating it was fairly insensitive.

Principle Axis factor analysis with Direct Oblimin oblique rotation was repeated on the remaining 21 items. The Kaiser-Meyer-Olkin measure ( $KMO = 0.79$ ) and Bartlett's Test of Sphericity ( $\chi^2 = 926.27, p \leq 0.001$ ) indicated that the data remained suitable for factor analysis. The same three-factor structure was retained. This model converged in 13 iterations, accounting for 34% of the variance before rotation. This is an estimate of the variance accounted for after rotation because oblique rotation allows factors to correlate

(Tabachnick & Fidell, 2007). There were negative correlations between Factors One and Three ( $r = -0.34$ ) and Two and Three ( $r = -0.21$ ).

As shown in Table 3, the factor loadings in the pattern matrix were all above 0.32, the minimum for claiming an item loads on a factor (Comrey & Lee, 1992). The “greater the loading the more the variable is a pure measure of the factor” (p. 625) (Tabachnick & Fidell, 2007). Loadings above 0.55 have 30% overlapping variance with the factor and can be considered good whilst fair loadings, over 0.45, share 20% of the factor’s variance (Comrey & Lee, 1992). Items 6 and 24 had two loadings. These items were theoretically consistent with, and thus considered part of, the factors on which they loaded highest.

Table 3

*Pattern Matrix Factor Loadings for EMP-LD Items*

| Item   | Factor loadings |          |          |
|--|-----------------|----------|----------|
|  | Factor 1        | Factor 2 | Factor 3 |
| 14. I use my own life experiences to help imagine what it might be like to have a learning disability                                | <b>0.61</b>     | 0.18     | 0.04     |
| 4. I imagine myself in the place of someone with a learning disability when working with them  | <b>0.56</b>     | 0.05     | -0.02    |
| 17. Seeing the world through the eyes of the person with a learning disability helps me understand what they want                    | <b>0.51</b>     | 0.23     | -0.05    |
| 8. I wonder whether someone with a learning disability is feeling the same way as I would in a particular situation                  | <b>0.51</b>     | -0.02    | 0.01     |
| 10. I feel upset when I see someone with a learning disability is sad  | <b>0.51</b>     | 0.02     | -0.13    |
| 7. I feel frustrated when someone with a learning disability is unable to do something important to them e.g. go on a local day trip | <b>0.44</b>     | -0.20    | -0.05    |
| 5. I get angry when I think of how people with learning disabilities have been treated   | <b>0.42</b>     | -0.07    | -0.21    |

|   |             |             |              |
|---|-------------|-------------|--------------|
| 18. If a person with a learning disability is depressed it brings my mood down  | <b>0.41</b> | -0.20       | -0.03        |
| 9. It is hard to put yourself in the shoes of someone with a learning disability.   | 0.09        | <b>0.69</b> | 0.25         |
| 16. Because no two people with learning disabilities are alike, it is difficult for me to see things from their perspective | 0.11        | <b>0.66</b> | 0.01         |
| 3. It is difficult for me to see things from the points of view of people with learning disabilities                        | 0.08        | <b>0.65</b> | 0.07         |
| 13. I find it hard to understand why people with learning disabilities behave the way they do                               | 0.02        | <b>0.58</b> | -0.15        |
| 6. I find it hard to pick up on the moods of people with learning disabilities  | -0.14       | <b>0.46</b> | <b>-0.32</b> |
| 22. It is hard to know how people with learning disabilities feel if they can't speak or don't choose to say                | -0.20       | <b>0.44</b> | -0.19        |
| 26. I find it difficult to work out why someone with a learning disability is crying  | -0.12       | <b>0.39</b> | -0.25        |
| 27. I take a moment to consider whether I've understood what a person with a learning disability is trying to communicate   | 0.13        | -0.13       | <b>-0.60</b> |

|   |             |       |              |
|---|-------------|-------|--------------|
| 11. I take a moment to consider what the person with a learning disability might be thinking before I respond to them           | 0.20        | 0.11  | <b>-0.55</b> |
| 21. I can pick up on the mood of someone with a learning disability without them needing to tell me                             | -0.09       | 0.12  | <b>-0.55</b> |
| 1. I always try to tune into the feelings of people with learning disabilities around me  | 0.21        | 0.05  | <b>-0.48</b> |
| 24. I try to understand what is going on in the mind of a person with learning disabilities by paying attention to what they do | <b>0.35</b> | -0.02 | <b>-0.42</b> |
| 23. It's important to find out about a person with a learning disability's life to be able to put yourself in their place       | 0.21        | -0.07 | <b>-0.33</b> |

Note. Factor loadings > 0.32 are in boldface.

Factor One contained eight items pertaining to shared psychological experiences between the self and people with learning disabilities. Item 17 suggests physical closeness or merging. Consequently, Factor One was named *Proximity*. Factor Two contained seven items about whether it is difficult to empathise with people with learning disabilities. It was named *Challenge*. Factor Three contained six items about actively working to understand people with learning disabilities' internal experiences. It was named *Active Attunement*.

Repeating the factor analysis on males' and females' scores separately indicated that the three-factor structure was stable across genders. Due to the small sample ( $n = 49$ ), sampling adequacy for males ( $KMO = 5.55$ ,  $\chi^2 = 1000.26$ ,  $p \leq 0.001$ ) was only just acceptable (Kaiser, 1974).

The EMP-LD was thus understood to have three factors, which were considered subscales. All subscales had acceptable internal reliability (Proximity: Cronbach's  $\alpha = 0.73$ ; Active Attunement: Cronbach's  $\alpha = 0.73$ ; Challenge: Cronbach's  $\alpha = 0.76$ ) for a scale in the early stages of development (Rattray & Jones, 2005). Each participant's mean average score on the items in each subscale was calculated. Mean scores were not calculated when data were missing.

### **Construct Validity**

Gender affects IRI and MRC subscale scores (Davis, 1980; Reizer & Mikulincer, 2007). However, independent samples t-tests indicated that gender did not have the expected effects on IRI or MRC scores in the current data, perhaps because the effect of gender operates differently in a population of carers. Consequently, males' and females' subscale scores were only analysed separately where there were significant differences in score in the current data.

The distribution of scores on the EMP-LD, IRI and MRC subscales, together with total scores on the MCSDS, were examined, separately for men and women where necessary. Distributions are unlikely to be normal if the standard score (z-score) for either skew or kurtosis exceeds 3.29 (Tabachnick & Fidell, 2007). Based on this criterion, all distributions were considered normal, except Altruism which was consequently analysed separately.

Hypotheses one to three were tested using one-tailed Pearson correlations. Scatter plots revealed no curvilinear relationships between variables. Many significant correlations between subscale scores were found (see Tables 4 and 5).

Table 4

*Correlations Between EMP-LD and IRI Subscales*

|                    | Factor                  |         |                         |         |                         |         |
|--------------------|-------------------------|---------|-------------------------|---------|-------------------------|---------|
|                    | Proximity               |         | Challenge               |         | Active Attunement       |         |
|                    | Correlation coefficient |         | Correlation coefficient |         | Correlation coefficient |         |
|                    | P value                 |         | P value                 |         | P value                 |         |
|                    | n                       |         | n                       |         | n                       |         |
| Perspective taking | 0.21**                  |         | 0.17*                   |         | 0.24***                 |         |
|                    | 0.004                   |         | 0.015                   |         | 0.001                   |         |
|                    | 165                     |         | 163                     |         | 170                     |         |
| Empathic concern   | 0.19**                  |         | 0.18*                   |         | 0.20**                  |         |
|                    | 0.007                   |         | 0.013                   |         | 0.005                   |         |
|                    | 164                     |         | 162                     |         | 169                     |         |
| Fantasy            | 0.13                    |         | 0.18*                   |         | 0.09                    |         |
|                    | 0.051                   |         | 0.012                   |         | 0.121                   |         |
|                    | 164                     |         | 161                     |         | 167                     |         |
| Personal distress  | Males                   | Females | Males                   | Females | Males                   | Females |
|                    | -0.01                   | 0.01    | -0.07                   | -0.15   | -0.44**                 | -0.27** |
|                    | 0.477                   | 0.945   | 0.327                   | 0.094   | 0.002                   | 0.002   |
|                    | 41                      | 122     | 42                      | 119     | 42                      | 126     |

\*Significant at the 0.05 level

\*\* Significant at the 0.01 level

\*\*\* Significant at the 0.001 level

Table 5

*Correlations Between EMP-LD and MRC Subscales*

|   | Factor                  |                        |                         |                         |                          |                         |
|---|-------------------------|------------------------|-------------------------|-------------------------|--------------------------|-------------------------|
|   | Proximity               |                        | Challenge               |                         | Active Attunement        |                         |
|   | Correlation coefficient |                        | Correlation coefficient |                         | Correlation coefficient  |                         |
|   | P value                 |                        | P value                 |                         | P value                  |                         |
|   | n                       |                        | n                       |                         | n                        |                         |
| Egoistic motivations  | 0.01<br>0.426<br>168    |                        | -0.15*<br>0.029<br>166  |                         | -0.23***<br>0.001<br>173 |                         |
|   | Males                   | Females                | Males                   | Females                 | Males                    | Females                 |
| Perceived ability to recognize others' needs                | 0.08<br>0.302<br>42     | 0.06<br>0.517<br>124   | 0.43**<br>0.002<br>43   | 0.38***<br>0.000<br>121 | 0.42**<br>0.002<br>43    | 0.25**<br>0.005<br>128  |
| Appraisal of others as worthy of help                       | -0.04<br>0.409<br>42    | 0.08<br>0.366<br>124   | 0.08<br>0.317<br>43     | 0.05<br>0.601<br>121    | 0.10<br>0.253<br>43      | 0.11<br>0.237<br>128    |
| Perceived ability to provide effective help (effectiveness) | 0.26*<br>0.049<br>42    | 0.28**<br>0.002<br>124 | 0.31*<br>0.021<br>42    | 0.25**<br>0.005<br>121  | 0.59***<br>0.000<br>43   | 0.37***<br>0.000<br>128 |

\*Significant at the 0.05 level

\*\* Significant at the 0.01 level

\*\*\* Significant at the 0.001 level

Analysing data by gender reduced the sample sizes. Post-hoc power analyses on the significant effects obtained using these smaller samples were undertaken. Power was below 0.8 for the correlations between effectiveness and males' scores on Proximity and Challenge.

Participants were grouped into quartiles by Altruism scores. MANOVA was used to examine the one-tailed hypothesis that participants in quartiles indicating greater altruism would score more highly on the EMP-LD subscales than less altruistic participants. Altruism quartile had significant effects on Active Attunement ( $F(3, 169) = 6.83, p = 0.005$ ) and Challenge ( $F(3, 162) = 3.15, p = 0.026$ ). Its effect on Proximity did not quite reach significance ( $F(3, 165) = 2.62, p = 0.053$ ). Bonferroni post-hoc tests revealed significant differences in Active Attunement score between the 1<sup>st</sup> and 3<sup>rd</sup> and 1<sup>st</sup> and 4<sup>th</sup> altruism quartile groups ( $p = 0.004$  or lower) and between the 2<sup>nd</sup> and 4<sup>th</sup> quartile groups ( $p = 0.039$ ). For Challenge, significant differences were found between the 1<sup>st</sup> and 3<sup>rd</sup> quartile groups ( $p = 0.030$ ). For all differences, participants in higher altruism quartiles obtained greater empathy scores.

Hypothesis three was tested by correlating EMP-LD subscale scores with MCSDS scores. Active Attunement ( $r(165) = 0.19, p = 0.006$ ), but not Proximity ( $r(162) = -0.12, p = 0.060$ ) or Challenge ( $r(160) = 0.09, p = 0.127$ ), scores were significantly correlated with tendency to respond in a socially desirable manner.

Hypotheses four and five were explored using one-tailed independent samples *t*-tests. There were no significant differences between men's and women's scores on Active Attunement or Challenge. For Proximity, Levene's test was significant ( $F(1, 168) = 5.42, p = 0.021$ ) so equal variances were not assumed. Women obtained higher Proximity scores ( $M =$

4.51,  $SD = 0.66$ ) than men ( $M = 4.25$ ,  $SD = 0.86$ ). This difference was significant ( $t(62) = -1.80$ ,  $p = 0.038$ ). Cohen's (1988) criteria indicated the effect size ( $d = 0.43$ , based on the square root of the pooled variance) was just below medium.

Knowing a person with a learning disability outside of work had no effect on Active Attunement or Challenge. However, participants who knew a person with a learning disability outside of work obtained higher Proximity scores ( $M = 4.54$ ,  $SD = 0.67$ ) than those without such a relationship ( $M = 4.26$ ,  $SD = 0.75$ ). This difference was significant ( $t(166) = 2.46$ ,  $p = 0.007$ ), representing a small to medium (Cohen, 1988) effect ( $d = 0.40$ ).

### **Test-retest Reliability**

The distributions of scores obtained by participants who completed the EMP-LD twice were tested for normality using Shapiro-Wilk tests. Although Challenge from the first administration was not normally distributed ( $W = 0.88$ ,  $p = 0.026$ ), the standard scores for skew and kurtosis were significantly below 3.29 and normal probability plots indicated normality. Scores on the two administrations were significantly positively correlated for Proximity ( $r(18) = 0.56$ ,  $p = 0.006$ ), Active Attunement ( $r(17) = 0.82$ ,  $p = 0.001$ ) and Challenge ( $r(18) = 0.86$ ,  $p = 0.001$ ). A non-parametric Wilcoxon matched pairs test indicated that the null hypothesis of no difference between Challenge scores obtained in the two administrations could not be rejected ( $Z = -0.76$ ,  $p = 0.223$ ).

## **Discussion**

The current research aimed to develop a measure to capture individual differences in paid carers' empathy towards people with learning disabilities. We hoped the questionnaire's factor structure would illuminate the nature of empathy in this context. The

final 21-item EMP-LD had three factors, each containing items with substantial factor loadings and theoretical similarities. However, cognitive and affective empathy (Davis, 1980) do not map clearly onto this structure.

Instead, Proximity contains items about carers (a) experiencing an emotion related or similar to that felt by the person with a learning disability; (b) drawing on their own emotions and experiences to understand the person with a learning disability's experience; (c) imagining how they would feel in the person with a learning disability's situation, a form of perspective taking called *imagine-self* (Batson, Early, & Salvarani, 1997). We suggest the defining feature is shared experience and psychological closeness between the self and a person with a learning disability. In contrast, Active Attunement emphasises the carer striving to understand the person with a learning disability's internal experience, even if that differs from their own experience. More affective items describe sensitivity to the person with a learning disability's non-verbal communications. More cognitive items feature *imagine-other* perspective taking, defined as imagining how the other person feels in their situation (Batson et al., 1997).

Such components are consistent with empathy theory. Batson, Lishnet, Cook, and Sawyer (2005) suggested that people have a tendency to nurture. They demonstrated that subjects evoking this tendency strongly are afforded greater empathy than others. Similarly, people are more empathic towards adults with infant-like faces or voices than their adult-like counterparts (Lishner, Oceja, Stocks, & Zaspel, 2008). Other research suggests that people experience greater empathy when they perceive subjects as similar to themselves (Barnett, Tetreault, & Masbad, 1987; Hodges, Kiel, Kramer, Veach, & Villanueva, 2010), especially if subjects are from an outgroup (Dovido et al., 2010).

Batson et al. (2005) proposed that imagine-other, which involves focussing on others as separate people, might be “aligned with the other-orientated sensitivity and vigilance characteristic of nurturance” (p. 24). Imagine-self may evoke both empathy and vicarious personal distress and be associated with perceptions of similarity. Consistent with this, imagine-self is associated with merging of cognitive representations of the self and others and decreased stereotyping of others from outgroups (Galinsky & Moskowitz, 2000).

Active Attunement may represent the imagine-other/nurturance cluster. Proximity may represent the imagine-self/similarity cluster. We therefore suggest that these skill clusters may determine empathy towards people with learning disabilities. Their salience is logical. People with learning disabilities are often an outgroup: whether carers perceive them as similar to themselves is likely to influence their empathy. People with learning disabilities may evoke nurturance tendencies due to their level of need, the perception of them as childlike or because they present as childlike as a psychological defence (Sinason, 1992). Individual differences in nurturance tendencies may account for more of the variance in empathy towards people with learning disabilities than they would to other subjects.

The final factor, Challenge, may represent an individual difference between carers; some have no difficulty whilst others consistently experience difficulty empathising with people with learning disabilities. The subject communicating their experience is an essential component of empathy (Barrett-Lennard, 1981, Zaki, et al., 2008). People with learning disabilities’ difficulties communicating their internal worlds may make empathising difficult. Indeed, carers have described the effortful process of interpreting people with learning disabilities’ idiosyncratic cues in order to understand their needs (Antonsson, Graneheim, Lundstrom, & Astrom, 2008). Empathising with some people with learning disabilities may

demand particularly high empathy. Consequently, even if most carers may have relatively high *dispositional* empathy, there remain individual differences in whether empathising with people with learning disabilities is challenging. Imagine-self perspective taking may help with empathising when subjects are hard to read (Chambers & Davis, 2012), implying Proximity might be important for empathising with people with learning disabilities.

In summary, we suggest cognitive and affective processes are not the most salient feature of empathy towards people with learning disabilities. We are not saying these processes do not occur when subjects have learning disabilities, merely that other influences become influential. *One* interpretation of the significant but weak relationships between the EMP-LD and IRI subscales is consistent with our proposals. Correlations between Active Attunement and Proximity with perspective taking and empathic concern were similarly in magnitude. This might be because perspective taking and empathic concern are features of both Active Attunement and Proximity, i.e. IRI and EMP-LD domains are orthogonal. Indeed, Davis (1983) found very small correlations between empathic concern and cognitive empathy and between perspective taking and affective empathy. Active Attunement and Proximity contain both items that should correlate strongly and items that should not correlate with perspective taking and empathic concern. The net result is significant but weak correlations. An alternative explanation is that the EMP-LD has poor validity as an empathy measure. However, several lines of reasoning evidencing construct validity support the former explanation.

Firstly, Batson et al. (1997) suggested that imagine-self, but not imagine-other, perspective taking evokes personal distress. Active Attunement was *negatively* correlated whilst Proximity was unrelated to personal distress. This is consistent with Active

Attunement involving imagine-other and Proximity involving imagine-self perspective taking. Attachment style might influence the form of perspective taking used. Securely attached caregivers balance interpersonal proximity, thus feel empathy whilst maintaining a sense of self. Anxiously attached caregivers may desire interpersonal closeness, leading them to experience personal distress and a tendency to mentally merge with others (see Mikulincer & Shaver, 2007 for a review of this topic).

Secondly, attachment representations may influence caregiving representations by determining whether individuals have the psychological resources for empathy (Mikulincer & Shaver, 2007). The correlations between the MRC and EMP-LD subscales thus broadly support the claim that the EMP-LD measures empathy. The pattern of correlations provides further evidence of the validity of our interpretation of the factors.

Active Attunement was negatively correlated with egoistic motivations for caregiving and positively correlated with perceived abilities to recognize others' needs and be an effective caregiver. Altruistic motivations also affected scores on these factors. Active Attunement is therefore associated with (a) a focus on and confidence that one is good at recognising others' needs; (b) being motivated to care by others' needs rather than one's own. Since Challenge shares these relationships we propose it measures whether it is easy or difficult to actively attune. With the exception of perceiving that one is an effective caregiver, Proximity did not share these relationships, supporting our proposal that Proximity is less other-focussed.

Thirdly, knowing a person with a learning disability outside of work affected Proximity. Carers with such a relationship may perceive themselves as more similar to people with learning disabilities, which might increase their use of skills from the

similarity/imagine-self cluster. Consistent with our conceptualisation, Active Attunement and Challenge were unaffected by this variable.

Research demonstrates that gender influences affective reactivity more than cognitive empathy (Davis, 1994; Gilson & Moyer, 2000). The EMP-LD items about experiencing emotion load on Proximity, which might explain why gender only affected Proximity. Notably, males' scores appeared to be more correlated than females' scores with personal distress, recognising others' needs and effectiveness. Perhaps females have higher baseline nurturance tendencies than males therefore individual differences in empathy are less associated with caregiving representations. Similarly, maybe all professional caregivers perceive others as worthy of care hence why this caregiving belief was unrelated to empathy.

We propose that all three factors represent components of empathy. However, the negative correlations between factors suggest that carers who find it easy to empathise, or feel more proximal to people with learning disabilities, may use Active Attunement less. Perhaps such carers perceive less need to actively attune. Alternatively, as suggested by the potential links between attachment style and perspective taking (see above), carers who score highly on Proximity may be less able to actively attune, for example to separate cognitive representations of self and others so as to focus purely on the person with a learning disability's internal world. However, the weak correlations mean some individuals will still score highly or lowly on both factors.

Limitations of this research include that the three-factor solution only accounted for 34% of the total variance in EMP-LD scores before rotation. Males' data just reached sampling adequacy for factor analysis (Kaiser, 1974). Analysis of a larger sample is required

to confirm the factor structure applies. Additionally, the items loading on Challenge were negatively worded: They may have formed a factor because this impacted on participants' responses rather than because the items share meaning. Although evidence of construct validity makes this unlikely, this possibility requires exploration.

Several issues weaken the evidence supporting the EMP-LD's validity. Whilst we have discussed (above) the weak correlations between the EMP-LD and IRI subscales, some significant correlations with MRC subscales were also only small to medium in size (Cohen, 1988). The correlations under 0.2 and some correlations obtained when males' data were analysed separately were not detected with sufficient power. The likelihood of incorrectly accepting these effects as significant is slightly raised. Furthermore, Active Attunement and MCSDS scores were weakly but significantly correlated. Variation in Active Attunement scores could be attributable to variation in tendency to respond in a socially desirable manner instead of individual differences in attuning. Finally, the low response rate means findings might not generalise well to the wider population of carers, for example if particularly empathic carers chose to participate.

This research suggests that empathy is associated with paid carers' mental representations of caregiving. Previous research suggests such representations predict actual caregiving behaviour (Shaver et al., 2010). Recruiting care providers are advised to consider applicants' empathy towards people with learning disabilities and implement strategies to support carers to maintain this valuable trait. This might include encouraging carers to process the emotions underlying defences that decrease empathising, for example emotions that may make carers reluctant to perceive people with learning disabilities as psychologically similar to themselves. Organisations need to foster an ethos where spending

time attuning to people with learning disabilities is a valued activity. Interventions to increase empathy could incorporate exercises to increase use of the identified empathy skill clusters. In conjunction with previous research (Giesbrecht, 2008; Reizer & Mikulincer, 2007; Shaver et al., 2010), this investigation indicates that attachment representations are likely to influence carers' empathy and caregiving for people with learning disabilities. Regular, reflective supervision with a consistent supervisor and working in just one or two locations might enhance carers' momentary or felt security.

Exciting directions for research include exploring how self-reported empathy relates to demonstrations of empathy. Clarification of the nature, determinants and significance of the empathy skill clusters is warranted. In particular, exploration of how attachment styles might influence carers' empathy towards people with learning disabilities and caregiving behaviour would now seem possible. The EMP-LD may facilitate investigation of whether an empathic stance towards people with learning disabilities influences attributions, emotions and helping behaviour. Ultimately, empathy might be the link by which situational attribution models and dispositional attachment models can be integrated to predict quality caregiving. Additionally, we hope the EMP-LD will facilitate research into how organisations can help carers maintain empathy.

In conclusion we suggest that empathising with a person with a learning disability exacerbates particular processes used in empathising more generally. Cognitive and affective components may exist but these domains become less salient. Instead, empathy may be influenced by carers' willingness to consider themselves similar, and be psychologically close, to people with learning disabilities. Empathy may also be determined

by carers' active efforts and skill in truly attuning to people with learning disabilities' internal worlds.

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## SECTION C: CRITICAL APPRAISAL

Word count: 1956 (plus 24 additional words)

**What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?**

Since this was the first time I have undertaken research to develop a new measure, I learned about the steps involved in measure construction. My supervisor advised me to spend time developing the items, before using far greater resources to establish the measure's psychometric properties. With hindsight I appreciate that this was critically important to developing a measure that was likely to be demonstrably valid. I have learned the importance of taking a methodological approach to work towards achieving a high quality end product. I also learned to combine my ambitions for research with pragmatism. To exemplify, I initially considered measuring attitudes, in order to potentially obtain further evidence of construct validity. However, completing yet another questionnaire might have discouraged staff from participating, leading to an insufficient sample. I learned how researchers must be proactive in encouraging participation and potentially recruit in several ways. I developed the ability to apply for ethics approval and design information forms and consent sheets for participants. I learned the theory and practice of factor analysis from scratch and, to a lesser extent, thematic analysis. I now feel confident to use these approaches.

I now need to gain skills in a range of other research methods that might be appropriate for investigating different aims, for example skills in conducting interviews and using various qualitative methods. I am aware of the importance of user led consultation, as outlined in the Research Governance Framework for Health and Social Care: Second Edition (Department of Health, 2005). I would like to learn how to include service users and carers in a manner that adds genuine value to research. This project did not involve my applying

for NHS ethical approval: learning to do this may be key to my continuing to be an active researcher throughout my career.

I have also learned just how challenging it is to manage all aspects of sizeable research project, especially when recruitment takes place across multiple sites. I have learned that, if I am to be responsible for the quality of the project, I must communicate clearly and at times more assertively than perhaps I have previously. This does not mean being unwilling to collaborate: I think collaboration is one of the most effective ways to be involved in research, especially as a busy psychologist in the NHS. It does mean communicating well with colleagues and stakeholders and following my convictions whilst remaining mindful of maintaining good working relationships, even when power dynamics make this difficult. This learning will be particularly useful if I contribute to research networks. I have also learned that research requires a time frame of several years, to allow for the various negotiations that may be required.

**If you were able to do this project again, what would you do differently and why?**

This project partially evolved because one of my supervisors had developed a draft empathy measure. We undertook some exploration of the construct of empathy in order to create additional items, using psychologists' views because we wanted information that pertained specifically to empathy, in a somewhat technical sense. At this point it was hard to include people with learning disabilities or carers in a meaningful way because both groups might have struggled to talk specifically about, or comment on whether items were good at measuring, empathy in its technical sense. However, both groups would have held important wider views about caregiving relationships and some of these views may have

pertained to empathy. With hindsight, I would explore the construct of empathic care more widely, incorporating the views of people with learning disabilities and carers, before focussing on item development.

I would also investigate whether the internet might facilitate recruitment and distribution of feedback. Our choice of a written response format was based on the belief that many carers do not have easy access to the internet. However, we could have used both methods or asked carers for their opinions on this matter.

Furthermore, social desirability bias was a threat to the validity of the results. Participants show less social desirability bias when questionnaires are online and anonymous than when they are written and not anonymous (Joinson, 1999). Designing items that were less susceptible to social desirability bias was difficult because they tended to have less face validity, indeed the expert panel responses resulted in these items being removed. If I repeated the study, I would balance these factors differently and risk losing some validity in order to design less transparent questions. I would consider alternative response formats, for example a forced-choice method where each option portrays an equal mix of desirable and less desirable qualities but only one indicates empathy. Such forced-choice methods distort construct validity less than other self-report methods (Christiansen, Burns, & George, 2005). I would also ask carers to suggest items that might be less susceptible to social desirability bias.

Reflecting on my decisions about the response format, I realise that I was strongly influenced by the design of the draft measure. I now appreciate the tension between taking a practical approach to research, which efficiently builds on what has been done before, and

taking a more considered, potentially time consuming approach that might ultimately result in higher quality output. If I repeated the study, I would not necessarily change my decision about the response format, but I would make it with greater insight and appreciation of the costs and benefits of following various paths. Realising how I was influenced by the draft measure makes me appreciate the importance of noticing my assumptions and finding ways to maintain creativity during research.

**Clinically, as a consequence of doing this study, would you do anything differently and why?**

Conducting this research has expanded my understanding of attachment theory and how it might influence empathy and caregiving. This understanding will alter my clinical work with all client groups, not just within learning disability services, for example it will influence my work with families, couples and staff at all stages in the life cycle.

My awareness of how insecure attachment *may* make it harder for caregivers to change their behaviour (Schuengel, Kef, Damen, & Worm, 2012) will be incorporated into my formulations and interventions. I might allow more time for psychological interventions with insecure care staff or be mindful of the extra support they *might* need from colleagues or managers. This understanding will also help me to be empathic and more able to problem solve if carers are not responding to interventions. Within services for people with learning disabilities, I may use the conceptualisation of empathy derived here to develop exercises for increasing empathy. To exemplify, I might facilitate carers to discuss and reflect on the various similarities between themselves and their clients.

My work at an organisational level will also be influenced. I am now interested in whether staff have the psychological resources to be effective caregivers and how they can be supported to develop and maintain these capacities. I will therefore carefully consider the appropriate level at which to intervene, for example it might be appropriate to consult with service managers rather than work with individual members of staff. The latter approach could potentially contribute to staff being constructed as *the problem*. They might experience this as persecutory and it would be unlikely to lead to behaviour change. In my opinion it is important to approach direct work with carers with the same empathy and unconditional positive regard that I might foster towards clients. However, perhaps this is even more important if carers' attachments and empathy are part of my formulation.

Many psychological interventions spanning a range of therapeutic modalities involve increasing empathy, both within and outside learning disability services. To exemplify, systemic practitioners use *interviewing the internalised other* (Burnham, 2000; Lynggaard & Baum, 2006; Tomm, 1989) whilst Mentalization practitioners encourage adopting an attitude of active curiosity to understanding others' minds (Allen, Fonagy, & Bateman, 2008). The application of Weiner's (1980) attribution model to carer behaviour (e.g. Dagnan & Cairns, 2005) might result in psychologists encouraging carers to view clients' behaviours as a result of situations as well as internal dispositions. The common element in all these interventions is increased empathy. Recognising this commonality will allow me to integrate different models and work comfortably within a range of approaches.

However, there is also a risk that my interest and research into empathy could make me blinkered to other ways of understanding situations. I hope that insight into this possibility will help me to remain flexible and maintain an intellectually curious approach.

I hope to be aware of times when I experience personal distress rather than altruistic empathy and consequently able to manage this through supervision. Without this recognition, personal distress might sometimes impact adversely on my clinical work, for example I may be unable to bear and contain clients' painful emotions, limiting therapeutic progress. I will be cautious to be mindful of how much empathy I am portraying, especially at times when I have markedly weak or strong feelings of similarity, psychological 'closeness' and wish to nurture.

**If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?**

In future work I plan to conduct a full thematic analysis on the qualitative data obtained during this study. Subject to having the authors' and participants' consent and appropriate ethical approval, I might also use the current data to establish the psychometric properties of the MRC when used with professional caregivers. Additionally, it would be desirable to further establish the psychometric properties of the EMP-LD, perhaps by undertaking confirmatory factor analysis and investigating whether subscale scores are related to attachment representations. However, before investing additional resources in the EMP-LD, it is important to further understand how carers empathise with people with learning disabilities, and specifically whether processes akin to Proximity and Active Attunement are indeed key. The aim of further research might therefore be to establish theory or understanding about what paid carers do to empathise with people with learning disabilities and whether and how they might use Proximity and Active Attunement to do this.

Such an aim might be appropriately investigated by interviewing employed carers.

Research questions might include:

- What are carers' experiences of empathising with people with learning disabilities?
- What are carers doing when they are empathising with people with learning disabilities?
- What differences to empathy does it make if carers perceive themselves as psychologically similar or different from people with learning disabilities?

Grounded theory (Glaser & Strauss, 1967) might be a suitable approach to analysis because it is characterised by developing theory from data (Strauss & Corbin, 1998). In fact, grounded theory is particularly appropriate because it emphasizes the importance of establishing phenomena in a number of different ways. My quantitative data suggesting that Proximity and Active Attunement may be important aspects of empathising could therefore be used for triangulation. If qualitative analysis also suggests this, there would be strong evidence that the EMP-LD is worth further development. However, the aim of grounded theory is to build rather than test theory and creativity and open-mindedness are crucial (Patton, 1990). I would therefore need to be mindful that the factor analysis might bias my interpretation of the data and lead me to make assumptions. One way to overcome this would be to check my emerging hypotheses with participants (Strauss & Corbin, 1998).

I would envisage initially sampling paid carers working in direct care roles with people with learning disabilities, for example support workers working in residential settings or day services. I would initially try to include both male and female carers, since evidence suggests that empathy is influenced by gender. I would then follow the principle of *theoretical*

*sampling* (Strauss & Corbin, 1998) in order to maximise opportunities to discover variation among concepts. The very definition of theoretical sampling (i.e. that sampling is determined by the emerging theory) makes it impossible to specify how sampling might evolve. However, Strauss and Corbin (1998) recommend that researchers “sample incidents, events or happenings and not persons per se” (p. 202). I envisage that carers *might* discuss how organisational factors influence their empathy, which would lead me to study empathy when carers work in organisations with different values and procedures.

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## SECTION D: Appendices

This review was based on four literature searches. All searches used the electronic search engines Psychinfo, British Nursing Index (BNI), Social Policy and Practice (SPP), Medline and Applied Social Sciences Index and Abstracts (ASSIA). Final searches were performed on 15<sup>th</sup> June 2012. Searches within Psychinfo, ASSIA and BNI were limited to peer reviewed journals but this facility was not available in Medline and SPP. All searches were restricted to literature published in English. Table 1 shows the results yielded from the four searches. Many papers were found by multiple search engines.

1. Search one aimed to find research implicating empathy as a substrate by which attachment influences caregiving behaviour. In Psychinfo, Medline and SPP the search terms were as follows:

- *Attachment* and the subjects areas *attachment theory* and *attachment behaviour* where available.
- *Empath* and the subject area *empathy* where available.
- *Help*, *care* and the subject area *prosocial behaviour* where available.

Terms indicating *attachment*, *empathy* and *helping* were combined using the operator AND.

In ASSIA searching for the terms *attachment* AND *empath* across all fields except full text produced two results. The same search in BNI produced no results. Consequently, further searches including the additional condition that papers refer to caring or helping were not performed.

Research that pertained to adults caring for other unrelated adults and measured attachment, empathy and caring/helping behaviour was considered most relevant to the review and selected for inclusion.

2. Search two aimed to find research pertaining to the impact of health and social care workers' attachments on their empathy and helping interactions with clients. For Psychinfo, Medline and SPP search terms were as follows:

- *Attachment* in the paper title.

- Subject areas *health personnel, clinicians, counsellors, paraprofessional personnel, home care personnel, social workers, therapists, therapist characteristics and caregivers.*

Terms indicating *attachment* and *staff* were combined using the operator AND.

In BNI and ASSIA the thesaurus was used to identify equivalent broad search terms that would identify papers about health and social care staff. In BNI these were *health care assistants, psychology, staff* and *social work*. In ASSIA they were *staff, employees, unlicensed staff, nurses, psychologists, counsellors, personal characteristics, professionals, paraprofessionals, social workers* and *carers*. Terms indicating *health and social care staff* were combined, using the operator AND, with a search for *attachment\$* in any field except full text.

Research a) pertaining to both attachment and empathy or b) pertaining to how attachment representations influence the relationships of staff without therapeutic training was considered most relevant to the review and selected for inclusion.

3. Search three aimed to find literature pertaining to how the attachment representations of paid carers and people with learning disabilities influence their relationships. In Psychinfo, Medline and SPP search terms were as follows:

- *Attachment\$* and the subject areas *attachment theory, attachment behaviour* and *attachment disorders* where available.
- *Learning disabilit\$, intellectual disabilit\$, mental\$ retard\$, developmental disabilit\$* and the subject areas *learning disabilities, developmental disabilities* and *intellectual development disorder* where available.
- *Care\$, staff, nurs\$, health care assistant\$, support worker\$* and the subject areas *nurses, health personnel, caregivers* and *paraprofessional personnel* where available.

Terms indicating *attachment, learning disability* and *staff* were combined using the operator AND. A search removing the condition that papers refer to staff was also performed.

In BNI and ASSIA the thesaurus was used to find relevant broad search terms. In BNI these were *learning disabilities*, *learning disability services* and *learning disability nursing*. In ASSIA they were *learning disability nursing*, *learning disability nurses*, *community learning disability nurses*, *learning disabilities*, *mental retardation* and *carers*. These subject areas were combined, using the operator AND, with a search for *attachment\$* in any field except full text.

Abstracts were reviewed. All papers pertaining to a) adults with learning disabilities and b) how attachment impacts on the care giving relationship were included.

4. Search four aimed to find literature pertaining to paid carers' empathy towards people with learning disabilities. The terms used to indicate learning disability were the same as those used for search three. Papers pertaining to empathy were obtained by searching for the truncated keyword *empath\$*. Terms indicating *learning disability* were combined with the search for *empathy* using the operator AND. Given the highly specific aim of this search, results were not restricted to peer reviewed journals. An additional search was undertaken by entering the terms *learning disability* and *empathy* and *staff* into Google Scholar.

The references of relevant papers and review articles produced by all literature searches were inspected for other potentially relevant papers. The author also searched for relevant books in the university library.

Table 1

*Total Results Yielded From Literature Searches*

| Search engine   | Results yielded<br>from search<br>one | Results yielded<br>from search<br>two | Results yielded<br>from search<br>three | Results<br>yielded from<br>search four |
|---|---------------------------------------|---------------------------------------|---|--|
| Psychinfo   | 109                                   | 222                                   | 38                                      | 190                                    |
| British Nursing Index   | 0                                     | 5                                     | 0                                       | 3                                      |
| Social Policy and Practice  | 18                                    | 0                                     | 20                                      | 58                                     |
| Medline   | 108                                   | 105                                   | 65                                      | 102                                    |
| Applied Social Sciences Index<br>and Abstracts  | 0                                     | 8                                     | 5                                       | 0                                      |
| Total number of relevant<br>papers meeting inclusion<br>criteria  | 4                                     | 4                                     | 8                                       | 3                                      |
| Additional papers found from<br>searching references, the<br>university library and, for<br>search 4, Google Scholar. | 0                                     | 1                                     | 1                                       | 1                                      |

## 5. MANUSCRIPT TYPES ACCEPTED

**Original Articles, Review Articles, Brief Reports, Book Reviews** and **Letters to the Editor** are accepted. **Theoretical Papers** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

## 6. MANUSCRIPT FORMAT AND STRUCTURE

### 6.1 Format

**Language:** The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at [http://authorservices.wiley.com/bauthor/english\\_language.asp](http://authorservices.wiley.com/bauthor/english_language.asp). All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

### 6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

**Cover Page:** A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

**Running Title:** A short title of not more than fifty characters, including spaces, should be provided.

**Keywords:** Up to six key words to aid indexing should also be provided.

**Main Text:** All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

**Style:** Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

- Include all figure legends, and tables with their legends if available.
- Do not use the carriage return (enter) at the end of lines within a paragraph.
- Turn the hyphenation option off.

- In the cover email, specify any special characters used to represent non-keyboard characters.
- Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
- Use a tab, not spaces, to separate data points in tables.
- If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

### 6.3 References

The reference list should be in alphabetic order thus:

- 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

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here:

<http://www.endnote.com/support/enstyles.asp>

Reference Manager reference styles can be searched for here:

<http://www.refman.com/support/rmstyles.asp>

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see [www.doi.org/](http://www.doi.org/) for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

### 6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

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### **Summary of research findings**

|                   |   |
|-------------------|---|
| Title of research | The EMP-LD: A new measure of employed carers' empathy towards people with learning disabilities                           |
| Researchers       | Kirsten Mellows (Trainee Clinical Psychologist), Celia Heneage, Caroline Gratton and Dave Dagnan (Clinical Psychologists) |

#### **Background**

Empathy has been defined as a) experiencing an emotion that is related to or similar to what someone else is feeling and b) trying to intellectually understand what someone else might be thinking or feeling. When people feel empathy they are more likely to care for someone else effectively. This means it is important that staff working in services for people with learning disabilities are empathic towards the people they support. It is especially important because some people with learning disabilities may find it hard to describe their feelings so need empathic carers who are skilled at understanding them.

However, not much is known about the empathy that paid carers, such as support workers, feel towards people with learning disabilities. There is not a good questionnaire for measuring this, which makes it difficult to do research about empathy.

#### **What we did**

We developed a new questionnaire to find out more about and measure the empathy that paid carers feel towards people with learning disabilities. We asked Psychologists to share their ideas about carers' empathy and used these ideas, and some from things that have already been written, to write the questions. We called the new questionnaire the "EMP-LD".

We gave packs of five questionnaires, including the EMP-LD, to 800 staff working with people with learning disabilities. This included people in many different jobs, for example support workers,

nurses, service managers and other healthcare professionals. About a quarter of the staff (194) returned the questionnaires.

### **What we found out**

Using statistics we found out that the EMP-LD highlights and measures three different aspects of the empathy of care staff towards people with learning disabilities. This means it can be divided into three distinct subscales.

- One subscale measures whether carers find it easy or difficult to empathise with people with learning disabilities. We called this 'Challenge'.
- A second subscale measures whether carers actively try to get in touch with the thoughts and feelings of people with learning disabilities. We called this 'Active Attunement'.
- A third subscale measures a) the extent to which carers see themselves as psychologically similar to (or in some ways the same as) people with learning disabilities and b) whether they personally experience an emotion similar or related to the emotion which a person with a learning disability might be feeling. We called this subscale 'Proximity' because it was about being psychologically close to people with learning disabilities.

The carers also completed four other questionnaires. In general, carers' scores on the EMP-LD were related to their scores on the other questionnaires in the ways we expected. This was helpful in allowing us to conclude that the EMP-LD probably measures empathy.

### **What we learned**

We learned that feeling psychologically close to people with learning disabilities and making an active effort to tune-in to their thoughts and feelings may help carers to empathise, and that carers can vary in how easy or difficult they find it to do this.

We also learned that our questionnaire, the EMP-LD, is a reasonably good way of measuring carers' empathy towards people with learning disabilities. We think that it is a good-enough measure of

empathy to be used in other research. This could, for example, look at (a) what makes it easier and more difficult for paid carers to empathise and (b) how empathy influences caregiving towards people with learning disabilities. It could also be used by managers and health professionals to help them support other staff effectively.

Faculty for Learning Disabilities

Dear Psychologists,

I am a second year trainee Psychologist (at Salomons) conducting my major research project in the learning disability field.

My supervisors and I are developing a questionnaire to measure the empathy that paid carers (i.e. carers working in residential homes and day services) feel towards people with learning disabilities. We hope such a questionnaire will facilitate further research into empathy in carer-client relationships and also be useful for direct clinical work and evaluation of training initiatives.

I would like to ask for your help with the early stages of developing the questionnaire. Please could you kindly take a few minutes to email me (km269@canterbury.ac.uk) with a response to the question:

What comes to mind when you think of the empathy of paid carers towards people with a learning disability?

I intend to use the responses to develop questionnaire items. It would be really helpful if your ideas could contain enough detail to facilitate this. Please be aware I may include some of your comments in my thesis write-up. Please could I have your responses by the end of January.

If you are interested in knowing more about the project or being recruited onto an expert panel to evaluate the questionnaire items then please do get in touch and I would be really happy to explain the project further.

Many thanks for your help.

Kirsten Mellows

2nd Year Trainee (Salomons)

Supervised by Dave Dagnan, Celia Heneage and Caroline Gratton

“what comes to mind when you think of the empathy of paid carers towards people with a learning disability?”

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Table 1 presents, describes and exemplifies the codes used during the initial phases of the thematic analysis.

Table 1

*Codes Used for Thematic Analysis*

| Code               | Description   | Example  |
|--------------------|---|--|
| Expression         | Extracts that describe how carers' empathy is displayed through their interactions and behaviour with clients.  | <i>Shows respect to a person with an LD and even though this can take many forms it is quite striking when you see it (E4).</i>  |
| Cognitive weakness | Extracts referring to carers' understanding that people with learning disabilities may have impairments in intellectual functioning or limited communication abilities. | <i>...doesn't take into account the difficulties that people with learning disabilities might have in processing and understanding information. I think this can (in some cases) lead to an over-expectation about what people with learning disabilities can achieve (E29).</i> |
| Interpretation     | Extracts describing how carers need to interpret, guess or hypothesise in order to understand what people with learning disabilities think or feel.                     | <i>...which places a lot of demands on the carer to be able to clinically judge or interpret (E9).</i>   |

|                             |   |   |
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| Taking the other's position | Extracts describing carers imagining the position of a person with a learning disability in order to understand their experience. | <i>Whether the carer spends time trying to imagine what the person is experiencing 'in their shoes' (E5).</i>   |
| Client's life story         | Extracts describing carers seeking to understand the person with a learning disability's life history or account of themselves.   | <i>To take the time to find out about the person they are supporting, their past experiences and how these may have affected them (E19).</i>  |
| Listening                   | Extracts describing carers listening to what people with learning disabilities communicate.                                       | <i>...and listening closely to the other person's responses (E21).</i>  |
| Pleasure in their company   | Extracts describing whether carers gain enjoyment from some interactions with people with learning disabilities.                  | <i>...not being afraid to gently tease the person with LD and not being so concerned to be politically correct to the point of being a robot. A sense of taking genuine pleasure in the company of people with LD (E4).</i> |

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| Non-verbal connection                      | Extracts indicating that some carers experience and demonstrate empathy through non-verbal processes such as transference processes and behavioural displays of empathy. | <i>Staff mirror and reflect the body language of the person being supported in a compassionate manner. That there is a dialogue at a pre-verbal level between a carer and the person being supported (E20).</i> |
| Identity                                   | Extracts describing carers treating people with learning disabilities as individuals with their own personalities and preferences.                                       | <i>...allowing the individual with a learning disability to have their own interests and beliefs (E17).</i>   |
| Encouraging participation                  | Extracts describing carers promoting people with learning disabilities' involvement in tasks and activities.   | <i>Acknowledges positive actions or actions attempting to contribute and does not dismiss or ignore joining in efforts (E20).</i>   |
| Understanding the client's emotional world | Extracts describing carers understanding people with learning disabilities'  | <i>Recognising emotional upset (E17).</i>   |

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|                                       | emotional experiences.  |   |
| Difficulty making sense of behaviours | Extracts describing carers misjudging or failing to understand why a person with a learning disability performs a particular behaviour.               | <i>I often wonder to what extent carers empathise with... ..their clients with learning disabilities as often it seems as if emphasis is placed on situational and behavioural factors (E15).<br/><br/>Need empathy to even see challenging behaviour as a manifestation of emotional distress (E22).</i> |
| Blame                                 | Extracts describing carers experiencing negative emotions because they deem people with learning disabilities to be responsible for their behaviours. | <i>Blame or attribute stereotypical behaviours due to attention seeking rationale (E20).</i>  |
| Doing not being with                  | Extracts describing carers interacting with people with learning disabilities in a manner non-contingent with the person with a learning              | <i>Where a carer is talking AT rather than TO a person with LD (E4).</i>  |

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|  | disability's preferences or responses.  |  |
| Misunderstanding cognitive limitations | Extracts describing carers over or under estimating a person with a learning disability's cognitive impairment.     | <i>Calling someone manipulative when the reality is that they wouldn't have the theory of mind or cognitive ability to do that (E3).</i>   |
| Parental                               | Extracts describing how carers approach relationships with people with learning disabilities in a parental manner.  | <i>I think its hard for carers to generate true empathy for the people they look after, because the nature of the caring relationship taps into vulnerability, power imbalance etc and brings up the dynamics of protection/mothering as compensation (E10).</i> |
| Seeing client as a child               | Extracts describing how carers regard or behave towards adults with learning disabilities as if they were children. | <i>My guess is that residential staff will adopt a 'parental' type of attitude (E16).</i>  |
| Power                                  | Extracts describing how people with learning disabilities may not have  | <i>Recognising that their position in society is different for each person and if you have a learning disability it is different to the</i>  |

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|            | the same social power as others.   | <i>mainstream population group, understanding (to some level at least) issues of power, opportunity and knowledge (E31).</i>  |
| Rights     | Extracts describing how people with learning disabilities may not be afforded the same rights, choices and privileges as others. | <i>Never as an equal adult with rights and responsibilities (E23).</i>  |
| Rejection  | Extracts describing how people with learning disabilities are often rejected.  | <i>Do we want to give care to a group who are rejected and who receive little of it? (E7).</i>  |
| Less able  | Extracts describing how people with learning disabilities experience being less able than others.                                | <i>Seen as a pupil needing teaching (E23).<br/>Is it our sense of being damaged and imperfect? Do we know that we can understand something of what is like? (E7).</i> |
| Boundaries | Extracts describing whether and how carers differentiate between   | <i>I would be wanting to explore the boundary issue for paid carers- between keeping their professional stance and how</i>  |

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|   | personal and professional relationships.   | <i>much personal information gets shared and how involved they become emotionally with the client (E8.)</i>   |
| Client characteristics                    | Extracts describing how empathy might vary according to the characteristics of the person with a learning disability with whom the carer is empathising. | <i>Does the type of behaviour a client typically engages with affect how easy or difficult it might be to empathise with them, either generally or when they are behaving in specific ways? (E6).</i> |
| Individual differences in carers' empathy | Extracts indicating that some carers are more empathic than others.  | <i>Individual personalities and attachment styles of carers make it easier or harder to empathise with certain people (E28).</i>  |
| Emotional impact                          | Extracts suggesting that it can be painful for carers to empathise with people with learning disabilities.   | <i>Where clients' distress and needs are high and hence staff have difficulty in being in touch with the emotions of their clients (E9).</i>  |
| Strategies to manage emotions             | Extracts describing how carers attempt to manage the intense emotions that arise from  | <i>The person's emotional world is so overwhelming that there's a need to shut down from that, which might get in the way of people who do have the skills using</i>                                  |

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|                            | empathising with people with learning disabilities.  | <i>them (E3).</i>  |
| Like me                    | Extracts indicating that carers perceive people with learning disabilities as alike or similar to themselves.            | <i>Using the self to empathise e.g. its easier to empathise with her because she is like me, has similar interests etc (E28).</i>  |
| Different from me          | Extracts indicating that carers perceive people with learning disabilities as unlike or dissimilar to themselves.        | <i>... it is really hard to empathise with someone when you assume that many of their experiences are likely to be different (E18).</i><br><br><i>Carers see people with learning disabilities as different from themselves (E11).</i> |
| Comes from own experiences | Extracts suggesting that carers draw on their own experiences to understand people with learning disabilities' feelings. | <i>I think carers own life experiences have a lot to do with their level of empathy (E31).</i>   |
| Motivation                 | Extracts describing carers' motivations for undertaking care work,   | <i>Motivation for working as a paid carer for people with learning disabilities, e.g. family member with LD, financial</i>   |

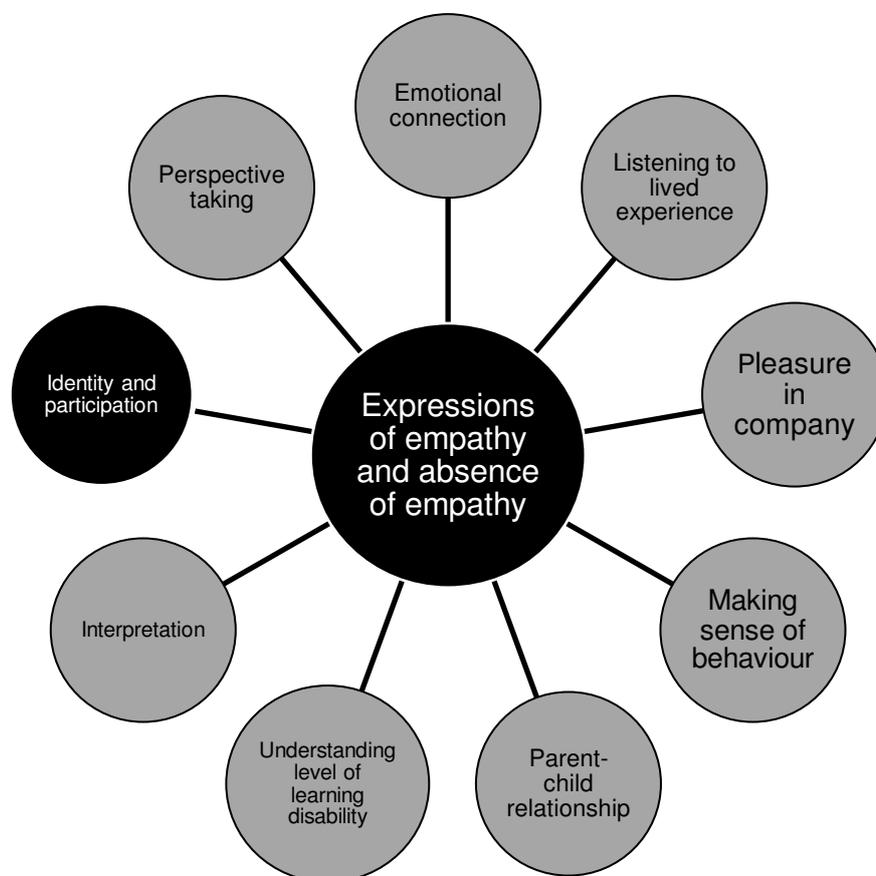
|                              |   |   |
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|                              | including emotional and financial gain.   | <i>motivation, etc? (E14).</i>  |
| Colleagues                   | Extracts referring to how relationships between staff members influence empathy.                      | <i>Group think, peer pressure, scape-goating. To explain, I worked as a nursing assistant in between assistant psychology posts many years ago. What became abundantly clear was that my enthusiasm, client centred approach and new ideas was going to cost me a heavy penalty in terms of group dynamics and that I was clearly treading on the toes of a NA who called the shots! (E12).</i> |
| Immediate contextual factors | Extracts describing specific situations in which it might be more difficult to empathise.             | <i>If the person with LD has done something that has harmed another person they [carers] may have reduced empathy (E27).</i>  |
| Empathy and wider world      | Extracts describing how others view the empathy care staff show to people with learning disabilities. | <i>How do we position ourselves and our empathy when we feel estranged by our neighbour's comments? (E7)</i>  |
| Support                      | Extracts suggesting that mechanisms of support  | <i>Supported positively to feel valued, skilled and empowered (E2).</i>   |

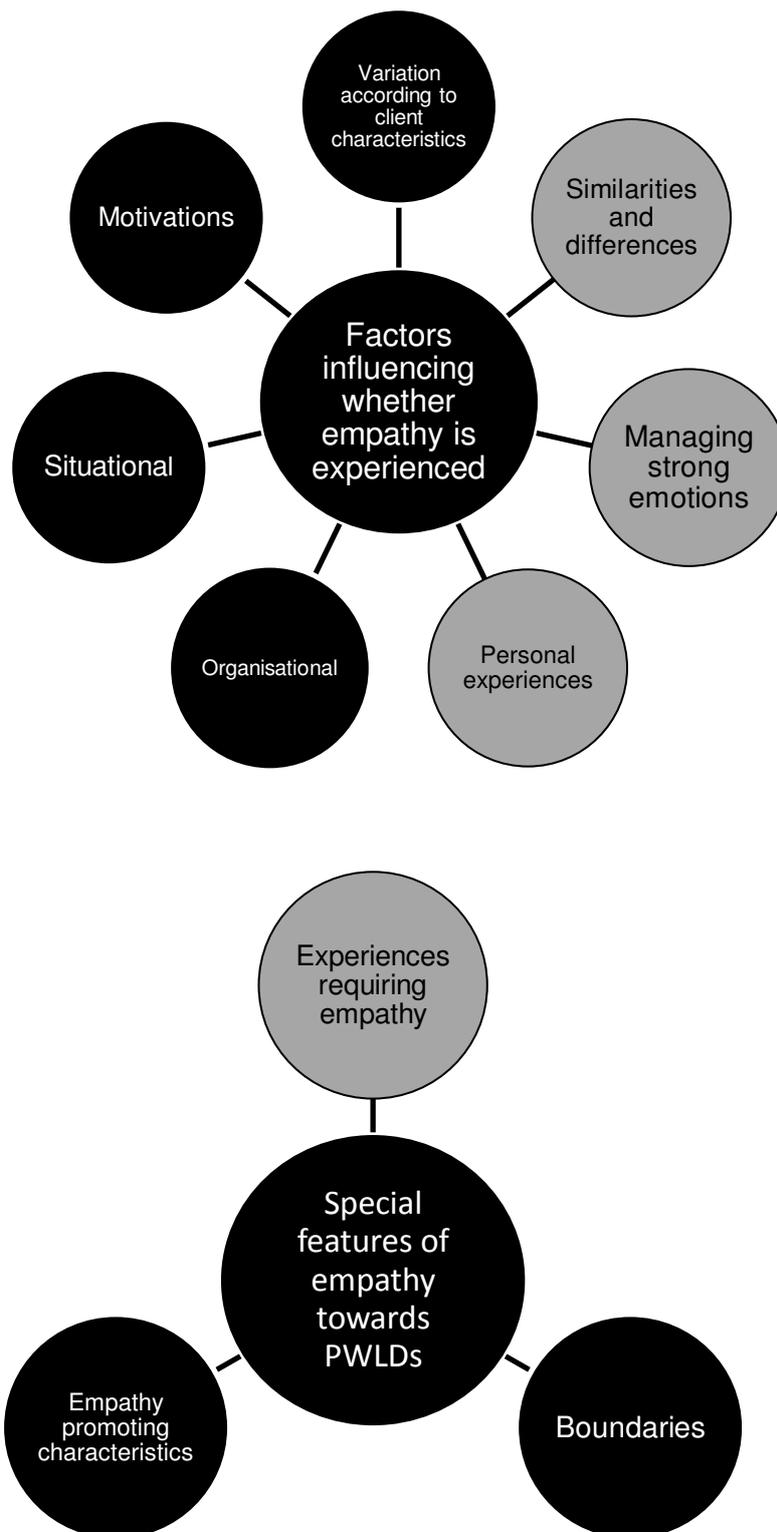
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|                          | help carers be empathic.  |  |
| Organisational structure | Extracts referring to the influence of the employing organisation's policies and strategies on carers' empathy. | <i>Whether there is a team manager in post/ clear leadership. Are there regular team meetings? Training received? (E14).</i>   |
| Service culture          | Extracts describing how working culture influences empathy.   | <i>I wonder whether there is something about working in a more institutionalized setting that makes carers more likely not be to seeing each client as an individual and therefore not so empathic (E24).</i>                          |
| Sympathy                 | Extracts describing sympathy as distinct from empathy and leading to a different model of caring.               | <i>There are a lot of attitudes about the 'poor' person with LD (E31).</i>   |
| Attachment               | Extracts suggesting carers' attachments influence their relationships with people with learning disabilities.   | <i>Is it just quality and caring for them, responding to their needs with a strong sense of duty, attachment or love? (E1).<br/><br/>There's an ambivalence between taking a professional role and a personal-attached role (E16).</i> |

|                            |   |  |
|----------------------------|---|--|
| Important for quality care | Extracts indicating that the ability to empathise is important for giving quality care. | <i>Cultivating empathy I feel is fundamental to quality care (E25).</i><br><br><i>I think having strong empathy skills are vital to be a good carer (E30).</i> |
| Self-report                | Extracts suggesting that carers may be poor judges of their own empathy.                | <i>Carers (as with anyone) can be really bad at rating their own empathy skills (E3).</i>  |

*Note. E denotes which expert wrote each extract.*

In phase three of the thematic analysis, codes were used to produce initial themes. Figure 1 shows a thematic map of the three initial themes (central circles) and their subthemes (outside circles). Subthemes in grey circles were considered both prevalent and relevant to the development of the empathy measure and were used to generate items for the questionnaire. Subthemes in black were not used to develop items for one of the following two reasons. Some subthemes pertained to concepts that the authors considered distinct from empathy e.g. boundaries, identity and participation, motivations. Others pertained to how the person with a learning disability or environmental factors influence carers' empathy i.e. they were not about influences internal to the carer.





*Figure 1.* Initial thematic map of the whole data corpus. This figure illustrates the three main themes and their subthemes.

The authors developed questionnaire items from the subthemes identified as prevalent and relevant. Table 1 presents the items based on each subtheme. Although items are only presented once, many could belong to more than one subtheme.

Table 1

*Items Generated From Selected Subthemes*

| Sub theme                                  | Items   |
|--|---|
| Understanding level of learning disability | <p>I adapt the way I communicate to fit the ability of each person with a learning disability.</p> <p>I consider the amount of support each person with a learning disability requires to do a task.</p> <p>If someone with a learning disability can speak they will understand what I am saying.</p> <p>Too much is made of people with learning disabilities not understanding things.</p> |
| Interpretation                             | <p>I take a moment to consider whether I've understood what a person with a learning disability is trying to communicate (27).</p> <p><i>It is hard to know how people with learning disabilities feel if they can't speak or don't choose to say (22).</i></p>   |
| Parent-child relationship                  | <p>People with learning disabilities have a right to be upset if they are not treated like adults.</p> <p><i>I find it helpful to think of adults with learning disabilities as just like children.</i></p>   |

|                             |  |
|-----------------------------|--|
| <p>Perspective taking</p>   | <p>It is important to try to understand each individual's needs and wishes (19).</p> <p><i>I don't give the feelings of people with learning disability much thought.</i></p> <p>I take a moment to consider what the person with a learning disability might be thinking before I act (11).</p> <p>Seeing the world through the eyes of the person with a learning disability helps me understand what they want (17).</p> <p>I feel I understand the daily struggles of people with learning disabilities.</p> <p><i>It is hard to put yourself in the shoes of someone with a learning disability</i> (9).</p> <p><i>It is difficult for me to view things from the perspective of people with learning disabilities</i> (3).</p> <p>People with learning disabilities respond better when I try to understand their feelings.</p> <p>I try to understand what is going on in the mind of a person with learning disabilities by paying attention to what they do (24).</p> <p><i>Because no two people with learning disabilities are alike, it is difficult for me to see things from their perspective</i> (16).</p> |
| <p>Emotional connection</p> | <p>I can pick up on the mood of someone with a learning disability without them needing to tell me (21).</p> <p><i>I find it hard to pick up on the moods of people with learning disabilities</i> (6).</p> <p>I automatically change my behaviour to fit with the mood of a person with a learning disability (12).</p>   |

|                                      |   |
|--------------------------------------|---|
|                                      | <p>I always try to tune into the feelings of people with learning disabilities around me (1).</p> <p>If a person with a learning disability is depressed it brings my mood down (18).</p> <p>I find it easy to imagine how a person with a learning disability might be feeling (25).</p> <p><i>People with learning disabilities don't seem to feel things as strongly as other people.</i></p> <p>I feel upset when I see someone with a learning disability is sad (10).</p> <p><i>Understanding how people with learning disabilities feel does not help me work effectively with them.</i></p> |
| <p>Listening to lived experience</p> | <p>Learning about a person with a learning disability's life history helps me understand them better (2).</p> <p>It's important to find out about a person with a learning disability's life to be able to put yourself in their place (23).</p> <p>When I am listening to a person with a learning disability they have my undivided attention.</p> <p>I would like more time to listen to people with learning disabilities.</p>  |
| <p>Pleasure in company</p>           | <p><i>I don't enjoy the company of people with learning disabilities.</i></p> <p>When people with learning disabilities are laughing I join in.</p>   |
| <p>Making sense of behaviour</p>     | <p><i>People with learning disabilities who behave in difficult ways are usually trying to wind someone up.</i></p> <p><i>People with learning disabilities should learn to be less attention seeking.</i></p> <p><i>People with learning disabilities who display difficult behaviour are being</i></p>  |

|                                      |   |
|--------------------------------------|---|
|                                      | <p><i>manipulative.</i></p> <p>When someone with a learning disability is smiling I assume they are happy.</p> <p><i>I find it hard to understand why people with learning disabilities behave the way they do (13).</i></p> <p><i>People with a learning disability often get upset for no real reason (28).</i></p> <p><i>I find it difficult to work out why someone with a learning disability is crying (26).</i></p> <p>When I don't know exactly why someone with a learning disability is upset, I test out a number of guesses.</p>  |
| <p>Experiences requiring empathy</p> | <p>I feel frustrated when someone with a learning disability is unable to do something which is important to them (7).</p> <p>I get angry when I think of how people with learning disabilities have been treated (5).</p> <p>It makes me cross to see someone with a learning disability treated unjustly (15).</p> <p>I feel happy when someone with a learning disability achieves something important to them.</p> <p>Stigma affects the way many people with learning disabilities feel and behave.</p> <p><i>People with learning disabilities have the same amount of choice in life as everyone else.</i></p> |
| <p>Similarities and</p>              | <p>I imagine myself in the place of someone with a learning disability when working with them (14).</p>   |

|                          |   |
|--------------------------|---|
| differences              | <p><i>People with learning disabilities will feel <u>exactly</u> the same way as I would in any particular situation.</i></p> <p>I wonder whether someone with a learning disability is feeling the same way as I would in a particular situation (8).</p> <p><i>People with learning disabilities don't feel the same emotions that I do.</i></p> <p><i>People with learning disabilities don't understand emotions in the same way as I do.</i></p>   |
| Managing strong emotions | <p>I can feel the pain of people with a learning disability.</p> <p><i>I try not to get too emotionally close to people with learning disabilities.</i></p> <p><i>I sometimes switch off from the people I support and get on with the tasks I need to do.</i></p> <p><i>I feel frustrated when I see someone with a learning disability is sad (20).</i></p> <p>I expect to experience strong emotions in my work with people with learning disabilities.</p> <p>I have to do something when I see someone with learning disabilities who is upset.</p> <p><i>I believe that emotion has no place in working with people with learning disabilities.</i></p> |
| Personal experiences     | <p>I use my own life experiences to help imagine what it might be like to have a learning disability (14).</p>  |

*Note.* Numbers in brackets indicate the numbers assigned to items included in the 28-item questionnaire used for the psychometric study. For items in normal face, a high score indicates high empathy. For items in italics, a high score indicates low empathy.

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## **Complete our questionnaire research and be entered into a draw to win £100 of Amazon vouchers**

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve. Please ask us if there is anything that is unclear or if you would like further information.

### **Designing a questionnaire about professional carers' feelings in their work with people with learning disabilities**

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

The purpose of the study is to design a new questionnaire to measure how professional (paid) carers feel in their work with people with learning disabilities.

We recognise that working with people with learning disabilities can arouse strong emotions. These emotions can make it easier or harder to do the work. Knowing how carers feel helps healthcare professionals to provide appropriate, effective and high quality support and guidance. Ultimately, we know good support for staff can mean better care for people with learning disabilities.

The new questionnaire will allow professionals to very quickly find out about the feelings of staff. Health professionals will be able to use it to guide their work with staff teams. It will also make it possible to do future research into how staff can be supported to feel the positive emotions that make it easier to do the work.

We need to get lots of staff to complete a pack of questionnaires about feelings in their work with people with learning disabilities and some other related topics. This is so that we can do statistics to find out whether the new questionnaire is a good measure of how carers feel.

We will be looking at the statistical properties of what the whole group of respondents say. We will not be thinking about your individual answers or how they relate to you personally. **We are hoping for honesty in all answers** as individual data will not be scrutinised, only group data.

#### *Who is running this research?*

The researcher (Kirsten Mellows) is a Trainee Clinical Psychologist completing a Doctorate in Clinical Psychology at the University of Canterbury. Kirsten works for the NHS. Three senior Clinical Psychologists, also working in the NHS, are overseeing the project. They are Celia Heneage, Caroline Gratton and Dave Dagnan.

*Why have I been invited?*

We are asking about 800 paid carers to participate. We are asking you because you work for an organisation who gave us permission to approach their staff.

We would like as many people as possible to take part. However, you cannot take part if you are under 18 because the law means that you cannot consent to research under the same conditions. Unfortunately, you will be unable to take part if you cannot read the questionnaires in English. We regret that we are unable to support individuals to read the questionnaires. If you are under 18 or cannot read the questionnaires please do not attempt to complete them.

*Do I have to take part?*

It is up to you to decide. If you take part you will need to sign a consent form to show you have agreed to participate. You are free to withdraw at any time, without giving a reason. This would not affect your job or employment in any way.

If you do decide to take part then you can choose to enter a draw to win £100 of Amazon vouchers. The winner will be drawn at random. You will need to tick the box and put your address on the consent form so that we can contact you if you win.

*What will I have to do?*

We will ask you to complete five questionnaires. This might take about 30 minutes. We will ask whether you agree to complete one questionnaire for a second time, a few months later. If you agree, we will post this questionnaire to you.

*Will I be told what the research finds out?*

We will send a summary of our findings to the organisations that let us approach their staff. The summary will not contain information that would identify any individuals or organisations. You will be able to tick a box if you would like to receive this summary by post.

*Will my taking part be confidential?*

**Yes.** We will follow ethical and legal practice. **The information you provide will be entirely confidential to the researchers** (Kirsten and the three senior Psychologists). **Under no circumstances will the information be released to anyone else.**

We would like you to put your name and address on the questionnaire so that, if you wish, we can send you the follow up questionnaire and/or the summary of our findings. We will also need your name and address so we can contact you if you win the prize draw. If you **only** wish to receive the summary of findings (and DO NOT wish to enter the prize draw) then you are welcome to provide an email address rather than your name or postal address.

The completed questionnaires will be kept in a locked filing cabinet. Your name will be removed and replaced with a number before the information is put into a computer file. The computer file will be protected by a password which only the main researcher (Kirsten) will know. The electronic data will be kept by the researcher and one of her supervisors for ten years, after which it will be destroyed.

*What will the information be used for?*

The information will be used for the research described above. We intend to publish the research so that health professionals can use the new questionnaire and learn from the research we have done. This is common practice and ensures the research benefits as many people as possible. The publication will not contain information that could identify any individuals or their employers.

*What if there is a problem?*

The research has been reviewed by an independent group of people, called an ethics committee, to protect the safety, rights and dignity of participants. This research has been given a favourable opinion by the Salomons Ethics Committee at the University of Canterbury.

Completing the questionnaires is extremely unlikely to cause distress. If you experience distress you should stop completing the questionnaires. If you experience distress after participating or have any other problems because of the research you could contact one of the researchers. You could phone Caroline Gratton on [phone number] or email her on [email address]. You could contact Celia Heneage by phoning [phone number]. You will need to leave a message and they will phone you back as soon as they can. If you have any difficulty completing the questionnaires you could contact Kirsten by emailing km269@canterbury.ac.uk.

*What if I change my mind?*

If you change your mind you can contact Kirsten. Your information will be destroyed by shredding the questionnaires and deleting the electronic data.

**Thank you for taking the time to read about our research. If you are willing to take part then please read on.**

## Consent to participate in research

**Project: Designing a questionnaire about professional carer's feelings in their work with people with learning disabilities**

**Researcher: Kirsten Mellows (Trainee Clinical Psychologist)**

In order for you to participate in the project we require your consent. This does not mean you are committed to participate. You can still choose not to participate at any time.

I have read the information sheet for the above study and agree to take part. I am aware that my participation is voluntary. I am free to withdraw at any time, without giving a reason. I give permission for the research to be published for the benefit of health professionals and so they can use the new questionnaire.

Please sign below to give your consent to participate.

.....

Name

Date

Signature

Please tick here if you are willing to complete one more questionnaire in a few months time. We would send this in the post.

Please tick here if you would like to enter the prize draw to win £100 of Amazon vouchers. The winner will be drawn at random and contacted by post after all participants have returned their questionnaires.

Please tick here if you would like to receive a summary of what we find out. This will be posted to you when the project is completed, probably in Summer 2012.

If you ticked any of the above boxes, please provide a contact address below.

Building/house name or number: .....

Road name: .....

Town: .....

Postcode: .....

**Thank you very much** for agreeing to take part. Now please turn over to complete the questionnaires. The information is most useful if you answer the questions as honestly as you can. ALL information you provide will be strictly confidential.

We would like some information about you and your work. Please answer the following questions.

### About you

|  |      |        |
|--|------|--------|
| <b>Your age</b>  |      |        |
| <b>Your gender</b>   | Male | Female |
| <b>Do you have a relevant qualification (e.g. NVQs)? If so, please say what.</b> |      |        |
| <b>Outside of work, do you have a care-giving responsibility?</b>                |      |        |
| <b>Outside of work, do you know anyone with a learning disability?</b>           |      |        |

### About your work experience

|   |                    |                    |   |                                 |                       |                       |                  |
|---|--------------------|--------------------|---|---------------------------------|-----------------------|-----------------------|------------------|
| <b>Your current employer</b>  |                    |                    |   |                                 |                       |                       |                  |
| <b>Your job title</b>   |                    |                    |   |                                 |                       |                       |                  |
| <b>Do you work in...</b>  | A residential home | A day service      | With people with learning disabilities in their own homes | Other (please specify)<br>..... |                       |                       |                  |
| <b>Do you work...</b>   | Full time          |                    | Part time   |                                 | As bank staff         |                       |                  |
| <b>How much experience do you have of working with people with learning disabilities?</b> | Less than 1 month  | Less than 6 months | Less than 1 year  | Between 1 and 3 years           | Between 4 and 6 years | Between 7 and 9 years | 10 years or more |

### About the people you support

Please consider the people you support in a typical week. If you are bank staff, please consider the people you work with the most often. Please circle all the answers that apply.

|  |   |   |                                    |  |
|--|---|---|------------------------------------|--|
| <b>Do you work with people with learning disabilities who...</b>   | Speak fluently?   | Speak but this is limited to short phrases? | Just say single words?             | Are unable to speak? (they may use speech noises or behaviours to communicate) |
| <b>Do you work with people with learning disabilities who...</b>   | Can manage their personal care with no or little prompting? |   | Need some help with personal care? | Need full assistance with personal care?                                       |
| <b>Do you work with people with learning disabilities who display behaviours you find challenging to manage?</b> | Yes   |   | No                                 |  |
| <b>If so, on average, how often do you manage challenging behaviours?</b>  | Less than once a week                                       | More than once a week                       | More than once a day               | Every hour   |

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**Thank you very much for completing the questionnaires. Please put the five questionnaires and the consent form into the prepaid envelope and put the envelope in the post.**

If you requested feedback, we will post this to you, probably in Summer 2012.

If you said you are willing to complete one more questionnaire we will send this by post in a few months time. The winner of the Amazon voucher will be contacted by post in Summer 2012 at the very latest.

**Thanks again!**

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Interpersonal Reactivity Index).

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