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University  
of Glasgow

**What is special about family relationships? Familial attributions and  
emotional responses to relatives who present with challenging  
behaviour & Clinical Research Portfolio**

**Volume I**

*(Volume II bound separately)*

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**University of Glasgow**

**March 2013**

*Submitted in partial fulfilment of the requirements for the Degree of Doctor  
of Clinical Psychology*

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## Acknowledgements

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**CHAPTER ONE**  
**SYSTEMATIC LITERATURE REVIEW**

**Staff attributions, emotions and behavioural responses to individuals who  
present with challenging behaviour: A systematic review.**

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Prepared in accordance with guidelines for submission to Journal of Intellectual Disability  
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## **Abstract**

**Background:** Research suggests that care staff responses to challenging behaviour displayed by individuals with intellectual disabilities can play a significant role in both the development and maintenance of such behaviours. Identifying factors which influence staff responses to incidents of challenging behaviour may increase professionals' understanding of staff behaviour and, as a result, enable them to better support staff to respond in a helpful way. The aim of this review was to consider the applicability of Weiner's Attributional Model of Helping Behaviour (1992) in understanding care staff responses to challenging behaviour. **Method:** A systematic search was conducted and 12 studies of staff responses to challenging behaviour were identified for review. All studies were rated according to quality criteria developed for this review. **Results:** The evidence suggests that care staff's optimism for change and emotional responses are related to their helping behaviour. These results were specific to studies using written vignettes as stimuli. Evidence for the other associations suggested by the model is inconsistent, as is the evidence for the meditational roles of optimism for change and emotional responses of anger and sympathy. **Conclusions:** It appears that elements of the model may help explain care staff responses to challenging behaviour depicted in written vignettes. However the generalisation of these findings to real situations is unclear. It appears that both methodological issues and limitations of the model may contribute to the inconsistencies within the current evidence base.

**Keywords:** Intellectual disability, challenging behaviour, care staff responses

## **Introduction**

Intellectual disability (ID) services rely on care staff to provide support for individuals who display challenging behaviour (Rose and Rose, 2005). However, it has been found that staff responses to challenging behaviour (CB) can play a role in both the development and maintenance of such behaviours (Hastings and Remington, 1994). Therefore, it is important to develop an understanding of the factors influencing staff responses to CB.

Care staff's responses to CB have mostly been investigated within the framework of Weiner's Attributional Model of Helping Behaviour (Weiner, 1992). The model specifically highlights the importance of two attributional dimensions in governing an individual's helping behaviour. Namely controllability: whether the behaviour is under the control of the individual; and stability: whether the cause of the behaviour is constant or changeable (Weiner, 1992). These causal attributions are thought to evoke an emotional reaction (e.g. sympathy) which determines subsequent behaviour. Thus it is how behaviour is causally attributed and not the behaviour itself that determines subsequent reactions. For example, in relation to CB, the model predicts that if the behaviour is evaluated as being under deliberate control of the individual, feelings of anger will be evoked. However, if the individual is thought to lack control over their behaviour then feelings of sympathy will ensue.

Central to the Attributional Model of Helping Behaviour (Weiner, 1992) is the mediating role of emotional responses. It is posited that the behaviour elicits a causal search strategy in the observer. The attribution made then leads to an emotional response (anger versus sympathy) and this affects the observer's propensity to help: feelings of anger will result in rejection and feelings of sympathy will result in a wish to help. Recent literature (e.g. Dagnan, 2012; Dagnan et al., 1998; Stanley and Standen, 2000) has also explored the meditational role of optimism. Optimism for change, according to Weiner (1974), is based on the perceived stability of the cause of behaviour. In turn, these reactions affect the possibility that the observer offers help. These mediated relationships are illustrated in figures one and two.

(INSERT FIGURE 1 HERE)

(INSERT FIGURE 2 HERE)

Whilst research supports the use of the Attributional Model of Helping Behaviour in predicting helping behaviour in the general population outwith formal clinical settings (Weiner, 1985), the literature concerning the applicability of the model within the context of care staff supporting those with ID who engage in CB is inconsistent. Willner and Smith's (2008a) critical literature review found that no existing study provided unequivocal support for the model's applicability to this population. Their results suggested that a number of studies reported no relationship between the attribution of stability and/or controllability, emotional response, optimism and helping behaviour. However, not all of the studies included in their review involved staff working with individuals with ID. For example, the study by Sharrock et al. (1990) focused on care staff responses to CB displayed by adult mental health patients who were not identified as having an ID. The review therefore covered a broader range of care staff, not only those supporting adults with ID who display CB. Since Willner and Smith's (2008a) review, there has been additional research published examining the relevance of Weiner's Attributional Model of Helping Behaviour (1992) to the ID population and those who care for them. Furthermore, no review has investigated the applicability of Weiner's model specifically to staff supporting adults with ID who also engage in CB. This is therefore the focus of the current review.

### **Review Question**

Does the available evidence for Weiner's Attributional Theory of Helping Behaviour (1992) explain staff responses to challenging behaviour displayed by adults with intellectual disabilities?

### **Search Strategy**

Studies were identified by searching the following electronic databases: Medline; Embase; PsycINFO; CINAHL; Web of Science and the Cochrane Library (all 1980 – May 2012). Keyword searches of these databases were carried out using (*intellectual disabilit\** or *learning disabilit\** or *intellectual impair\** or *mental\* retard\** or *mental\* handicap\** or *mental\* deficiency*) AND (*challenging behavio?r\** or *problem behavio?r\** or

*behavio?r\**) AND (*staff or care\**) AND (*attribution\* or attribution\* theor\* or belief\**). Truncating was used to ensure identification of relevant terms where word endings may differ e.g. plural or adjectives. Furthermore, both UK and US terminology was taken into account. As Weiner's model was initially published in 1980, the date range was limited to 1980 – 2012.

### **Search Process**

Each inclusive search term was matched to the subject headings in each database. The Medline subject heading search yielded 22 results. The Embase subject heading search yielded 28 results. The PsycINFO subject heading search yielded 52 results, with CINAHL and Web of Science yielding 31 and 37 results, respectively. The following inclusion/exclusion criteria were applied to the abstracts of these studies in order to screen for suitability.

### **Inclusion Criteria:**

1. Studies published in the English language.
2. Studies which specifically explored a) staff attributions; b) emotional responses and c) subsequent behavioural responses to CB (including aggression, self injurious behaviour, sexually inappropriate behaviour, stereotypy and destructive behaviour).
3. As many studies did not specify the age range of the adults with ID whom their participants worked with and/or whose behaviour they recalled, a specific age range was not included in the criteria. However it is assumed that if participants were working in adult services, the individuals they cared for would have been 16 years old or over.

### **Exclusion Criteria**

1. Studies where participants consisted of unpaid or voluntary carers, including family carers.
2. Studies examining the impact of training/teaching programmes on carer attributions or focused on the development of an assessment measure.
3. Studies which did not contain primary data.

Following removal for duplication and failure to meet the above criteria, full text copies of the remaining 32 articles were obtained. Twenty one of these articles were then removed as the studies did not fulfil correct criteria due to the inclusion of participants who cared for children (five articles); a failure to explore the carers' helping behaviour in response to their attributions (seven articles); exploring other attributional models or factors other than beliefs and emotional responses that may impact upon staff responses (eight papers) and one paper which did not contain empirical data. This resulted in 11 papers to be included in this review.

In addition to the database search, references from key articles were also examined and a hand search was conducted of the following key journals, from 1980 – May 2012: Journal of Applied Research in Intellectual Disabilities, Journal of Intellectual Disability Research and British Journal of Learning Disabilities. This search yielded one further relevant article, thus leaving 12 articles that were suitable for the current review. A flowchart detailing this process is presented in figure three.

(INSERT FIGURE 3 HERE)

### **Methodological Quality and Rating Criteria**

In considering the most suitable method of assessing quality, it was deemed important to acknowledge the various designs and methodologies used to investigate the applicability of Weiner's Attributional Model of Helping Behaviour (1992) in explaining staff responses to CB. Published guidelines, the Consolidated Standards of Reporting Trials (Altman et al., 2001) and the Clinical Trial Assessment Measure (Tarrier and Wykes, 2004) were consulted; however they were developed to assess the quality of intervention studies and Randomised Control Trials. Consequently, four key characteristics for this field of study were identified in order to rate the quality of the papers included in this review.

#### *1. Participants' experience of challenging behaviour*

How participants perceive and respond to CB may differ as a result of their particular experiences of CB. Thus studies whose participants were identified as having experience of working with individuals with ID *and* CB were awarded the highest grade

of 3. Studies which identified their participants as having experience of working with individuals with ID, but gave no details about the nature of their experience were awarded a grade of 2. Finally, studies that provided no information about their participants' experience were graded the lowest at 1.

### *2. Appropriate Stimuli*

In order to elicit participants' emotional, attributional and behavioural responses, the stimuli used must contain sufficient contextual and behavioural information to evoke emotional and cognitive responses in participants. Therefore, the highest grade (3) was awarded to studies in which a clear description of CB, including topography, was evident. This is defined by and could include video vignettes, written vignettes where a clear and detailed description of the CB is given (e.g. client engaged in physically aggressive behaviours by punching the wall) or where participants were required to give a clear behavioural description of a real incident they had experienced. Studies that did not provide a clear description of the CB were graded a 2, and included studies in which the written vignettes were poorly described and those where participants were not asked to give a clear behavioural description of the behaviour they recalled. Finally, studies which provided no contextual or descriptive detail of the stimuli used were given the lowest grade of 1.

### *3. Adequacy of Measures*

In order to ascertain the applicability of the Attributional Model of Helping Behaviour (Weiner, 1992), it is important that assessment measures utilised by studies cover the range of responses predicted by the model (i.e. attributions of controllability and stability; optimism for change; the emotional response of anger or sympathy and helping behaviour). Studies which employed standardised and / or valid and reliable measures that address ALL of the predictive key areas of the model were graded highest (3). Studies that used standardised and / or valid and reliable measures that partially address key areas of the model were graded (2), with studies using non-standardised and / or invalid and unreliable measures graded last (1).

#### 4. *Sophistication of Analysis*

Weiner's Attributional Model of Helping Behaviour (1992) not only predicts a relationship between attributional responses and behavioural responses, it also emphasises the mediation of this relationship by emotion and optimism. In order to assess the applicability of the model, the researchers' chosen method of analysis should enable the evaluation of this mediated relationship. Therefore, studies that utilised a planned mediation analysis of at least two components of the model (e.g. emotional response of anger and attribution of controllability) were given the highest grade (4); studies using regression analysis to determine which variables are independent predictors of helping behaviour were graded 3; studies which used planned correlational analysis of at least two components of the model (as above) were graded 2; and finally those which detailed a broad correlational matrix, searching for relationships between any components, rather than those specified by Weiner, were graded 1.

Each study's total grade was calculated and categorical ratings were allocated accordingly. Studies were therefore rated as *excellent*, having received an overall grade of 13, if they:

- included participants that were identified as having experience of working with individuals with ID *and* CB;
- utilised stimuli that allowed for a clear description of CB, and thus contained sufficient information for participants to experience desired responses;
- employed standardised and / or valid and reliable measures that address ALL of the predictive key area of Weiner's model:
- utilised a planned mediation analysis of at least two components of the model.

Studies achieving grades between 12 – 9 were rated as *good*; between 8 – 5 were rated as *adequate* and finally studies graded at 4 were rated as *poor*. The quality criteria rating scale is presented in table one.

(INSERT TABLE 1 HERE)

Each paper was reviewed twice, initially by the author and subsequently by a second independent rater (a fellow Trainee Clinical Psychologist) in order to ensure reliability

of the quality ratings. Inter-rater reliability for the key characteristics was 96% and reliability for the overall quality category was 100%. The quality ratings given by both raters to the included studies are detailed in table two.

(INSERT TABLE 2 HERE)

### **Data Extraction**

Details of the studies were placed within data extraction tables to facilitate cross referencing of study designs and outcomes. In line with the quality criteria detailed above, participant demographics and characteristics, methodology, assessment measures and data analysis were examined during data extraction. In addition to the quality criteria, study findings and effect sizes (where applicable) were also reported. The magnitude of correlation coefficients were established using Cohen's criteria. Thus, correlations between 0.1 – 0.3 were labelled as weak, those between 0.3 – 0.5 moderate and those between 0.5 – 1.0 as strong (Cohen, 1988).

### **Results**

The categorical ratings of the 12 reviewed studies resulted in two papers achieving an 'excellent' rating, seven papers meeting criteria for a 'good' rating, and three papers receiving an 'adequate' rating. The reviewed studies were assigned to one of three categories based on their methods: Real Life Experiences, Written Vignettes and Video Vignette of CB. One paper (Wanless and Jahoda, 2002) is discussed in more than one section. Additionally, relevant findings are subdivided into the quality ratings of studies. The methodological considerations and overall findings are also discussed.

#### ***Real Life Experiences***

Of the twelve studies, four examined care staff responses to real experiences of CB. Details of these studies are shown in tables 3.1 and 3.2. All four studies examined the relationship between emotions, attributions and helping behaviour, while only two studies measured participants' optimism for change (Bailey et al., 2006; Wanless and Jahoda, 2002).

### *Relevant Findings*

Three studies exploring care staff responses to real life incidents of CB were rated as 'good' (Bailey et al., 2006; Wanless and Jahoda, 2002; Lambrechts et al., 2009). Two of these studies measured participants' reported optimism for change and thus were able to explore the relationship illustrated in figure one (Bailey et al., 2006; Wanless and Jahoda, 2002). As shown in table 3.1, Bailey et al. (2006) did not report any relationship between participants' attributions about CB and optimism for change. Furthermore, they found no association between participants' optimism for change and willingness to help. Similarly, Wanless and Jahoda (2002) reported no significant associations between participants' attributions and their optimism or willingness to help.

All three studies detailed in table 3.1 examined the relationship between emotions, attributions and helping behaviour. Two studies reported a moderate correlation between an increase in the attribution of controllability and an increase in reported anger (Bailey et al., 2006; Wanless and Jahoda, 2002), which is consistent with the Attributional Model of Helping Behaviour (Weiner, 1992). Wanless and Jahoda (2002) also found moderate correlations between participants' emotional response and their willingness to help. Hence, an increase in sympathy was associated with an increase in willingness to help, whereas an increase in anger was associated with a decrease in a participant's desire to help (stated by A. Jahoda on the 25<sup>th</sup> January 2013 in conversation). As shown in table 3.1, Lambrechts et al. (2009) assessed participants' emotional responses to incidents of CB using the revised Emotional Responses to Challenging Behaviour Scale (Jones and Hastings, 2003). This is a 23 emotional reactions item scale with two categories: positive (8 items) and negative emotional reactions (15 items). The negative emotional reaction items are further divided into fear/anxiety and depression/anger and the positive reaction items into cheerful/excited and confidence/relaxed dimensions. Contrary to what is suggested by Weiner's Attributional Model of Helping Behaviour (1992), Lambrechts et al. (2009) reported no association between controllability and either negative affect sub-scales in the revised Emotional Responses to Challenging Behaviour scale.

(INSERT TABLE 3.1 HERE)

One study utilising real life experiences of CB as stimuli was rated as 'adequate' (Dagnan and Weston, 2006). This study did not measure participants' optimism for change and thus did not explore the relationship illustrated in figure one. With regards to emotional responses, they reported a moderate, positive correlation between an increase in participants' perception of controllability and an increase in their feelings of anger (as shown in table 3.2), which is consistent with Weiner's Attributional Model of Helping Behaviour (1992). However they found no evidence for an association between perceived controllability and sympathy or between emotional response and helping behaviour, which is inconsistent with the model.

(INSERT TABLE 3.2 HERE)

#### *Methodological Considerations*

As mentioned, of the four studies examining care staff responses to real life experiences of CB displayed by individuals with ID, three were rated as 'good' and one as 'adequate', according to the criteria detailed earlier. However, other methodological issues need to be considered when interpreting the findings of these studies. For example, when using real life experiences as stimuli it is possible that participants struggled to recall aspects of their experience, including their emotional responses and attributions experienced at the time. Furthermore, since the event, participants may have ruminated over the event, which could have led to their views changing. Therefore, the answers provided may not be an accurate reflection of the immediate responses they had when the event occurred.

Another consideration when using real life incidents as stimuli, is that the participants will be talking about their experience of different topographies and severities of CB. Only two studies advised their participants on the type of CB they should consider (Dagnan and Weston, 2006; Wanless and Jahoda, 2002), whereas participants in Bailey et al's (2006) study referred to incidents of self injurious behaviour or aggression. Furthermore, in the study by Lambrechts et al. (2009) participants referred to incidents of CB of various topographies. The variance across the studies' findings may therefore represent the differing emotional responses known to be influenced by the topography of the CB displayed (Hastings et al., 1995). This could have been controlled for if the

researchers guided participants in recalling only incidents where a client engaged in a specific topography of CB. However, despite the methodological issues that arise from drawing upon real life experiences, this method has the advantage of being more ecologically valid, as it deals with events that have personal significance for participants (Wanless and Jahoda, 2002), which is paramount in eliciting authentic emotional responses.

As stated previously, two studies did not measure optimism and thus did not assess the relationship between participants' perceived stability of the CB, optimism for change and their helping behaviour (Lambrechts et al., 2009; Dagnan & Weston, 2006). The same two studies also measured the type of 'helping behaviour' participants engaged in (i.e. positive alternative interventions or physical / nonphysical interventions). However the Attributional Model of Helping Behaviour (Weiner, 1992) aims to predict whether or not the observer will offer help, not the 'type' of help offered. Thus it can be argued that the measures used by these studies prevented the authors from fully assessing the model within the current population.

Finally, it is important to note that, as shown in tables 3.1 and 3.2, all the studies employing real life stimuli used correlational analyses. Whilst they were therefore able to explore associations between the main components of the model, they failed to assess the possibility of a mediating role being played by optimism and emotion, which is the crux of the model. Therefore, any associations reported, even in the predicted direction, do not necessarily equate to evidence for the model's applicability to this population.

### ***Written Vignettes***

Studies using written vignettes as stimuli varied in their use of unnamed and named vignettes. Unnamed vignettes provide participants with a description of a hypothetical scenario in which a fictional individual engages in CB. Whereas in a named vignette, although the scenario remains hypothetical, the vignette identifies the individual engaging in CB as a client whom the participant knows and works with (and therefore has an existing relationship with). Where studies did not state the type of written vignette used, it is assumed they were unnamed vignettes. Overall eight studies

examined care staff responses to written vignettes depicting CB, of which two did not measure participants' optimism for change (Dagnan and Cairns, 2005; Hill and Dagnan, 2002). However, all eight studies investigated the relationship between participants' emotions, attributions and helping behaviour. Details of these studies are presented in tables 4.1, 4.2 and 4.3.

### *Relevant Findings*

Two studies using written vignettes as stimuli were rated as 'excellent' (Dagnan, 2012; Willner and Smith, 2008b). Although the latter study found a moderate, negative association between participants' increased perceptions of the stability of the CB and decreased levels of optimism for change, the former found no evidence for this association, as shown in table 4.1. Both studies did report moderate associations between participants' increased levels of optimism for change and their increased willingness to help. Furthermore, Willner and Smith's (2008b) study also found that optimism *mediated* the relationship between participants' perceptions of stability of the CB and their wish to help, (i.e. low perceived stability - high optimism - high effort to help), thus supporting this component of Weiner's Attributional Model of Helping Behaviour (1992).

With regards to the second mediated relationship between controllability, emotion and willingness to help, Willner and Smith (2008b) reported that participants' perception of clients' control of their CB was not significantly correlated with any other variable. Whereas Dagnan (2012) found both a weak and moderate positive correlation between increased levels of perceived controllability and increased feelings of anger in response to both unnamed and named vignettes, respectively. As detailed in table 4.1, both studies reported a positive association between participants' increased levels of sympathy and their increased willingness to provide help. Dagnan (2012) also reporting a moderate, negative correlation between participants' reported increased levels of anger and decreased willingness to provide help in response to unnamed vignettes. Furthermore, Dagnan's (2012) study also found evidence for a mediated effect of anger on the participants' perception of clients' control of their CB and reported willingness to offer help (i.e. increased control - increased anger - decreased effort to help).

(INSERT TABLE 4.1 HERE)

Five of the studies employing written vignettes as stimuli achieved a rating of 'good' (table 4.2). With regards to the predicted relationship between stability, optimism and helping behaviour, Dagnan et al. (1998), using Path analysis, found that when the cause of the CB was perceived as less stable, participants were more likely to feel optimistic regarding the potential for change and therefore report being more likely to help. As shown in table 4.2, no other studies reported any significant relationships for optimism for change. Dagnan et al. (1998) also reported an increase in participants' perception of the clients' control of CB to be associated with a decrease in staff's positive affect and an increase in their negative affect. Both Dagnan and Cairns (2005) and Hill and Dagnan (2002) found that an increase in participants' sympathy was moderately associated with an increase of reported willingness to provide help. Moreover, Dagnan et al. (1998) found that an increase in participants' anger was associated with a decrease in their willingness to provide help.

As shown in table 4.2, Hill and Dagnan (2002) reported that staff's perception of the individual's control over the behaviour independently predicted participants' willingness to provide help, thus implying that the relationship between controllability and willingness to provide help is not mediated by an emotional response. Furthermore, the study by Rose and Rose (2005) did not find any associations consistent with Weiner's Attributional Model of Helping Behaviour (1992), rather they reported a weak but positive association between participants' perceptions of clients' control over their CB and optimism for change, and both stability and optimism were associated with negative emotions, inconsistent with the model.

(INSERT TABLE 4.2 HERE)

One study using written vignette stimuli was rated as 'adequate' (see table 4.3). Stanley and Standen (2000) found a direct relationship between stability and help, thus concluding that optimism does not appear to have a mediating role between the perceived stability of the client's CB and staff's reported willingness to help. They also

found that an increase in perceived controllability of CB was associated with a decrease in staff's positive affect and an increase in their negative affect, consistent with the Attributional Model of Helping Behaviour (Weiner, 1992).

(INSERT TABLE 4.3 HERE)

### *Methodological Considerations*

Although the eight studies discussed above employed written vignettes, aspects of the vignettes differed across studies, which may have influenced the findings. For example, Dagnan (2012) employed named *and* unnamed vignettes. As stated earlier, unnamed vignettes describe a hypothetical scenario where a fictional individual engages in CB, whereas named vignettes depict the exact same hypothetical scenario and CB, however the individual displaying the behaviour is identified as a client the participant knows. Dagnan's (2012) study found that staff made significantly more internal and global attributions in response to named rather than unnamed vignettes (with a similar non-significant trend observed for the attributions of controllability and stability). Participants were also significantly less optimistic about change in response to named vignettes. Thus the type of written vignette used in studies may account for some of the variance in participants' responses.

Rose and Rose (2005) reported participants' emotional responses in two categories, namely positive and negative affect. However negative affect may include not only anger, but also emotions that are qualitatively different from anger, such as depression and fear. Positive affect may also include emotions that are distinct from sympathy, such as happiness. Sympathy is also not necessarily associated with positive emotions and can be linked to sorrow and anguish (Collins Concise Dictionary, 1995). Therefore, the global categories of emotion used by Rose and Rose (2005) provide limited insight into the staff members' emotional reactions to CB.

### ***Video Vignette***

One study employed a video vignette method to examine care staff responses to CB (Jones and Hastings, 2003). As the study did not measure optimism, findings from this study will only be discussed in relation to the second key relationship between

controllability and willingness to engage in helping behaviour, mediated by emotional response. As detailed in table five, participants were shown one of two video vignettes. One video depicted an individual ('Mikey') engaging in self injurious behaviour that was attention maintained and the other depicted the same individual displaying self injurious behaviour that was escape maintained. Findings relevant to the present review are related to participants' responses to vignettes of attention maintained self injurious behaviour.

### *Relevant Findings*

Jones and Hastings (2003) used the Revised Causal Dimension Scale in their study, which they adapted to refer to the third person. The term 'personal control' therefore refers to participants' perception of the control 'Mikey' has over his behaviour. And 'external control' refers to participants' perception that the CB is controllable by individuals other than 'Mikey' (i.e. 'Mikey' has no control). Their study found that staff who perceived the cause of the self injurious behaviour as outwith 'Mikey's' control (external control) scored higher on the depression/anger subscale of the Emotional Responses to Challenging Behaviour scale. Furthermore, participants who perceived the CB as being controlled by 'Mikey' (described as personal control) scored higher on the confident/relaxed subscale developed by the authors. These findings are inconsistent with the Attributional Model of Helping Behaviour (Weiner, 1992).

(INSERT TABLE 5 HERE)

### *Methodological Considerations*

Whilst the use of a video vignette allows for more control in comparison to real life incidents, it remains an artificial stimuli that lacks personal 'investment' and the interpersonal history underpinning real life experiences of dealing with an individual engaging in CB. Therefore, it cannot be assumed that such stimuli would evoke similar emotional responses in participants to those experienced in response to real encounters of CB. Furthermore, Jones and Hastings (2003) asked participants to respond to the video vignette as a whole, not only 'Mikey's' engagement in self injurious behaviour but also the 'teacher' interacting with him. It may be that the participants' responses were influenced by the behaviour of the 'teacher' and not solely the behaviour of 'Mikey'.

As stated above, the use of global emotional categories, such as the collapse of anger and depression into the same subscale within the Emotional Responses to Challenging Behaviour scale, prevents the Attributional Model of Helping Behaviour (Weiner, 1992) from fully being tested. A further difficulty in assessing the applicability of the model comes from the way in which Jones and Hastings (2003) measured participants' helping behaviour. The model aims to predict whether or not the observer will offer help. However, Jones and Hastings required participants to select a response from a list of common interventions to CB. This can be seen as an assumption by the authors that their participants would have been willing to offer help.

### **Discussion**

Overall, the evidence appears to support a tentative relationship between care staff's optimism for change and their willingness to engage in helping behaviour (Dagnan, 2012; Willner and Smith, 2008b; Dagnan et al., 1998). It should be noted however, that the number of studies reporting these findings is limited, although this may be due to several studies failing to measure participants' optimism for change, rather than the absence of this finding. However, caution must be exercised as studies using real life experiences as stimuli found no evidence of this relationship (Bailey et al., 2006; Lambrechts et al., 2009; Wanless and Jahoda, 2002; Dagnan and Weston, 2006). Furthermore, there is inconclusive evidence that optimism plays a mediational role in helping behaviour (Willner and Smith, 2008b; Dagnan, 2012).

With regards to the relationship between emotional responses and helping behaviour, there is strong evidence from studies of 'excellent' and 'good' quality for an association between care staff's emotional response and their subsequent helping behaviour (Willner and Smith, 2008b; Dagnan, 2012; Dagnan and Carins, 2005; Hill and Dagnan, 2002). Once again, these findings are specific to care staff responses to written vignettes. Evidence for the mediational role of emotion is inconsistent, with both 'excellent' studies reporting contradictory findings (Dagnan, 2012; Willner and Smith, 2008b). Therefore, evidence suggests that *elements* of Weiner's Attributional Model of Helping Behaviour (1992) are helpful in understanding care staff responses to written vignettes depicting incidents of CB displayed by individuals with ID. Possible reasons

for the inconsistency within the evidence base have been highlighted by previous studies and have been attributed to methodological limitations of the studies and more recently to limitations of the model itself.

### ***Methodological Limitations***

The first limitation derives from the type of stimuli utilised by the reviewed studies. Current research suggests that participants' evaluations of the individual engaging in CB are stronger when responding to real incidents rather than vignettes and to named rather than unnamed vignettes (Wanless and Jahoda, 2002; Dagnan, 2012). Thus it may be that the more removed participants are from the stimuli, the less likely it is that their responses reflect the reactions of staff day to day. Jahoda and Wanless (2005) argued that variation in staff responses to differing stimuli are created by the fact that staff responding to CB in real life are not doing so in a vacuum, but within the context of an interpersonal history with the individual. This is significant when considering that the strongest evidence for the aforementioned elements of the Attributional Model of Helping Behaviour (Weiner, 1992) comes from studies using written vignettes for stimuli. With this in mind, it appears that studies employing real life experiences as stimuli can accurately reflect the responses that staff experience day to day. However, when using this method, it is possible that participants' might recall incidents involving differing topographies of CB, which has been shown to influence staff's responses (Mitchell and Hastings, 1998; Hastings et al., 1995). Furthermore, it is possible that staff ruminate over salient incidents of CB after the event. Thus when asked to call to mind these incidents, their recalled responses may have been influenced by rumination and therefore are not reflective of the immediate thoughts and emotions experienced at the time.

The second methodological issue relates to the characteristics of the samples. Studies within the current review included participants from several settings, including residential and day services. Only three studies advised of participants' formal qualifications and / or educational background (Dagnan and Weston, 2006; Jones and Hastings, 2003; Lambrechts et al., 2009). However participants' qualifications and level of behavioural knowledge have been found to impact upon their responses to CB (Dagnan, 2012; Dagnan et al., 1998; Hastings et al., 1995). Therefore, it is possible that

the variation of findings across studies are, at least partly, attributable to the differences between participants. However, whilst greater control over the participants' experience and backgrounds may help address methodological issues in the research, it may also limit the generalisability of findings. The variety of participants included in the studies could be reflective of the diversity of care staff working in ID settings. Consequently, whilst the diversity of the sample may be a strength in terms of generalisability of the findings, education and qualifications could be covariates.

Finally, the validity of asking care staff about their willingness to help an individual they care for has been questioned (Rose and Rose, 2005). Helping the individual is essentially the reason for the staff members' employment, and consequently they are likely to respond in a socially desirable way that is consistent with their employer's guidelines and the service ethos.

### ***Limitations of the model***

Several limitations of the model have come to light during the course of this review. Firstly, it is important to consider that the model was originally intended to apply to low frequency behaviours (Willner and Smith, 2008a), such as explaining an individual's decision to help a person who has fallen down on the street (Weiner, 1992). However, by its very definition, CB is a behaviour of "...intensity, frequency or duration" (McClellan and Grey, 2007). Thus staff are not responding to an isolated incident of behaviour.

Secondly, within the context of CB, the definition of 'helping behaviour' changes. In Weiner's original vignette, helping behaviour can be clearly defined as helping the person and / or to seek help. However, within the context of CB, helping behaviour is not so easily defined. Within the framework of functional analysis, practical strategies such as ignoring the challenging behaviour may prove helpful (in terms of reducing the incidents of CB and helping the individual to use more appropriate methods to achieve their goals). However, in the immediate situation, planned ignoring may not be viewed as helpful in terms of ending the CB and any discomfort experienced by the staff. The difficulty of defining helping behaviour is reflected in the studies' methods of measuring help. Whilst many studies enquired as to participants' willingness to help, Jones and Hastings (2003) focused on whether the participants' response would be likely to help

maintain the CB. This issue highlights that, for the population in question, perhaps the important consideration is not whether help *will* be offered but rather *what* type of help will be offered.

Furthermore, recent literature has highlighted that individuals respond not only to *what* other people do, but *how* they do it (Zijlmans et al., 2012). Therefore, it may be relevant to consider not only what factors influence *what* care staff do but to also take account of their interpersonal style when responding. Another issue with the model itself within the current context is the limitation of the proposed emotional responses of anger and sympathy. As mentioned, within the context of staff supporting individuals with CB, a broader range of emotional responses might be expected, including fear, anxiety, depression and disgust (Mitchell and Hastings, 1998). Furthermore, care staff have been reported to habituate to the CB (Bailey et al., 2006), and this is likely to impact upon their emotional responses over time.

Perhaps it is appropriate to consider an alternative, more meaningful and formulation based way of understanding care staff responses to CB displayed by those with ID. In doing so, it is important to look across factors not only related to the staff member, but also to the individual engaging in the CB, the immediate environment and the wider context. For example, care staff responses to CB may differ depending on the individual displaying the behaviour and so it is important to consider the staff member's perception of the individual and the history of their relationship. It would also be pertinent to look beyond anger and sympathy and take into account the wide range of emotional responses that care staff might experience and which may influence their response. Beyond these factors, it is also important to remember that care staff are only human and their own life events or current circumstances may impact upon their responses to CB. For example, they may be concerned with family events or may feel low in mood and as a result their response may differ than if they did not feel this way. Finally, it is important to consider that staff, as professionals, are likely to do what they are trained and employed to do, rather than what they *want* to do when responding to CB. However, although the above factors may not influence *what* a staff member does, they may have an effect on *how* the staff member engages with the individual whilst responding to their behaviour. As staff's interpersonal style has been reported to

contribute to the maintenance of CB (Zijlmans et al., 2012) it would be important to account for this dynamic.

Factors specific to the individual displaying the CB that may influence care staff responses include the frequency in which they engage in such behaviour and the challenge this creates for others. It is also important to remain cognisant of the topography of the CB and the severity of the individual's ID, both of which are known to influence the response of care staff (Hastings et al., 1997; Tynan and Allen, 2002). Other factors important to consider are those specific to the immediate environment in which the CB is taking place. The presence of other staff members may influence how someone responds, as will the presence of other vulnerable individuals who may be at risk as the result of the person's actions. The culture and outlook towards CB may differ across organisations. Furthermore, wider society's stance on CB and responses that are deemed to be appropriate may also influence staff behaviour.

### **Limitations**

There are two limitations of the current review which are noteworthy. Firstly, the review may have been limited by the search strategy, which excluded studies that were not reported in English and those which were unpublished. As such, the review may have excluded pertinent evidence relating to the area under investigation and may have been subject to publication bias. Secondly, the quality criteria were designed to fit the purpose of the review and thus questions regarding its validity could be raised. However, it was not possible to identify a suitable measure, as most quality instruments are developed for randomised controlled trials, which were not the focus of investigation for the present review.

### **Conclusions**

The majority of the studies included in the review were found to be of 'good' or 'excellent' quality and spanned a period of 14 years of research. The overall findings support the applicability of two distinct elements of Weiner's Attributional Model of Helping Behaviour (1992) in understanding care staff responses to written vignettes only. Namely the evidence supports an association between staff's positive emotional responses and willingness to help. Evidence also suggests that their optimism for

change may be associated to their willingness to help. However, as optimism for change was not assessed by all studies, there is less supporting evidence for this association. Weaknesses of Weiner's model when applied to staff perceptions of CB, as well as the methodological difficulties with studies in this area, ultimately mean that this body of research offers few insights of practical use.

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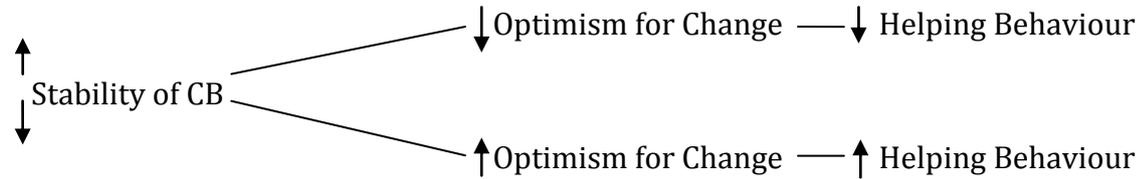
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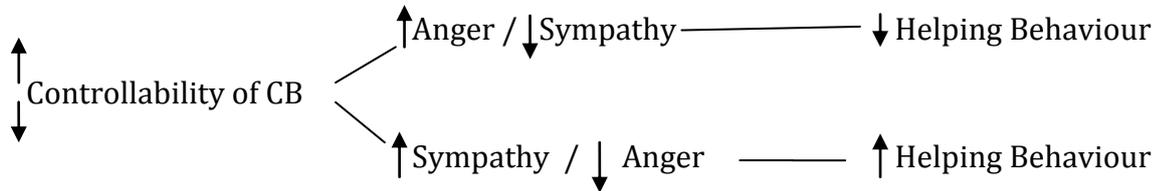
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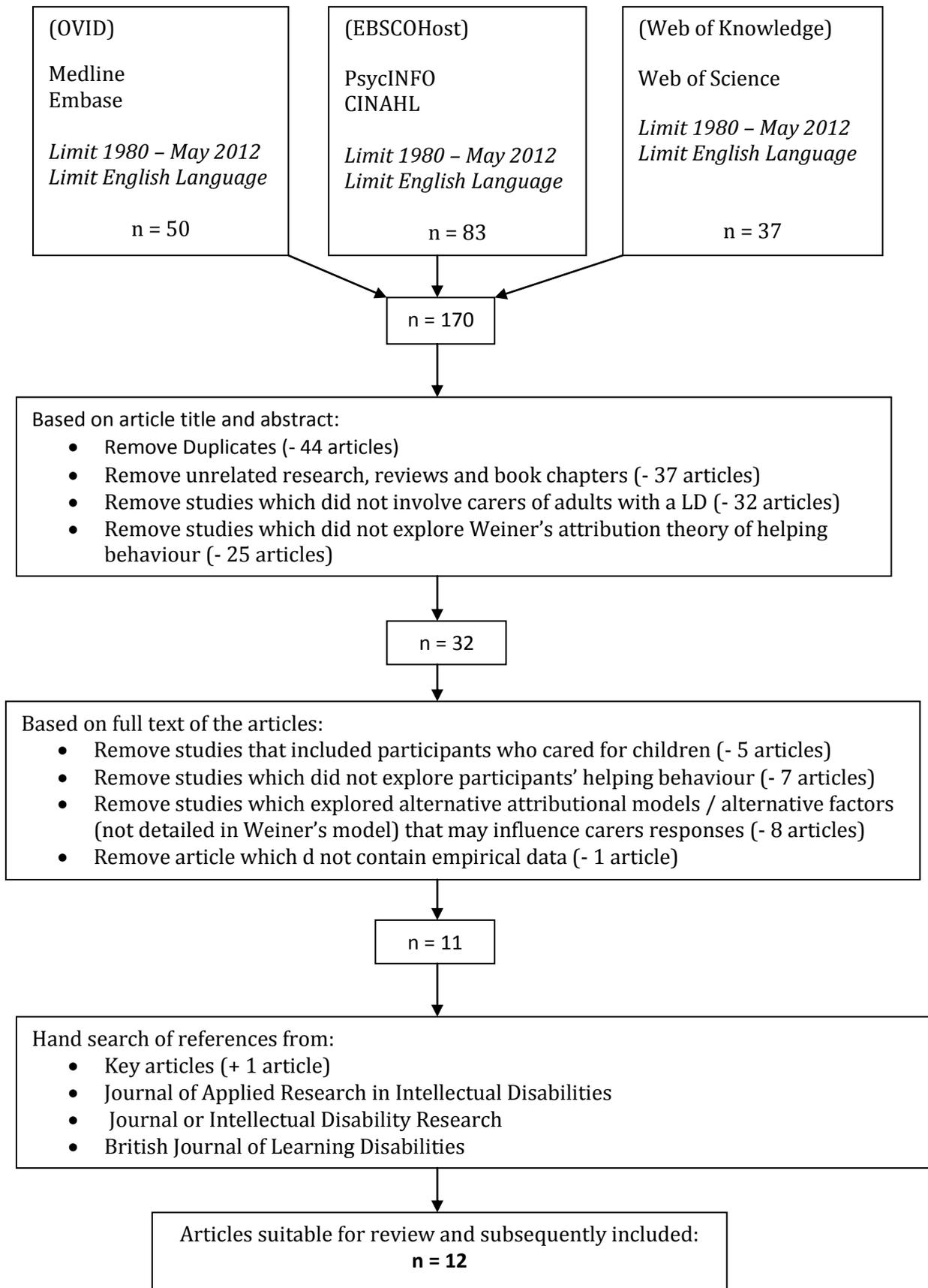
**Figure 1** - Representation of the relationship between perceived stability of the challenging behaviour and likelihood of engaging in a helping behaviour, as mediated by optimism for change.



**Figure 2** - Illustration of the relationship between perceived controllability of the challenging behaviour and likelihood of offering helping, mediated by emotional response.



**Figure 3** – Flowchart of search strategy and results



**Table 1 - Quality and Criteria Rating Scale**

<u>Quality Standards</u>	<u>Achieved</u>
<i>Please select one from each section when rating</i>	
<b>Participants' experience of challenging behaviour</b>	
Identified as staff with experience of working with individuals with learning disabilities who ALSO display challenging behaviour.	3
Clearly Identified staff group with experience of working with individuals with learning disabilities	2
No information about participant sample	1
<b>Appropriate Stimuli</b>	
Video <b>OR</b> written vignette where a clear and detailed description of the behaviour is given (eg client engaged in physically aggressive behaviours by punching the wall) <b>OR</b> Participants asked to give a clear behavioural description of a real experience of challenging behaviour	3
Written vignette that alludes to a broad category of CB, but provides no other detail, eg <i>Self Injurious Behaviour</i> <b>OR</b> Participants' recall of real incidents but does <i>not</i> state participants were asked to provide a clear behavioural description of the behaviour.	2
No description of stimuli used	1
<b>Adequacy of Measures</b>	
Standardised and / or valid and reliable measures that address ALL of the predictive value of the key areas of Weiner's model (i.e. controllability; stability; emotion; behaviour)	3
Standardised and / or valid and reliable measures that address SOME of the predictive value of the key areas of Weiner's model i.e. controllability; stability; emotion; behaviour)	2
Non-standardised and / or invalid and unreliable measures	1
<b>Sophistication of Analysis</b>	
Mediation analysis - aiming to identify if the core processes of Weiner's model are supported (minimum of two key elements analysed, e.g. emotional response of anger and attribution of controllability)	4
Regression analysis – aiming to determine which variables are predictors of helping behaviour	3
Planned correlation analysis (minimum of two key elements analysed)	2
A broad correlation matrix	1
<b>Total</b>	

**Table 2 - Quality ratings awarded to reviewed studies**

		Participants' Experience of CB	Appropriate Stimuli	Adequacy of Measures	Sophistication of Analysis	Quality Rating
<b>Dagnan (2012)</b>	<i>Rater 1</i>	3	3	3	4	Excellent (13)
	<i>Rater 2</i>	3	3	3	4	Excellent (13)
<b>Willner &amp; Smith (2008)</b>	<i>Rater 1</i>	3	3	3	4	Excellent (13)
	<i>Rater 2</i>	3	3	3	4	Excellent (13)
<b>Bailey, Hare, Hatton &amp; Limb (2006)</b>	<i>Rater 1</i>	3	3	3	2	Good (11)
	<i>Rater 2</i>	3	3	3	2	Good (11)
<b>Dagnan &amp; Cairns (2005)</b>	<i>Rater 1</i>	2	3	3	3	Good (11)
	<i>Rater 2</i>	2	3	3	3	Good (11)
<b>Hill &amp; Dagnan (2002)</b>	<i>Rater 1</i>	2	3	3	3	Good (11)
	<i>Rater 2</i>	2	3	3	3	Good (11)
<b>Wanless &amp; Jahoda (2002)</b>	<i>Rater 1</i>	3	3	3	1	Good (10)
	<i>Rater 2</i>	3	3	3	1	Good (10)
<b>Dagnan, Trower &amp; Smith (1998)</b>	<i>Rater 1</i>	3	1	3	3	Good (10)
	<i>Rater 2</i>	3	1	3	3	Good (10)
<b>Lambrechts, Kuppens &amp; Maes (2009)</b>	<i>Rater 1</i>	3	3	2	1	Good (9)
	<i>Rater 2</i>	3	2	3	1	Good (9)
<b>Rose &amp; Rose (2005)</b>	<i>Rater 1</i>	2	1	3	3	Good (9)
	<i>Rater 2</i>	2	1	3	3	Good (9)
<b>Dagnan &amp; Weston (2006)</b>	<i>Rater 1</i>	3	2	2	1	Adequate (8)
	<i>Rater 2</i>	3	2	2	1	Adequate (8)
<b>Jones &amp; Hastings (2003)</b>	<i>Rater 1</i>	2	3	2	1	Adequate (8)
	<i>Rater 2</i>	2	3	2	1	Adequate (8)
<b>Stanley &amp; Standen (2000)</b>	<i>Rater 1</i>	2	2	1	2	Adequate (7)
	<i>Rater 2</i>	2	2	1	2	Adequate (7)

**Table 3.1: Studies examining staff responses to real life experiences of CB – rated as ‘good’**

Study	Participant Demographics & experience of CB	Stimuli	Measures	Method of Analysis	Relevant Findings
					Methodological Considerations
Bailey et al..(2006)	<p>N = 43 day centre care staff.</p> <p>Mean age = 40.95</p> <p>All participants had experience of working with individuals who had IDs and displayed CBs</p>	<p>Participants' response to real incidents of CB were recorded.</p> <p>Recorded behaviours were categorised a self injurious behaviour (SIB) or challenging behaviour directed externally</p>	<p>The Checklist of Challenging Behaviour (Harris et al.. 1994) &amp; The Self Injurious Behaviour Checklist (Wisely et al.. 2002)</p> <p>Challenging Behaviour Attributions Scale, (Hastings 1997)</p> <p>Emotional Responses to Challenging Behaviour (ERCB)Scale (Mitchell &amp; Hastings, 1998)</p> <p>Optimism and willingness to help were assessed using Likert Scales (Stanley &amp; Standen, 2000)</p> <p>Collection of observational data were collected on a Psion Workabout MX</p>	Correlations	<p>↑ Control - ↑ Depression / Anger (SIB: <math>r = 0.433, p &lt; 0.021</math>; CB: <math>r = 0.417, p &lt; 0.006</math>)</p> <p>↑ Control - ↑ ERCB Score * (SIB: <math>r = 0.420, p &lt; 0.026</math>; CB: <math>r = 0.0365, p &lt; 0.018</math>)</p> <p>↑ Stability ↑ Depression / Anger (SIB: <math>r = 0.496, p &lt; 0.007</math>; CB: <math>r = 0.373, p &lt; 0.015</math>)</p> <p>↑ Stability ↑ ERCB Score* (SIB: <math>r = 0.473, p &lt; 0.011</math>)</p> <p>No association between Optimism and willingness to Help. Association between Affect – Helping; Attribution – Helping and between Attribution – optimism is not reported.</p> <p>* ERCB has two subscales: Depression / Anger &amp; Fear / Anxiety. The higher the score, the more often participants experienced emotions that made up the subscales.</p> <p>All correlations are within the moderate range.</p> <p>The use of the ERCB allows for only negative emotions to be measured, thus excluding more positive emotions, such as sympathy.</p> <p>As the ERCB combines the emotions of anger and depression into the same subscale, an increase of scores may be a result of participants' experience of depressive feelings, such as hopelessness and not anger.</p>

<p>Lambrechts et al. (2009)</p>	<p>N = 51 care staff from 20 residential services</p> <p>94.1% Female &amp; 5.9% Male</p> <p>Mean age = 34.27 years</p> <p>All participants had worked with a client who had a ID and who engaged in CBs, for at least 6 months</p>	<p>Recall of real incidents of CB</p>	<p>Behaviour Problems Inventory (Rojahn et al., 2001)</p> <p>Challenging Behaviour Attributions Scale (Hastings, 1997) – adapted by Bailey et al., 2006</p> <p>ERCB Scales (Mitchell &amp; Hastings, 1998; Jones &amp; Hastings, 2003) – with adjusted sub-scales.</p> <p>Reactions to Challenging Behaviour Scale (Lambrechts &amp; Maes, 2006 unpublished data)</p>	<p>A broad correlation matrix examining the relationships between all possible pairs of variables.</p>	<p>↑ Stability ↑ Confident / Relaxed <math>r = 0.28</math> <math>p &lt; 0.05</math></p> <p>No association between controllability and either negative emotion sub-scale on the ERCB.</p> <p>Optimism not measured.</p> <p>Correlation within weak range.</p> <p>Measurement of Helping behaviour included: positive alternative interventions; person related interventions and environment related interventions. Highlights issue with definition of helping behaviour.</p> <p>New measure used to assess reactions to CB, no details of validity of measure.</p>
<p>Wanless &amp; Jahoda. (2002)</p> <p><i>Additional information regarding the findings of the study was given by A. Jahoda in conversation on the 25<sup>th</sup> January 2013</i></p>	<p>N = 38 day centre staff from 6 centres</p> <p>22 Female &amp; 16 Male</p> <p>Mean age = 42.7 years</p> <p>All participants had worked with a client who had a ID and who engaged in frequent aggressive behaviours, for at least 6 months</p>	<p>Two brief vignettes describing incidents of physical and verbal aggression AND real incidents of CB with specific individuals</p>	<p>A modified version of the Harris Checklist of Challenging Behaviours (Harris et al., 1994)</p> <p>A modified form of the Attributional Style Questionnaire (ASQ; (Peterson et al. 1982) previously developed by (Dagnan et al., 1998).</p> <p>Ratings were also obtained for : optimism for the possibility of change; willingness to provide extra help; their emotional response to the CB; and a rating of the behaviour and the individual</p>	<p>Initial analysis examining differences between staff ratings of hypothetical and real incidents of aggression using a one-way ANOVA.</p> <p>Second stage of analysis - a broad correlation matrix examining the relationships between all possible pairs of variables.</p>	<p><u>Real Incidents:</u></p> <p>↑ Sympathy - ↑ Help <math>r = 0.372</math> <math>p &lt; 0.01</math></p> <p>↑ Anger - ↓ Help <math>r = -0.450</math> <math>p &lt; 0.01</math></p> <p>↑ Control - ↑ Help <math>r = 0.495</math>, <math>p &lt; 0.01</math></p> <p>↑ Control - ↑ Anger <math>r = 0.454</math> <math>p &lt; 0.01</math></p> <p>↑ Control - ↓ Sympathy <math>r = -0.431</math> <math>p &lt; 0.01</math></p> <p>Correlations with moderate range</p> <p>Small number of participants.</p> <p>Possible impact of the participants first completing measures for vignettes, and then for the recall of a real incident.</p> <p>2 participants did not complete all measures.</p>

**Table 3.2: Study examining staff responses to real life experiences of CB – rated as ‘adequate’**

Study	Participant Demographics & experience of CB	Stimuli	Measures	Method of Analysis	Relevant Findings
					Methodological Considerations
Dagnan & Weston (2006)	<p>N = 37 participants from 3 residential units.</p> <p>26 Female &amp; 11 Male</p> <p>Mean age = 33.9 years</p> <p>All participants had experience of working with individuals with IDs who had recently engaged in CB</p>	Recall of real incidents of CB	<p>Carers were interviewed regarding the incident and their response.</p> <p>The Attributional Style Questionnaire, modified according to Peterson et al. (1982)</p> <p>Ratings were also obtained for their emotional response to the CB; and a rating of the behaviour and the individual; satisfaction with the intervention.</p>	A broad correlation matrix examining the relationships between all possible pairs of variables.	<p>↑ Control ↑ Anger <math>r = 0.36</math> <math>p &lt; 0.05</math></p> <p>No association Control and Sympathy.</p> <p>Optimism not measured.</p> <hr/> <p>Correlation within moderate range.</p> <p>Intention to Help not measured. Rather type of intervention (Physical and Non-Physical) and participant satisfaction with intervention measured. This does not fit with Weiner’s model, and highlights a difficulty in defining Helping Behaviour within current context.</p> <p>Small number of participants.</p>

**Table 4.1: Studies examining staff responses to written vignettes depicting CB – Rated as ‘excellent’**

Study	Participant Demographics & experience of CB	Stimuli	Measures	Method of Analysis	Relevant Findings
					Methodological Considerations
Dagnan (2012)	<p>N = 62 paid carers working in homes for people with intellectual disabilities</p> <p>39 Female &amp; 23 Male</p> <p>Mean age = 34.0 years</p> <p>All staff worked with individuals who had IDs and displayed CB</p>	<p>Two vignettes describing aggressive behaviour of a named / unnamed individual pulling the hair of the participants</p>	<p>The Attributional Style Questionnaire, modified according to Peterson et al. (1982)</p> <p>Ratings were also obtained for participants’ optimism for the possibility of change; their willingness to provide extra help; and their emotional response to the CB.</p> <p>The Self Injury Behavioural Understanding Questionnaire (Oliver et al., 1996)</p>	<p>Correlations and Mediation Analysis</p>	<p><u>Unnamed vignette:</u></p> <p>↑ Optimism - ↑ Help <math>r = 0.30 p &lt; 0.05</math></p> <p>↑ Sympathy - ↑ Help <math>r = 0.39 p &lt; 0.39</math></p> <p>↑ Control - ↑ Anger <math>r = 0.27 p &lt; 0.05</math></p> <p>↑ Anger - ↓ Help <math>r = -0.41 p &lt; 0.01</math></p> <p><u>Named Vignettes:</u></p> <p>↑ Optimism - ↑ Help <math>r = 0.32 p &lt; 0.01</math></p> <p>↑ Sympathy - ↑ Help <math>r = 0.29 p &lt; 0.05</math></p> <p>↑ Control - ↑ Anger <math>r = 0.41 p &lt; 0.01</math></p> <p>An indirect effect is apparent for the effect of Control on the likelihood to Help which is mediated by Anger in both the named and unnamed vignettes. This is consistent with Weiner’s model.</p> <p>↑ Control - ↑ Anger - ↓ Help</p> <p>No association between Stability and Optimism.</p> <p>Majority of correlations are within the moderate range.</p>

<p>Willner &amp; Smith (2008b)</p>	<p>N = 121 participants: 65 care managers, 69% female &amp; 31% Male, Mean age = 38 years  56 direct care staff, 57% Female &amp; 43% Male, Mean age = 43 years  All participants had experience of working with individuals with IDs who display inappropriate sexual behaviour</p>	<p>Four vignettes were used, varying in topography (contact Vs non contact) and victim type (child Vs adult with a ID). Each vignette had a clear description of the behaviour.</p>	<p>A modified form of the Attributional Style Questionnaire (ASQ; Peterson et al., 1982)  Ratings were also obtained for participants' emotional response; optimism for the possibility of change; the level of supervision that would be appropriate; their optimism that the level of supervision they selected would improve the client's behaviours and their willingness to provide extra help.</p>	<p>Correlations, stepwise multiple regression analyses and mediation analyses</p>	<p>↑ Stability - ↓ Optimism <math>r = -0.39, p &lt; 0.001</math>          ↑ Optimism ↑ Help <math>r = 0.48, p &lt; 0.001</math>          ↑ Sympathy - ↑ Help <math>r = 0.20, p &lt; 0.05</math></p> <p>Optimism was found to mediate the effects of stability and sympathy on effort to help.  Controllability was not significantly correlated with any other variable</p> <hr/> <p>Correlations within moderate range.</p> <p>Measures and vignettes given to participants to complete and return in their own time. Possible issues of participants consulting with one another regarding responses.</p> <p>Issues of multiple testing.</p>
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**Table 4.2: Studies examining staff responses to written vignettes depicting CB – Rated as ‘good’**

Study	Participant Demographics & experience of CB	Stimuli	Measures	Method of Analysis	Relevant Findings
					Methodological Considerations
Dagnan & Cairns (2005)	N = 62 participants who were employed in a direct care role in residential settings  32 Female & 30 Male  Mean age = 36.2 years  All participants had experience of working in ID settings, but their experience of working with CB is not stated.	An unnamed vignette method was employed, describing an individual with a ID who is aggressive to others by pulling hair and / or hitting out.	The Attributional Style Questionnaire, modified according to Peterson et al. (1982)  Ratings were also obtained for participants’ emotional response, helping intention, responsibility for the development and the change of the behaviour.  The Self Injury Behavioural Understanding Questionnaire (Oliver et al., 1996)	Correlations and Multiple Regression Analysis	<p>↑ Sympathy - ↑ Help <math>r = 0.40 p &lt; 0.05</math></p> <p>Sympathy is the only independent predictor of Helping behaviour reported.</p> <p>No association between Control and Affect or between Anger and Helping.</p> <p>Optimism not measured.</p> <p>Correlation within moderate range.</p> <p>Issues of multiple testing.</p>
Dagnan et al. (1998)	N = 40 care staff from residential settings:  Group 1 – 20 participants working in homes with clients presenting CB. 10 Female & 10 Male. Mean age = 32.4 years  Group 2 – 20 participants working in homes where clients did not display CB. 16 Female & 4 Male. Mean age = 35.5 years.  All participants had	‘example behaviours’ were presented to participants. No other information is provided regarding the methodology.	The Attributional Style Questionnaire, modified according to Peterson et al. (1982)  Ratings were also obtained for their evaluation of the behaviour and the individual; their optimism for change; willingness to provide extra help and their emotional response to the behaviour.	Correlations, & path analysis using a recursive regression approach	<p><u>Results based on both groups:</u></p> <p>↓ Stability - ↑ Optimism <math>r = -0.34 p &lt; 0.05</math></p> <p>↑ Optimism - ↑ Help <math>r = 0.79 p &lt; 0.01</math></p> <p>↑ Control - ↑ Negative Affect <math>r = 0.52 p &lt; 0.01</math></p> <p>↑ Negative Affect - ↓ Help <math>r = -0.53 p &lt; 0.01</math></p> <p>↑ Control - ↓ Positive Affect <math>r = -0.42 p &lt; 0.05</math></p> <p>Path Analysis - Helping behaviour is most predicted by the level of Optimism, Optimism is most predicted by Negative Affect and Negative Affect is most predicted by</p>

	experience of working with individuals who have a ID, and Group 1 also had experience of working with those who also displayed CB.				Controllability. Correlations with moderate to high ranges. Analysis is based on data from both groups of participants – as one group had no previous experience of working with CB, their results may not reflect the population in question. Issues of multiple testing. Collapse of emotional responses measured into Positive and Negative Affect.
Hill & Dagnan (2002)	N = 33 participants who were on a training course regarding CBs 5 = nurses 18 = residential care workers 2 = day care workers 8 = 'other'  25 = Female 8 = Male  All participants had experience of working in ID settings, but their experience of working with CB is not stated.	Two vignettes describing aggressive behaviours where an individual pulls the hair of others and hits out. One vignette was unnamed and the other vignette (detailing the same behaviour) but was shown by a named person, with whom the participant worked with.	The Attributional Style Questionnaire, modified according to Peterson et al. (1982)  Ratings of emotional response (anger & sympathy) and helping intention (previously used by Dagnan et al., 1998).  The Shortened Ways of Coping – Revised Questionnaire (Hatton and Emerson, 1994).  The Self Injury Behavioural Understanding Questionnaire (Oliver et al., 1996)	Correlations and Regression Analysis	↑ Stability - ↑ Sympathy $r = 0.62 p < 0.01$ ↑ Sympathy ↑ Help $r = 0.43 p < 0.01$  No association between Control and Anger; Anger and Helping or between Control and Sympathy.  Optimism was not measured.  Attribution of controllability independently predicted effort in helping. (The more controllable the behaviour is seen to be, the less effort in helping is predicted.) Correlations within moderate to high range.  Small number of participants who were recruited from staff attending CB training. It is unclear how much, if any, of the training the participants had progressed through prior to completing measures.  Issues of multiple testing.

<p>Rose &amp; Rose (2005)</p>	<p>N = 107 participants who worked in residential community homes for individuals with IDs</p> <p>76 Female &amp; 31 Male</p> <p>Mean age = 35.73 years</p> <p>All participants worked in ID services, but their experience of working with CB is not stated</p>	<p>The use of vignettes is briefly mentioned, but no information regarding their content is given.</p>	<p>The Attributional Style Questionnaire, modified according to Peterson et al. (1982)</p> <p>Ratings of emotional response; optimism for change and helping intention (previously used by Dagnan et al., 1998).</p> <p>General Health Questionnaire, Version 12 (Goldberg 1972)</p> <p>Maslach Burnout Inventory, 3<sup>rd</sup> edition (Maslach et al. 1996)</p> <p>Aberrant Behaviour Checklist (Aman &amp; Singh, 1986)</p> <p>A six point Liker scale was used for staff to indicate how high they perceived the level of CB to be in their work place</p>	<p>Correlations and Structural Path Modelling</p>	<p>↑ Stability - ↓ Negative Affect <math>r = -0.198</math> <math>p &lt; 0.05</math></p> <p>↑ Optimism - ↑ Negative Affect <math>r = 0.202</math>, <math>p &lt; 0.05</math></p> <p>↑ Control - ↑ Optimism <math>r = 0.196</math>, <math>p &lt; 0.05</math></p> <p>Due to data distribution, unable to examine Helping Behaviour.</p> <p>Correlation is weak.</p> <p>Collapse of emotional responses measured into Positive and Negative Affect.</p>
<p>Wanless &amp; Jahoda (2002)</p>	<p><i>Discussed in Table 1a</i></p>	<p><i>Discussed in Table 1a</i></p>	<p><i>Discussed in Table 1a</i></p>	<p><i>Discussed in Table 3.1</i></p>	<p><u>Vignettes:</u></p> <p>↑ Anger - ↑ Help <math>r = 0.435</math> <math>p &lt; 0.01</math></p> <p>↑ Control - ↑ Help <math>r = 0.376</math> <math>p &lt; 0.05</math></p> <p><i>Discussed in Table 1a</i></p>

**Table 4.3: Studies examining staff responses to written vignettes depicting CB – Rated as ‘adequate’**

Study	Participant Demographics & experience of CB	Stimuli	Measures	Method of Analysis	Relevant Findings
					Methodological Considerations
Stanley & Standen (2000)	<p>N = 50 participants from CB day services</p> <p>72% Female &amp; 28% Male</p> <p>Mean age = 33.39 years</p> <p>All participants had experience of working with individuals who display CB, however their experience of working with those with ID is not specified.</p>	<p>Six vignettes were employed, representing combinations of topography (aggression, destructiveness and self-injury) and dependency (‘independent’ and ‘dependent’ functioning in communication and activities of daily living)</p>	<p>Participants were asked to rate control, negative affect, positive affect, locus, stability, optimism and helping, on a 9 point scale.</p>	<p>Two way ANOVAs, post hoc analyses, and correlations</p>	<p><u>All Vignettes:</u></p> <p>↑ Help - ↑ Positive Affect <math>r = 0.62</math> <math>p &lt; 0.01</math></p> <p>↑ Control - ↑ Negative Affect <math>r = 0.398</math> <math>p &lt; 0.05</math></p> <p>↑ Control - ↓ Positive Affect <math>r = -0.508</math> <math>p &lt; 0.01</math></p> <p>↑ Stability ↑ Help <math>r = 0.407</math> <math>p &lt; 0.01</math></p> <p><u>Aggressive behaviour by someone with high dependency vignette:</u></p> <p>↑ Optimism - ↑ Help <math>r = 0.324</math>, <math>p &lt; 0.05</math></p> <p>Optimism does not appear to have a mediating role between Stability and Help, rather they appear to have a direct relationship.</p> <p>↑ Stability - ↑ Help</p> <hr/> <p>Correlations within moderate and large ranges.</p> <p>Participants completed measures for all 6 Vignettes, which may have impacted their responses.</p>

**Table 5: Study examining staff responses to video vignette depicting CB - Rated as 'Adequate'**

Study	Participant Demographics & experience of CB	Stimuli	Measures	Method of Analysis	Relevant Findings
					Methodological Considerations
Jones & Hastings (2003)	<p>N = 123 staff working in services for adults with IDs</p> <p>50 worked in residential settings; 56 in day services and 12 in community nursing team</p> <p>76 Female &amp; 47 Male</p> <p>Mean age = 35.92 years</p> <p>All participants worked in ID services, but their experience of working with CB is not stated</p>	<p>Video stimuli, developed by Mossman, Hastings &amp; Brown (2002) were utilised. Participants viewed one of two videos - Self injurious behaviour (SIB) that was attention maintained or escape maintained.</p>	<p>Emotional Reactions to Challenging Behaviour Scale (Mitchell &amp; Hastings, 1998)</p> <p>A rating scale, following the same design as the measure above, was developed to measure potential positive affect.</p> <p>Revised Causal Dimension Scale, RCDSII (McAuley et al., 1992), adapted to refer to 3<sup>rd</sup> person</p> <p>A list of staff typical intervention responses were generated, and participants were asked, if they were in the situation in the video, how likely would they be to use each response.</p>	<p>Correlations</p> <p><i>(due to the lack of association between attributions, affect and helping responses, the authors conclude it is not appropriate to test for a mediated effect)</i></p>	<p><u>Attention Maintained SIB:</u></p> <p>↑ Personal Control* - ↑ Confident / Relaxed r = 0.26, p&lt;0.05</p> <p>↑ External Control* - ↑ Depression / Anger r = 0.34, p&lt;0.05</p> <p>No relevant findings for escape maintained SIB.</p> <p>There was also some evidence that negative affect may be associated with counter-habilitative behaviour on the part of staff.</p> <p>Optimism not measured.</p> <p>* Jones and Hastings adapted the RCDSII to refer to 3<sup>rd</sup> person. Thus personal control relates to participants' perception of the control 'Mikey' (the individual in the video) has over his behaviour. And external control relates to participants' perception that the CB is controllable by individuals other than 'Mikey'.</p> <p>Correlations within weak to moderate ranges.</p> <p>Measurement of counter habitative behaviour, whilst relevant clinically, is not in line with Weiner's model which seeks to understand the factors associated with the likelihood staff will offer help. Again this highlights difficulties with the definition of helping behaviour within the current context.</p>

**CHAPTER TWO**  
**MAJOR RESEARCH PROJECT**

**What is special about family relationships? Familial attributions and emotional responses to relatives who present with challenging behaviour.**

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## **Lay Summary**

How family carers respond to challenging behaviour that is displayed by their relative has been overlooked in existing research. We wanted to understand the relationships carers have with their relatives who engage in challenging behaviour. We also wanted to find out what thoughts and emotions carers experience when their relatives display these behaviours. We used an interview and rating scales to gather this information from eight participants. We found that carers not only felt negative emotions, like anger, towards their relative, they also felt negative emotions towards themselves, like shame. We also learnt that family carers can have different beliefs about their relative during these incidents. On one hand, they may think that their relative cannot help it, but on the other hand they may also feel as though their relative is treating them badly. Family carers also think of different ways of responding to the challenging behaviour, and how they initially want to respond is often different from what they actually do. This is important to learn because professionals cannot support family carers properly if they do not understand their experiences.

## **Abstract**

**Background:** The existing research on factors which influence carers' responses to challenging behaviour has focussed on paid staff and has largely ignored the experiences of family carers. The aim of this study was to explore family carers' interpersonal perceptions and responses to their relatives' challenging behaviour.

**Method:** Eight familial carers of adults with intellectual disabilities who engaged in frequent aggressive challenging behaviour were recruited. A semi-structured, interview was used to explore participants' interpersonal perceptions and responses at the time of a recent incident of challenging behaviour. This was supplemented with a modified version of the Attributional Style Questionnaire and other rating scales. **Results:**

Participants' ratings on the quantitative measures did not match the responses they described experiencing during the interview. Findings from the interview suggest that the majority of participants experienced a range of emotions in response to incidents of challenging behaviour. A minority struggled to recall any emotional responses. Conflicting interpersonal appraisals were made by all participants and appear to have influenced both their emotional and behavioural responses to their relative's behaviour.

**Conclusions:** It appears that family caregivers' responses to their relatives' challenging behaviour were complex and, at times, contradictory. Their immediate emotional and behavioural responses during incidents of CB may have been influenced by their interpersonal perceptions made at the time of the incident and their underlying compassion for their relative. Implications for services and future research directions are discussed.

## ***Keywords***

Interpersonal, family carer, intellectual disability, challenging behaviour, responses

## **Introduction**

Carers often play a vital role in supporting individuals with an intellectual disability (ID), particularly when they display challenging behaviour (CB). Research has shown that carer behaviour can have a significant influence in both the development and maintenance of CB (Hastings and Remington, 1994). It is therefore important to develop an understanding of the processes which determine their responses to CB. Researchers have attempted to conceptualise carers' responses to CB within a cognitive-behavioural framework, exploring how their attributions and emotional responses to CB may influence their behavioural response.

Weiner's Attributional Model of Helping Behaviour (1992) has previously been applied to enhance our understanding of care staff's responses to CB exhibited by those with ID (e.g. Dagnan et al., 1998; Jones and Hastings, 2003). Weiner (1980) asserts that humans seek out causal attributions in order to explain behaviour and specifically highlights the importance of two attributional dimensions: namely controllability (whether the cause of the behaviour is perceived to be under the control of the individual) and stability (whether the cause of the behaviour is constant or likely to change). These causal attributions are thought to evoke an emotional reaction which determines the likelihood that the observer will engage in helping behaviour. Thus, Weiner's model (1992) suggests that it is how a behaviour is causally attributed, not the behaviour itself, that determines if the observer is willing to offer help.

Weiner proposed that the emotional response evoked by observers' perceptions of an individual's controllability over the cause of an event will primarily be either anger or sympathy (Weiner, 1992). In relation to a negative behaviour such as CB, Weiner's model predicts that if CB is evaluated by a carer as being under the deliberate control of the client, the carer will experience anger. However if the CB is seen as being uncontrollable by the individual, then the carer will experience feelings of sympathy. It is this emotional response that is believed to determine helping behaviour: feelings of anger will result in rejection and feelings of sympathy will result in help.

The mediating role of the observer's (i.e. carer's) emotional response is central to the Attributional Model of Helping Behaviour (Weiner, 1992). Weiner found that even

when controlling for the effects of causal attributions, the observer's emotional responses were significantly correlated with their propensity to offer help. However, when emotional responses were held constant, attributional style was no longer correlated with their inclination to help (Weiner, 1980). Recent literature has also explored the mediational role of optimism (Dagnan, 2012; Dagnan et al., 1998; Stanley and Standen, 2000). Optimism for change, according to Weiner (1974), is based on the perceived stability of the cause of an event. Therefore, perceived controllability has been assumed to influence the emotional reactions of anger and sympathy, whereas perceived stability influences the observer's optimism for change. In turn, these reactions affect the willingness of the observer (i.e. carer) to offer help.

The evidence regarding the applicability of the Attributional Model of Helping Behaviour (Weiner, 1992) to the population of care staff supporting individuals with ID is inconsistent (Willner and Smith, 2008a). Both limitations of the model and methodological limitations of the research in this area have been thought to contribute to the inconsistent findings. In relation to the model itself, one limitation concerns the proposed emotional responses evoked by an individual's attribution of controllability being constrained to only anger or sympathy. As a result of this aspect of the model, studies have often limited their exploration of care staff's emotional responses to CB, enquiring only about feelings of anger or sympathy. However, CB has been shown to evoke various emotions in individuals, including anger, fear, irritation and disgust (Bromley and Emerson, 1995). Furthermore, the nature of the emotional response varies depending upon the topography of the CB. Aggressive behaviour has been shown to evoke fear/anxiety and depression/anger (Mitchell and Hastings, 1998), both of which are understandable responses to a perceived threat. Whereas self injurious behaviour was associated with feelings of pity and depression and exposure to stereotyped behaviours have been linked to feelings of annoyance (Hastings et al., 1995). Moreover, given the frequent and repetitive nature of CB, carers have been found to habituate to CB (Bailey et al., 2006). As a result of this, carers may become less aware over time of their emotional responses to incidents of CB. Thus previous literature would suggest that, within the context of CB, accounting for only anger and sympathy does not adequately capture the emotions evoked in carers.

The context in which the behaviour occurs may also impact upon the adequacy of Weiner's model as a framework for understanding carers' responses to CB. Willner and Smith (2008a) have previously highlighted that Weiner's Attributional Model of Helping Behaviour (1992) was originally intended to apply to low frequency behaviours. However by its very definition, CB is a behaviour of "...intensity, frequency or duration" (McClellan and Grey, 2007). Thus carers are not responding to one incident of CB in isolation, rather they are reacting to the latest in a series of incidents, for which it is possible they may already hold existing attributions. Furthermore, care staff responding to an individual's CB, have been found to do so within the context of an interpersonal history (Jahoda and Wanless, 2005). Carers are therefore not only responding to the behaviour, but to the individual as well. This was evidenced by Dagnan et al.'s (1998) findings that staff who perceived the client to be in control of their CB made negative evaluations not only of the observed behaviour, but of the individual also. Therefore, Weiner's Attributional Model of Helping Behaviour (1992) may not fully account for carers' responses to CB when it occurs within an existing interpersonal relationship.

Methodological limitations, such as the majority of studies' reliance upon vignettes as stimuli (Armstrong and Dagnan, 2011; Dagnan and Cairns, 2005; Dagnan et al., 1998; Hill and Dagnan, 2002; Stanley and Standen, 2000), may also account for the variation in outcomes. Vignettes are essentially abstract events which may not have a great deal of personal significance to carers (Wanless and Jahoda, 2002). Carers may therefore struggle to make causal attributions regarding the controllability and stability of the behaviour described (Willner and Smith, 2008a). It is also unlikely that carers' responses to vignettes are the same as their responses to real incidents of CB displayed by those they care for. Dagnan (2012) compared staff responses to two different types of vignette, unnamed and named. Unnamed vignettes provide participants with a description of a hypothetical scenario in which a fictional individual engages in CB. Whereas, although named vignettes describe the same situation and behaviour, the individual engaging in CB is identified as a client whom the participant knows and works with (and therefore has an existing relationship with). Dagnan's (2012) study showed that staff made significantly more internal and global attributions, with a similar non-significant trend observed for the attributions of controllability and

stability, in response to named versus unnamed vignettes. These results imply carers' existing interpersonal relationships with, and knowledge of an individual, play a central role in governing their responses to CB.

Furthermore, it has been reported that staff make significantly more negative evaluations of the individual engaging in CB when responding to real incidents of aggressive CB, as opposed to those depicted in vignettes (Wanless and Jahoda, 2002). This suggests that emotionally meaningful attributions made by care staff in situations characterised by conflict, are essentially interpersonal. Therefore, it would appear that, not only does Weiner's Attributional Model of Helping Behaviour (1992) fail to account for the influence of an existing interpersonal relationship, but the method employed by the majority of studies has prevented the exploration of such a relationship and its influence on carers' helping behaviour.

Jahoda and Wanless (2005) used real life incidents of CB to explore care staff's perceptions of clients who were frequently aggressive. They found that care staff's interpersonal perceptions did appear to have some bearing on their responses to clients engaging in aggressive CB. This interpersonal context may be especially relevant when considering the dynamics within a family relationship. Drysdale et al. (2009) assessed the utility of the Attributional Model of Helping Behaviour (Weiner, 1992) in understanding maternal beliefs regarding self-injurious behaviour. Although the attributions made by mothers were consistent with the attributional dimensions of stability and controllability, they were also "...contextual, dynamic and emotionally driven". However, to date, no study has explored the influence interpersonal perceptions might have upon familial carers' responses to their relative's CB.

Familial caregivers remain the key support persons for adults with ID (Metzel, 2005). Many family carers perceive positive effects of caring for their relative (Hastings et al., 2005) and having a family member with ID who displays CB does not necessarily induce increased levels of stress in the family (Baxter et al., 2000). However, there is evidence to suggest that some carers may be at increased risk of stress, depression, poor physical health and a restricted quality of life (Hatton et al., 2010; Emerson, 2001). Several factors have been proposed as mediating the levels of stress experienced by family

carers, including the supports available to the family, the caregiver's coping style and their attributions of CB (Sloper and Turner, 1993). Despite the number of adults with ID who continue to live at home, the majority of research regarding carer attributions towards CB has focused upon paid care staff, with families' views being largely neglected (Hyman and Oliver, 2001).

The aim of this study is therefore to explore the nature of family carers' interpersonal perceptions during incidents of CB. The nature of familial caregivers' attributional, emotional and behavioural responses to CB displayed by their relative with ID will also be explored. Although there are various types of CB, all of which elicit an emotional response from those involved, aggression is ordinarily interpersonal (Emerson and Bromely, 1995) and is therefore likely to impact upon relationships with others. For that reason, this study aims to explore the interpersonal perceptions and responses of familial caregivers of adults with ID who also display verbal and/or physical aggression.

## **Method**

### ***Design***

This study used a qualitative design, employing a semi-structured interview to explore the nature of responses and interpersonal perceptions held by family carers during a significant episode of aggressive CB displayed by their relative. Information regarding family carers' general attributions and responses was also gathered using a quantitative measure.

### ***Participants***

A total of eight participants took part in the study. The demographic characteristics of participants and that of their relatives are presented in table one below. Participants were included in the study on the basis that they were familial caregivers whose first language was English and included parents, adoptive parents, grandparents or siblings of individuals who: (i) were over 18 years old; (ii) had a diagnosis of mild – moderate ID, as indicated by the referrer and (iii) had displayed three or more incidents of serious verbal or physical aggression over a three month period, assessed using the modified version of the Checklist of Challenging Behaviours (Harris et al., 1994; see appendix B).

Non family carers were excluded, as were familial carers of individuals who had a diagnosis of dementia, or a severe or profound ID.

(INSERT TABLE 1 HERE)

Despite considerable and prolonged efforts to achieve a larger sample size, there were significant difficulties associated with the recruitment of participants (as fully explained in the amended proposal, appendix L). Furthermore, as participants were approached by professionals independent to the research, the exact number of individuals advised of the study is unknown. To the authors' knowledge, from returned consent forms and/or information from professionals, 13 family carers expressed an interest in the study. However, one carer was un-contactable, one did not meet inclusion criteria and a further three consented to participate but subsequently withdrew due to adverse personal circumstances.

### ***Materials***

Demographic Information Sheet: Details of participants' age, gender, marital status, and relationship to the individual with ID (e.g. mother) were obtained. Information on the age, gender and diagnosis (if known) of the participants' relative was also gathered. A copy of this form is provided in appendix C.

Semi structured interview concerning the nature of interpersonal perceptions held by participants and their desired actions at the time: This interview was adapted from a rational emotive behaviour therapy format (Trower et al., 1988) and was designed to elicit emotions experienced in a recent situation of conflict and the interpersonal appraisals which followed. Participants were initially asked to describe an incident of aggression involving themselves and their relative that still had a clear emotional trace, or still evoked unease when they thought about it. They were then asked to describe the incident from beginning to end, paying particular attention to how they had felt at the time. Once their key emotional responses were identified, participants were asked to keep in mind their feelings when answering open ended questions about (1) how they felt their relative was treating them at the time; (2) their perceptions of their relative at the time of the incident; (3) how they had wanted to react to their relative at

the time; (4) what had stopped them acting in that way; (5) their actual response; and (6) why they had chosen to react that way. By asking participants to keep in mind the key emotions they experienced during the event, it was hoped their responses would reflect their more immediate emotive views held at the time, rather than their cold reflections about the incident. This interview was previously employed by Wanless and Jahoda (2002) and is shown in appendix D.

Rating scales relating to Weiner's model: Following the interview, participants completed a modified version of the Attributional Style Questionnaire (Peterson et al., 1982; previously developed by Dagnan et al., 1998). They were asked to choose the most likely cause of the incident discussed during the interview and to rate their attributions of this cause on a 7 point bipolar scale for stability and controllability. A series of ratings were also obtained regarding participants' optimism for the possibility of change; their willingness to provide extra help and their emotional response to the CB. Participants were also asked to rate the behaviour of their relative during the incident, from 'completely neutral' to 'extremely bad'. An evaluation of the relative was scored in a similar way. Cronbach's alpha coefficients for both key attributions measured by the Attributional Style Questionnaire and both key emotional responses measured by the rating scale were previously calculated by Armstrong and Dagnan (2011). Coefficients ranged from 0.56 to 0.81. Although some coefficients are relatively low, this may be a result of the small number of items used by Armstrong and Dagnan (2011) to calculate the values. A copy of the questionnaire and rating scales is presented in appendix E.

### ***Research Procedure***

Research and development management approval was obtained from the following health boards: NHS Glasgow and Clyde; NHS Ayrshire and Arran; and NHS Lanarkshire. Ethical approval was granted by the University of Glasgow, the West of Scotland Research Ethics Committee and Glasgow Social Work Services. Copies of approval letters are in appendices F, G, H and I. Family carers were identified by health, social work and voluntary agency professionals, who provided potential participants with information packs. These individuals were then contacted by the researcher (having provided verbal consent to the professional for this initial contact) to answer any

questions they had. A modified version of the Checklist of Challenging Behaviours (Harris et al., 1994) was administered during this initial telephone conversation, in order to ensure their relative engaged in frequent, aggressive CB. Informed consent was subsequently obtained from each participant who met inclusion criteria and chose to take part in the study. The participant information sheet and consent form are shown in appendices J and K.

All participants elected to meet in person, at a time and place convenient to them. Due to the emotive content of the interview, time was initially spent developing rapport with participants and effort was made by the researcher to ensure that they felt at ease. Demographic information was gathered prior to conducting the semi structured interview. Participants quickly engaged with the subject matter and appeared keen to discuss their experiences. The complex nature of the interpersonal relationships participants have with their relatives became immediately apparent and is reflected in the data presented below. Completion of the interview and rating scales took between 60 – 90 minutes. Time was spent at the end of the interview talking more broadly about their relative (not solely focused on incidents of CB), with participants often describing their relatives' positive characteristics and recalling fond memories. As participation in the study involved discussing a sensitive subject, care was taken to ensure participants were fully debriefed before leaving. It was also agreed that, following completion of the study, an accessible summary of the outcome would be sent out to all those who took part.

### **Data Analysis**

Descriptive statistics relating to key elements of Weiner's Attributional Model of Helping Behaviour (1992) were produced, illustrating participants' global attributions; emotional responses; optimism for change; willingness to help and interpersonal appraisals. These elements were measured by the Attributional Style Questionnaire and other rating scales, discussed above. The qualitative data were then analysed using a content analysis approach detailed below.

Content analysis is often used to analyse verbal and written communication. Its goal is to "provide knowledge and understanding of the phenomenon under study" (Downe –

Wamboldt, 1992) and has been described as a systematic method of depicting and quantifying experiences (Krippendorff, 1980). This study adopted a conventional content analysis approach (Hsieh and Shannon, 2005). In this method, information is gathered from participants without imposing preconceived categories or theoretical perspectives (Kondracki and Wellman, 2002). Rather, the categories and their names flow from the data. Therefore, any knowledge generated is based upon “participants’ unique perspectives and grounded in the actual data” (Hsieh and Shannon, 2005). This approach was thought to be the most appropriate method of categorising the experiences reported by family carers of relatives who have ID and display CB because there is no existing data that could have been used to develop a relevant coding system.

### ***Development of Content Analysis Coding Framework for Interpersonal Interviews***

The structure of the interview schedule was used as a framework for analysis. Relevant interview sections relating to participants’ responses to the key questions were transcribed verbatim. Specifically their descriptions of: (i) the recalled incident of CB; (ii) their emotional responses experienced during the incident; (iii) how they felt their relative was treating them at the time; (iv) how they perceived their relative at the time; (v) how they had wanted to react to their relative at the time; (vi) what had stopped them acting in that way; (vii) how they did react to their relative at the time; and (viii) why they reacted in that way.

Pseudonyms were assigned to participants and identifying information, such as references to places and other people, were removed or anonymised. To accurately convey participants’ emotional responses their actual words were used where possible, although profanity has been censored. The symbols described below should assist in understanding the illustrative quotes.

... Words omitted to shorten quote

CAPS Illustrates when a participant raised their voice

[text] Explanatory information included by author

[name] Pseudonym of participant providing the quote

The researcher repeatedly read transcriptions for data pertaining to each question in order to achieve immersion and obtain a sense of the data as a whole. Codes were taken from exact words in the text that appeared to capture key concepts before categories were derived from the data and named using content – characteristic words (Hsieh and Shannon, 2005). Identified categories are patterns or themes that were expressed within the data for each question or were derived from them through analysis and interpretation. Emergent categories and relevant verbatim quotes were collated and given a descriptive label. This process was repeated for each question and the overall categories for each question were compared and integrated. The final categories are described in the following sections and illustrated with quotes.

### ***Reliability of Coding Framework***

To assess the reliability of the coding framework a subset of quotes were analysed by a second rater (a fellow Trainee Clinical Psychologist) who was experienced in qualitative research. In total 30 quotes pertaining to the responses of four participants across 15 categories were successfully matched to the coding framework giving an inter-rater agreement of 100%.

### **Results**

Data from the quantitative measures relating to key aspects of Weiner’s Attributional Model of Helping Behaviour (1992) will be presented initially. This will be followed by findings from the semi-structured interview. The qualitative data are essentially descriptive with quotes used to illustrate the categories of responses that emerged. Several participants’ responses to two questions asked during the interview came under more than one category and are identified as such. Finally, as the complex views expressed by participants were only captured by looking across the different responses they gave, two case studies will be presented in order to illustrate the complexity of familial carers’ responses to CB.

### ***Descriptive Quantitative Analysis***

#### ***(i) Attributions about the cause of the behaviour***

The most frequent rating of perceived control over the cause of the behaviour was ‘1 = not at all under relative’s control’ (n = 6), with the remaining two participants’ ratings

also being towards the lower end of the scale. The most frequent rating of perceived stability of the cause of the CB was '7 = always for the same reason' (n = 4). A further two participants also rated their perceived stability towards the higher end of the scale whereas the remaining two participants rated their perceived stability at '1 = never for the same reason'.

### ***(ii) Emotional Responses***

Ratings of emotional responses were obtained from all but one participant who was unable to identify experiencing any emotions at the time of the recalled incident. Participants ratings of the level of anger they experienced fell across the entire range of the 7 point scale, '1 = not at all angry' to '7 = extremely angry', with four of participants' ratings being towards the lower end of the scale and three being at the higher end of the scale. Three participants rated their level of sympathy as '7 = extremely sympathetic', with the remaining participants' ratings being grouped around the middle of the scale.

### ***(iii) Optimism for Change***

The majority of participants (n = 5) selected '1 = strongly agree' in response to the statement that *[their relative] will always have this behaviour now they have developed it*'. The remaining participants' ratings were grouped towards the higher end of the scale indicating that they disagreed with the statement. Participants' level of agreement with the statement that their *'relative's CB was resistant to treatment'* ranged across the whole scale, with three participants selecting '1 = strongly agree' with the statement, two selecting '7 = strongly disagree' with the statement and the remaining participants' ratings being grouped around the middle of the scale.

### ***(iv) Willingness to Help***

All eight participants indicated they were willing to offer '1 = as much extra effort as possible' to help their relative at the time of the incident.

### ***(v) Appraisal of the Behaviour and the Person***

The most frequent rating of participants' interpersonal appraisal of the CB was '7 = extremely bad' (n = 5), with the remaining three participants' ratings being grouped towards the top end of the scale, indicating a perception that the CB was bad, although

not extremely so. The most frequent rating of participants' perception of their relative as a person at the time of the incident was '1 = not at all bad' (n = 4), with only one participant rating their relative as '7 = extremely bad' at the time of the incident. The remaining three participants' ratings were grouped towards the lower end of the scale.

### ***Descriptive Data from the Content Analysis of the Semi-Structured Interviews***

#### ***(i) Recalled Incident of Challenging Behaviour***

Participants were initially asked to recall and describe a recent situation where their relative engaged in aggressive CB. As shown in table 2.1, they reported four types of situations.

(INSERT TABLE 2.1 HERE)

Two participants who described incidents of serious physical aggression were categorised as 'Physical Aggression Towards Participant'. An example quote from this category is:

*"She just lunged for me and literally just grabbed me by the hair and literally pulled out a full handful of hair. But wouldn't let me go ... [she] grabbed my glasses, took my glasses off – flung them. Grabbed me by the hair and put me down onto the bed."* [Laura]

A further two participants recalled incidents of serious verbal aggression and were categorised as 'Verbal Aggression Towards Participant'. One participant described her relative as cursing and shouting at her:

*"[he] started kicking off. In terms of shouting ... swearing at me, middle finger held up, right in front of my face...He told me to 'F\*\*\* off' and 'I'm not going to F\*\*\*ing do this' and 'I F\*\*\*ing hate you'."* [Elaine]

Three of the eight participants recalled incidents involving both serious verbal and physical aggression and were categorised as 'Verbal and Physical Aggression Towards Participant'. One participant described an incident that resulted in serious injury to herself:

*“...I was performing all sorts of tasks for him while getting hit, punched, screamed at ... I ended up with a dislocated shoulder” [Emily]*

The remaining participant described an incident of verbal aggression that she felt was not aimed at her directly and was categorised as ‘Verbal Aggression within Environment’.

*“...then all I heard was something like ‘NO NO NO!’ and I’m saying ‘What?’, so I looked at the television [seeing what daughter was reacting to]. She went absolutely squealing mad.” [Jennifer]*

### ***(ii) Caregivers’ emotional responses***

During the interview, participants were asked about their emotional response to the incident they had described. Two categories were identified: ‘Detached / Habituated’ (n = 2) and ‘Mixed’ (n = 6). Participants who were unable to identify the experience of any emotional responses at the time of the incident were categorised as ‘Detached / Habituated’. One participant stated that, upon reflection, detachment from her emotions helped her cope with the prolonged incident of CB:

*“[During the incident] I became totally detached from myself in so many ways ... But what they [professionals] had explained – it was actually a way to prevent mental illness on my part, by having such a controlled self... It was a strategy I had put in place to keep myself functioning” [Emily]*

Participants who reported several negative emotional responses that were both internally directed (e.g. helpless) and externally directed (e.g. anger) were categorised as ‘Mixed’. The following quote illustrates a participant’s experience of not only anger in response to the CB, but also disappointment:

*“I felt ‘fit to be tied’ [angry] ... it breaks your heart that your daughter is calling you ‘you F\*\*\*’ ... your heart just sinks ... I hate her. I hate every bone in her body. I hate every word that comes out her mouth ... And that’s terrible to hate your own daughter, but that’s the way she gets you sometimes.” [Naomi]*

### ***(iii) Caregivers' perceptions of how they were being treated by their relative***

Participants were asked how they felt they were being treated by their relative at the time of the recalled incident. As shown in table 2.2, four categories emerged from their responses.

(INSERT TABLE 2.2 HERE)

Three caregivers who believed the sacrifices they have made as a result of their caring role were not recognised or not valued by their relative were categorised as 'Underappreciated'. One participant described ruminating over the sacrifices she had made during the incident of CB:

*"...I've changed my entire life for this boy, you know. I've given up my job, career, my income to stay at home and look after him you know. I didn't really have a choice in that, you know. But all that goes through the back of my head when [son engaged in CB]. Obviously I'm thinking, you know: come on. Get a grip here!" [Elaine]*

Two participants who described feeling that their relative was treating them as a lesser person and they felt as if they were only there to serve their relative were categorised as 'Servant'. An example quote illustrating this category is:

*"For all intents and purposes I had to kinda put on this mask of 'yay!' I mean I was a robot. I was there only to perform all sorts of tasks for him" [Emily]*

As shown in table 2.2 above, two participants reported that their relative was treating them the same way they treated others and were categorised as 'Indiscriminate'. This is illustrated in the following quote: *"I don't think its personal, cause that's what she does with everybody" [Vanessa].* The remaining participant, categorised as 'Targeted', expressed the belief that she was always the target of her daughter's CB: *"It's always me. She doesn't have that reaction to my husband. It's always me" [Patricia].*

#### ***(iv) Caregivers' perceptions of the individual***

Participants were also asked about their perceptions of their relative at the time of the recalled incident. As shown in table 2.3, their answers fell into five categories, with all participants' responses falling into more than one category.

(INSERT TABLE 2.3 HERE)

One of the seven participants who believed that her relative was not in control at the time of the incident (and was categorised as 'out of control') attributed this to an impairment in his brain:

*"He's out of control ... but I don't think he means or wants to hurt me. But when he is in that sort of mode, he's just out of control. He's very aggressive when he's like that. Erm, just out of control really. Violent, aggressive er, just out of control really. It's an imbalance of neurotransmitters in his brain basically, it is like someone who's got depression or in his case, it's just uncontrolled outbursts of aggression ... I don't think he is capable of reversing that until it's run its course."* [Elaine]

Only one participant expressed the belief that her relative was deliberately creating the incident and was categorised as such. The quote illustrating this category is:

*"All she was wanting was for somebody to give her an excuse to kick off... She knows when she's doing it ... I don't think it is repetitive because she's learnt it. It's repetitive because she ken [knows] what's gonna happen at the end of it. And we all do that."* [Laura]

Half of the participants reported beliefs that their relative was not like others and were therefore categorised as 'Different'. An example quote from this category is:

*"Because I just wanted him to stop and behave like a normal human being. And I know that he can't"* [Elaine]

Three participants' described their relative's behaviour as typical for the individual and appeared resigned to their belief that this behaviour would be a permanent feature (categorised as 'Engaging in Typical Behaviour'). An example quote from this category is: *"That is our life now. We don't even think about it ... [the CB] is part of her"* [Patricia].

Three participants described perceiving their relative as a 'good person' at the time of the incident (and were categorised as such), with one participant highlighting that her relative had not intentionally hurt her:

*"She's not aggressive. She didn't hit, like come up and deliberately hit me ... It's not her fault. It's because of her learning disability"* [Vanessa]

#### **(v) Desired Action**

Participants were asked what they had wanted to do in response to these emotive situations. As shown in table 2.4, their answers fell into five categories with six participants' responses falling into more than one category.

(INSERT TABLE 2.4 HERE)

Three carers' responses expressed a desire to leave the family home and not return, and were categorised as 'Leave the Situation Permanently'. An example quote from this category is:

*"I feel I could just walk away. And not come back. And actually sometimes feel, when you're exhausted and you've had a week of that and think you know what? I could just get my coat on and walk out and not come back"* [Vanessa]

Three participants described a yearning to call someone who could help to manage their relative's behaviour. These responses were categorised as 'Call Someone for Help'. One participant believed that having access to an external source of support during the incident of CB would be helpful:

*"I'd love a phone number, for when you cannae manage it. Instead of it lasting for an hour or so ... I'd like a phone number where I can say, 'look, can you come out' ... I know anybody (not close family member) walking in that door would make a difference" [Jennifer]*

Those who expressed the desire to have their relative relocated and cared for away from the family home were categorised as 'Send Away'. An example quote from this category is:

*"Honestly, if there had been some place that I could have taken her up and said 'I don't want her any more. I've had it and I can't take anymore of this' I would have done it there and then ... And if there had been any place for her to go, I'd have had her put out the house." [Patricia]*

Two participants said they had initially thought about harming their relative and were categorised as 'Harm Individual'. Both quotes are provided below. Emily described feeling unable to cope anymore and thought, momentarily, that her only remaining option was to take the life of her son and herself. Her description of what she said to a professional at the time of the incident is given below. This is followed by Patricia's description of her desired response to her daughter's CB.

*"[my son] and I are better off not in this world anymore. I said it had got to the point I can no longer support him. And both him and I are a burden ... I had really thought, how am I going to plan this now? Cause I thought, I need to do it in a way that I'm not going to hurt my family ... But that's how bad it had got." [Emily]*

*"I wanted to kill her. I WANTED TO KILL HER! I could have very easily drawn my hand and landed her at the other end of the room." [Patricia]*

Finally, three participants talked about wanting a solution that would 'fix' the difficulties and were categorised as such. One participant, who had previously worked in institutions for adults with ID, described the use of medication to calm individuals down when they were at danger of harming themselves or another person and recalled thinking *"...I wish I had something like that to use"* [Elaine] at the time of the incident.

***(vi) Reasons participants gave for not following desired action***

Participants were then asked why they had not acted in the manner that they desired. As shown in table 2.5 below, their responses fell into five categories.

(INSERT TABLE 2.5 HERE)

Three participants described an overwhelming sense of responsibility for their relative and their responses were categorised as ‘Responsibility’. One participant whose response fell into this category highlighted a belief that there is no one else who they could rely on:

*“She needs you, she depends on you for everything ... there must be the common sense part of your brain saying that you can’t do that. Because you know she needs you. So you’ve got to be there for her. There’s nobody else.” [Vanessa]*

Another two participants explained that they did not follow through on their desired action as the ‘lack of resources’ made the desired response impossible. For example, one participant who wanted to send her relative away explained that *“There is nowhere for her to go”* [Patricia].

Following her phone call to services expressing her difficulty in coping, Emily received support from services and therefore did not need to follow through on their desired response. She was therefore categorised as ‘received support’. As shown in table 2.5, the other reasons provided by participants for not following through on their desired actions included a belief that it would exacerbate the situation (categorised as ‘It would make it worse’) and their own feelings of guilt about their relative’s situation.

***(vii) Behavioural Response***

Participants were asked to describe the action taken at the time of the incident and three categories emerged from their responses, as shown in table 2.6 below.

(INSERT TABLE 2.6 HERE)

As shown in the above table, over half the participants reported using 'passive strategies' in response to their relatives' CB. One participant described leaving her home temporarily until she herself had calmed down:

*"I had to walk away from it ... At that point I had to just walk away for five minutes, go out into the garden and calm down."* [Elaine]

Two participants who responded with a physical intervention were categorised as 'Physical Action'. An example quote from this category is:

*"I did eventually have to grab her wrist and twist it to get her to let go. Which to be quite honest, I'm not trained in any stuff like that ... I did literally have to hurt her to get her off of me..."* [Laura]

The remaining participant reported contacting professional services for assistance and was categorised as 'Contacted Services'.

#### ***(viii) Reasons participants gave for responding in the manner they described***

Finally, participants were asked why they had responded to their relative's CB in the manner that they described. As shown in table 2.7, four categories emerged from participants' responses.

(INSERT TABLE 2.7 HERE)

Three participants who explained they had responded in the same manner that they normally do in similar situations were categorised as 'Routine Response'. An example quote from this category is: *"I think you're just in that routine of doing it now"* [Vanessa]. Two participants who described trying to protect their relative from harming themselves were categorised as 'Protective'. An example quote from this category is:

*"I was feart [afraid] she would bump into something or break it and cut herself"* [Jennifer]

Two participants who described feeling as though they had no other choice were categorised as 'Last Resort', with one participant describing it as *"The final straw came"* [Emily]. The final category was following 'Professional Advice': *"It's what the psychologist says to do"* [Naomi].

### ***Case Illustrations***

Although answers to particular questions revealed the range of interpersonal perceptions, emotions, actions and attributions described by participants, the descriptive data does not illustrate the overall pattern of responses. The following case illustrations are therefore presented to offer insight into the interpersonal relationships familial carers have with their relatives. They are also intended to highlight the complex and conflicting views that were expressed by participants across their responses.

### ***Sinead***

Sinead is a 58 year old woman with a 25 year old son. Her son has a moderate ID, a diagnosis of Autism and frequently engages in both verbally and physically aggressive behaviours that are challenging to manage. During the interview, Sinead recalled a recent incident where her son became aggressive after she *"...didn't do EXACTLY what he [wanted]"*. Similar to other participants, Sinead's anger, although understandable in the circumstances, appears to have been difficult for her to acknowledge.

*"Frustration. Just sheer frustration. It's not anger. It's just sheer 'oh here we go again. I can't stand this anymore' ... It is totally and utterly helpless. It's very stressful. It's not happy at times ... It's more frustration, it's more – okay! I get angry. And I lost my temper ... but I would never physically, do you know what I mean, I'd never physically [hurt him]."*

A common observation made during the interviews was that the majority of participants initially denied feelings of anger or fear in response to their relatives' behaviours, preferring instead to describe them as frustration or anxiety. It was only after time was spent focusing upon their immediate responses at the time of the conflict, that the majority of carers acknowledged that they felt angry at or frightened of their relative. Participants' initial difficulty with describing these feelings may have been due

to a desire to portray their experiences in a socially desirable way. It could be argued that it is not 'socially acceptable' to express anger at a relative who is perceived as vulnerable and it was only after participants became comfortable with the researcher that they felt able to acknowledge these emotions.

Like many participants' expressions of anger, Sinead's feelings in response to her son's CB are understandable in light of her views about how she felt she was being treated by him at the time:

*"Nobody can stand that. It's mental torture ... He's the boss and I'm [the servant]. You know that's basically it. I am there for the sole purpose of being there with [son] you know. Erm, I'm not his mum as such. I'm there to look after him. And er, entertain him. And I'm just a sounding board as well ... I'm just the ears to listen and you're supposed to show interest all the time. You can't talk back because you've not to interrupt ... He's driving us [Sinead and her husband] insane. But I just want to wrap [son] up in cotton wool and shove him back up ... just protect him from everything ... The things he can do. He's amazing. Absolutely, he's brilliant. He should be running with the blooming torch instead of these blooming coco-cola folk [at the time of interview the Olympic torch was travelling through Scotland] ... And he's got the most fantastic wicked sense of humour. Cause I'm going on about the negative here. But ... he really is the most funny, brilliant person."*

Despite Sinead's appraisal of being treated as a servant at the time of the incident and her description of the CB as akin to 'mental torture', she goes on to express an overwhelming desire to protect her son. This pattern of experiencing both negative emotions and interpersonal perceptions, whilst maintaining love and compassion for their relative was evident in the narratives of many participants. In fact their experience of polar opposite emotional responses may help us to understand the differences between participants' desired responses and their undertaken responses.

*"I just wish he wasn't like that. I wish I could make him better, you know? Erm. I made him. I made a mistake somewhere, you know what I mean? My body's made a mistake somewhere to, erm, produce his problems. And I should be able to make him better. But I can't and that's what gets me ... I just want to escape ... gone through to our bedroom and*

*packed bags ... [I said to my husband] 'Why can't I pack my bags and go?' ... But we are the type of family who just want to get on with it ... This is [mine and my husband's] way of coping - 'oh I'm just getting out of here' you know. And one of us will go out and then back in ... I actually grabbed the car keys and gone out in the car and gone (sic). There is a lay by out in the forest ... that I [stopped in], miles from anywhere and just sit (sic) and scream until I can't talk for three days. Erm, and cry until my eyes are shut ... But then I came home and [my husband and I] had a right bubble between us"*

Therefore, despite experiencing strong negative emotions in response to her son's CB and thoughts about leaving the situation permanently, Sinead's underlying love for her son appears to be one factor that influences her actual response at the time.

### **Patricia**

Patricia is a 61 year old female with a 41 year old daughter who has a moderate ID and a diagnosis of autism. Her daughter also regularly engages in physically aggressive CB. Patricia began the interview by describing an incident where her daughter grabbed her by the hair, pushed her against a wall and slapped her. During this incident, she described feeling a range of emotions:

*"I was pure white ... I. Could. Have. Actually physically killed her ... I actually frightened myself, with the intensity of my, and it sounds stupid, but my hatred towards her. At that moment, everything that she had done wrong in years was all, like tunnelled. And I thought ... I just hate you... then you have all this guilt - 'God how could I hate? I'm a bad person'... then you've got to forgive yourself. But at the time I really resented her."*

As is evident from the above quote, Patricia, like the majority of participants, experienced fear and anger as well as feelings of guilt and shame. In fact, it appears that the acknowledgement of her fear and anger subsequently triggered her sense of guilt and shame. This sense of shame at feeling hatred towards their relative was described by many participants.

Whilst in isolation, the intensity of the emotions expressed by Patricia may appear extreme, they are understandable within the context of the opposing interpersonal

perceptions that she held about her daughter and how she was being treated. Initially Patricia said she thought her daughter was not in control of her behaviour and described her daughter as 'overflowing' with pent up emotions. However, she went on to say that she believed her daughter was intentionally directing the behaviour towards her and was in control of her actions. Many other participants also expressed mixed and contradictory perceptions about their relatives' actions.

*"She had no sense of responsibility or what might happen. You know, just immediate 'woof', you know. Temper explode. It's not even temper... it was emotion that didn't know where to go ... But it's always me. She's got a different reaction to everyone else. She doesn't have that [behaviour] to my husband, it's always me ... It's a funny kind of relationship on her side ... She's hard work. But she's good fun too ... Lots of things make her smile. We couldn't go anywhere without her"*

When describing her emotional responses, Patricia highlighted that she was no longer responding to the current incident but to previous episodes of her daughter's CB also: *"...Everything that she had done wrong in years was all, like tunnelled."* Patricia, like many other participants, also described ruminating over personal sacrifices she had made in order to care for her relative:

*"Ultimately I suppose you sort of think - Do you know I run about? I do all this stuff. I've gave up all of this. What for? THIS?"*

It is within this historical context that her strong, negative emotional responses and initially desired responses need to be understood.

*"Honestly, if there had been some place that I could have taken her up and said 'I don't want her anymore, I've had it, I can't take anymore of this' I would have done it there and then. I would have done it then...if there had been any place for her to go, I'd have had her out the house."*

Whilst, like many participants, Patricia's actual response of leaving the room differed greatly from her desired response, this appears to have been done in order to maintain

self-control. She described holding the door closed not only to prevent her daughter from causing further harm, but also to prevent herself from harming her daughter: *"I'm holding her in, but I'm also holding myself out"*. Thus, despite the strongly negative emotions that Patricia felt towards her daughter at the time, and her initial desire to send her away, her actual response can be seen as a means of protecting her. This again serves to highlight the contradictory emotions held by family carers during a time of significant conflict.

Overall Patricia's responses reaffirm the range of emotions family carers experience in response to their relative's CB and the apparent difficulty they have in acknowledging these emotions. Similarly to Patricia, several other participants described feeling a sense of shame or guilt after acknowledging their experience of anger in response to their relative. It is possible that some family carers believe they are not allowed or not supposed to feel angry at their relative.

When looking across participants' responses in this way, it is clear that their attributions, emotional responses and interpersonal appraisals are complex and often contradictory. Familial carers' emotional responses appear to be related not only to the CB they are faced with, but also to their interpersonal perceptions held about their relative. Moreover, their interpersonal appraisals appear to be inextricably linked with their relationship history.

## **Discussion**

An important observation from this study is the difference between data gathered from the quantitative measures and data from the qualitative interview. For example, when rating their emotional responses on the quantitative measure, half the participants' ratings suggested that they had experienced little or no anger at the time of the incident. In contrast, participants' responses during the interview indicated that all but two participants experienced high levels of anger, as well as describing other emotions at the time of the recalled incident. There was also a striking difference between participants' appraisals of their relative on the quantitative measure and the perceptions they described during the interview. The majority of participants rated their relative as 'not at all bad'. However, during the interview, only three participants

described viewing their relative as a 'good person' at the time of the incident, with the majority feeling that they had been treated badly. Therefore, it appears that participants' quantitative ratings failed to capture the complexity and variation in familial carers' responses to their relative's CB.

The modified Attributional Style Questionnaire (Peterson et al., 1982) and the other rating scales employed in the study were initially used by Dagnan et al. (1998) and then Wanless and Jahoda (2002), in studies aiming to examine the applicability of Weiner's model to the care staff population. The quantitative measures therefore focus on and, it might be argued, are limited by key elements of the Attributional Model of Helping Behaviour (Weiner, 1992). The semi structured interview employed in the present study was however specifically designed to elicit the emotional and interpersonal responses experienced by family carers and did not impose any constraints on participants' responses. The majority of studies that have examined carers' responses to CB, displayed by those with ID, have employed the same quantitative measures (Dagnan, 2012; Willner and Smith, 2008b; Dagnan and Cairns, 2005; Rose and Rose, 2005; Hill and Dagnan, 2002 and Stanley and Standen, 2000). It might be argued that this past research has, inadvertently, imposed constrictions on participants' responses. In the present study, these restrictions were explicitly acknowledged by one participant, who, when completing the quantitative measures, stated: *"The questions are black and white, but the answers aren't"* [Elaine].

The findings from the present study point to two significant limitations of Weiner's Attributional Model of Helping Behaviour (1992) when attempting to understand familial carers' responses to their relatives' CB. Firstly, the model restricts carers' emotions to only anger or sympathy. However, the majority of participants in the present study were found to experience a wide range of emotions in response to CB and a minority appeared to detach or be habituated to incidents. These findings are consistent with previous research (eg Mitchell and Hastings, 1998; Bailey et al., 2006). Secondly, Weiner's model does not account for the context of interpersonal relationships and the influence they can have upon carers' responses. The complexity of interpersonal appraisals made by participants in the semi-structured interview and the readiness with which they could recall them, serve to highlight the fact that familial

carers are not detached individuals responding objectively to a situation. These findings are consistent with previous research which has highlighted the importance of accounting for interpersonal dynamics when interpreting carers' responses to CB within an existing caring relationship (Drysdale et al., 2009; Jahoda and Wanless, 2005).

### **Strengths and Limitations**

This study is the first to explore the interpersonal perceptions made by familial carers' during incidents of CB exhibited by their relative. One of the key strengths of the study was the use of a semi-structured interview to elicit the emotive responses of carers when recalling real incidents of CB displayed by their relative. As mentioned earlier, research has typically relied upon participants' responses to vignettes (eg Armstrong and Dagnan, 2011), which are unlikely to evoke similar emotional or interpersonal reactions to those experienced by carers during real incidents. Thus the responses provided by participants in this study are possibly more reflective of carers' immediate responses. Furthermore, the participants were able to describe, in detail, their complex and often contradictory responses outwith the constraints of Weiner's Attributional Model of Helping Behaviour (1992).

As detailed in the research proposal and amendment (appendix L), it was originally planned that 21 participants would be recruited for a mixed methods study. It was intended that qualitative data would enable exploration of caregivers' interpersonal perceptions, emotional and cognitive responses during incidents of CB, whereas data from the quantitative measures would be used to obtain correlational data, allowing for the exploration of the applicability of Weiner's Attributional Model of Helping Behaviour (1992). Unfortunately difficulties with recruitment of participants meant that the data did not lend itself to the original design and intended analysis. Upon reflection, there were two main barriers to the recruitment of participants for this study. Firstly, several caregivers who were provided with information about the study did not believe their relative's behaviour was CB, as it only occurred within the family home. Despite assurances from the professionals advising them of the study, these caregivers were unwavering in their belief and did not see themselves as suitable for the study. Secondly, during the recruitment process an issue of 'gate keeping' by staff

became apparent. From discussion with professionals in the services approached, it appears that when considering possible participants, they held beliefs that certain carers would not participate, or that their situation was too challenging / difficult and participation in research would not be appropriate. Thus these family caregivers were never advised about the study.

Another limitation of the present study is that, although designed to evoke the responses experienced at the time, it is likely that some of the participants' thoughts, emotions and appraisals were developed after the event. Future research could use experiential sampling techniques, with a shorter time lag between incidents and obtaining participant reports, thereby gaining greater insight into their more immediate responses (Burke and Franzoi, 1988).

### **Implications for future research and clinical practice**

The complex nature of familial carers' responses to their relative's CB has important implications for clinicians providing support. Some family carers may habituate to their relative's CB and may therefore be unaware of their emotional responses at the time these incidents. Other family carers may be initially reluctant to openly acknowledge their true emotional responses to professionals. They may worry about the possibility of being judged or feel it is not acceptable to express, or even to feel, negative emotions such as anger towards a vulnerable individual. It is therefore important that professionals working with this population remain cognisant of these possibilities and take time to establish a relationship with carers in which difficult emotions can be acknowledged openly and discussed.

The interpersonal and emotional dimensions of familial caregivers' responses also have a significant impact upon the interventions suggested by professionals. Currently recommended guidelines for managing an individual's CB are often derived from applied behavioural analysis and typically require the carer to act as an objective observer (e.g. implementing planned ignoring). However, the findings from the present study highlight that family carers may struggle to implement guidelines as a detached individual when it concerns their daughter / son or brother /sister, with whom they

have a lifelong relationship. Further research exploring family carers' ability to implement guidelines in a detached and objective manner would be warranted.

Furthermore, recent research by Zijlmans et al. (2012) found that CB can be inadvertently maintained not only by a carer's behavioural response, as mentioned earlier, but also by their interpersonal behavioural style (i.e. whether their helping behaviour is friendly, neutral or hostile in nature). Therefore, CB can be maintained by both a carer's actions *and* the way they implement those actions. This is important when considering the way in which several participants in the current study described employing passive strategies. For example, prior to walking away from the incident, one participant reported telling her daughter to "*Just go away.*" [Jennifer]. Thus although she did leave the situation (a passive response) her interpersonal behavioural style may not have been experienced as passive or neutral by her daughter and may have subsequently maintained the CB. It may be that familial carers, like Jennifer, are unaware of their interpersonal style during these highly emotive incidents and are focused on *what* they do rather than *how* it is done. Interventions that aim to support family caregivers become more aware of their interpersonal behavioural style during incidents of CB may therefore prove helpful. Previously mindfulness based approaches have been successfully used with care staff and ultimately helped them deal more effectively with aggression (Singh et al., 2006). It would be interesting to explore whether a similar approach could help family carers better manage incidents of CB.

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**Table 1:** Characteristics of participants and their relatives

Variable	Laura (52)	Naomi (45)	Patricia (61)	Jennifer (not provided)	Sinead (58)	Emily (43)	Vanessa (53)	Elaine (48)
<b>Marital Status</b>	Partner	Married	Married	Married	Married	Married	Married	Divorced / Partner
<b>Relationship to relative</b>	Sister	Mother	Mother	Mother	Mother	Mother	Mother	Mother
<b>Does carer reside with relative</b>	Resides apart	Resides with	Resides with	Resides with	Resides with	Resides apart	Resides with	Resides with
<b>Relative's age</b>	43 yrs	19 yrs	41 yrs	21 yrs	25 yrs	18 yrs	20 yrs	20 yrs
<b>Relative's gender</b>	Female	Female	Female	Female	Male	Male	Female	Male
<b>Severity of LD</b>	Mild	Moderate	Moderate	Mild	Moderate	Mild	Mild – moderate	Mild – moderate
<b>Any known diagnosis</b>	Epilepsy	ASD**	ASD**	N/A	ASD**	ASD**	Epilepsy	ASD**
<b>Type of aggressive CB</b>	Physically aggressive	Both verbally & physically aggressive	Physically aggressive	Both verbally & physically aggressive	Both verbally & physically aggressive	Both verbally & physically aggressive	Verbally aggressive	Both verbally & physically aggressive
<b>Frequency of aggressive CB*</b>	Often	Very often	Very often	Very often	Very often	Very often	Very often	Very often
<b>Engagement in other topography of CB</b>	Yes	No	Yes	Yes	No	yes	No	Yes

\* Frequency of aggressive CB as defined by Checklist of Challenging Behaviours (Harris et al., 1994). Often = more than 4 times in past month. Very often = daily or more often

\*\* Autistic Spectrum Disorder

**Table 2.1:** Recalled incidents of aggressive challenging behaviour

<b>Nature of Incident Recalled</b>	<b>Definition of Category</b>	<b>n</b>
Physical Aggression Towards Participant	Individual engaged in serious physical aggression directed at the participant	2
Verbal Aggression Towards Participant	Individual engaged in serious verbal aggression directed at the participant	2
Verbal & Physical Aggression Towards Participant	Individual engaged in both serious verbal and physical aggression directed at the participant	3
Verbal Aggression within Environment	Individual engaged in verbal aggression that was NOT directed at the participant but rather towards an environmental stimuli	1

**Table 2.2:** Participants' perceptions of how relatives were treating them

<b>Perceptions of treatment by relative</b>	<b>Definition of the Category</b>	<b>n</b>
Underappreciated	Beliefs that their sacrifices and changes in life as a result of their caring role are not recognised or appreciated by the individual	3
Targeted	Belief that the individual only engaged in such behaviour in response to themselves and it was therefore personal	1
Indiscriminate	Belief that the individual was not treating them a particular way as this is how they were with others	2
Servant	Perception that individual was treating them as someone who was purely there for them	2

**Table 2.3:** Participants' perceptions of their relative

<b>Caregivers' perceptions of their relatives</b>	<b>Definition of Category</b>	<b>n*</b>
Out of Control	Belief that the client was out of control	7
Deliberately Creating Incident	Belief that their relative was deliberately creating the incident	1
Different	Perception that the individual is not like others	4
Engaging in Typical Behaviour	Perception that the individual was doing what they normally do and is unlikely to change in the future	3
Good Person	Belief that the individual was ultimately good	3

\*n > 8 as all participants produced more than one category of response

**Table 2.4:** How participants desired to respond in the situation

<b>Desired responses</b>	<b>Definition of the Category</b>	<b>n*</b>
Leave the situation permanently	Participants expressed the desire (experienced in the moment) to leave the home and not return	3
Call someone for help	Participants expressed a wanting for someone to call who could help	3
Send away	Participants expressed the desire to have the individual placed and cared for away from the home	3
Harm Individual	Participants initially thought about harming their relative	2
Fix	Participants expressed a wanting for a solution that did not exist that would 'fix' the difficulties	3

\*n > 8 as six participants produced more than one category of response

**Table 2.5:** Participants' reasons for not acting in the desired manner

<b>Reason for not acting</b>	<b>Definition of Category</b>	<b>n</b>
Received Support	Participant received support and access to services which supported them and therefore did not need to follow through on desired response	1
Lack of Resources	The lack of resources and available others prevented them following their initial desired action	2
Responsibility	Carers described an overwhelming sense of responsibility for their relative	3
It would make it worse	Belief that responding with a particular action would make the situation worse	1
Feelings of Guilt	Participant's feelings of guilt regarding the individual's situation prevented them from following through on desired response	1

**Table 2.6:** How participants responded in the situation

<b>Behavioural Response</b>	<b>Definition of Category</b>	<b>n</b>
Physical Action	Participants engaged in physical contact with the individual	2
Passive Strategies	Participants used strategies that did not involve physical contact	5
Contacted Services	Participant contacted professional services for assistance	1

**Table 2.7:** Participants' reasons for responding in their chosen manner

<b>Reasoning for Behavioural Response</b>	<b>Definition of Category</b>	<b>n</b>
Professional Advice	Participants reported engaging in a particular action as it had previously been advised by professionals	1
Protective	Participant was attempting to protect their relative her from acting on their feelings of anger	2
Routine Response	Participants stated they were responding in the way they normally do to similar situations	3
Last Resort	Participant reported feeling as though they had no other choice	2

## CHAPTER 3

### ADVANCED CLINICAL PRACTICE I: REFLECTIVE ACCOUNT

**What is my role in a multi-disciplinary team? And what *actually* makes a team multi-disciplinary?**

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## **Abstract**

Drawing upon Kolb's Learning Cycle (1984) as a frame for my thoughts, I reflect upon my experiences of working within a Multi-Disciplinary Team in a tier 4 service. I explore my initial feelings and confusion in joining the team, and my struggle to find my role within a team of professionals, the majority of whom, are psychologically minded, and undertake psychological assessments and interventions. By referring to the New Ways of Working for Applied Psychologists (BPS, 2007), and reflecting upon the means and importance of the Clinical Psychologist's key role of communication, I explore how I found my role within the team. I also take time to reflect upon my pre-existing belief about what constitutes a multi-disciplinary team. Contemplating both what makes a team multi-disciplinary, but also the impact on professionals when roles are blurred and over-lap regularly as a consequence of trans-disciplinary working. This account has enabled me to develop a greater understanding of the informal ways in which Clinical Psychologists contribute to their teams, and has supported my development and mindful awareness of communication and reflective skills I hope to take with me, and continue to develop during my career.

## CHAPTER 4

### ADVANCED CLINICAL PRACTICE II: REFLECTIVE ACCOUNT

**In anticipation of qualifying: The evolving role of Clinical Psychologists within teams.**

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## **Abstract**

Drawing on Rolfe et al.'s framework for reflective practice (2001) I take the opportunity to reflect on the various ways I have attempted to foster the development of psychological mindedness and formulation in a Community Mental Health Team. I also consider the evolving role of a Clinical Psychologist within such a team, whilst reflecting upon my readiness for these roles. Drawing upon current policies and relevant research, I have been encouraged to reflect upon what I can bring to a team and how I will go about this within my first post as a qualified Clinical Psychologist. This account has enabled me to think about my own future development and consider the way in which I will take the opportunity to continue my professional development once qualified.

## APPENDICES

### Appendix A – Requirements for submission to *Journal of Intellectual Disability Research*

#### 1. GENERAL

*The Journal of Intellectual Disability Research* is devoted exclusively to the scientific study of intellectual disability and publishes papers reporting original observations in this field. The subject matter is broad and includes, but is not restricted to, findings from biological, educational, genetic, medical, psychiatric, psychological and sociological studies, and ethical, philosophical, and legal contributions that increase knowledge on the treatment and prevention of intellectual disability and of associated impairments and disabilities, and/or inform public policy and practice. Such reviews will normally be by invitation. The Journal also publishes Full Reports, Brief Reports, Letters to Editor, and an 'Hypothesis' papers. Submissions for Book Reviews and Announcements are also welcomed.

*The Journal of Intellectual Disability Research* will feature four Annotation articles each year covering a variety of topics of relevance to the main aims of the journal or topics. Senior researchers, academics and clinicians of recognised standing in their field will be invited to write an Annotation for the journal covering an area that will be negotiated with the Associate Editor, Prof. Chris Oliver, on behalf of the Editorial team. Anyone expert in his/her particular field wishing to submit an uninvited review is advised to seek prior guidance from the Associate Editor.

All papers are assessed by expert referees.

Please read the instructions below carefully for details on the submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication in [The Journal of Intellectual Disability Research](#). Authors are encouraged to visit Wiley-[Blackwell's Author Services](#) for further information on the preparation and submission of articles and figures.

#### 2. ETHICAL GUIDELINES

*The Journal of Intellectual Disability Research* adheres to the ethical guidelines for publication and research summarised below.

##### 2.1. Authorship and Acknowledgements

**Authorship:** Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the Journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship and, except in the case of complex large-scale or multi-centre research, the number of authors should not exceed six.

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It is a requirement that all authors have been accredited as appropriate upon submission of the manuscript.

Contributors who do not qualify as authors should be mentioned under Acknowledgements.

**Acknowledgements:** Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interests if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

## 2.2. Ethical Approvals

**Experimental Subjects:** experimentation involving human subjects will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 [www.wma.net/e/policy/b3.htm](http://www.wma.net/e/policy/b3.htm)) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included. Editors reserve the right to reject papers if there are doubts as to whether appropriate procedures have been used.

All studies using human participants or animal subjects should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

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*The Journal of Intellectual Disability Research* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public clinical trials registries: [www.clinicaltrials.gov](http://www.clinicaltrials.gov), [clinicaltrials-dev.ifpma.org/](http://clinicaltrials-dev.ifpma.org/), [isrctn.org/](http://isrctn.org/). The clinical trial registration number and name of the trial register will then be published with the paper.

## 2.4 Conflict of Interest and Source of Funding

**Conflict of Interest:** Authors are required to disclose any possible conflict of interest. These include financial (for example patent, ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflicts of interest) will be published under a separate heading entitled 'Conflict of Interests'.

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If the author does not include a conflict of interest statement in the manuscript then the following statement

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Authors who wish to appeal the decision on their submitted paper may do so by e-mailing the Editorial Office with a detailed explanation for why they find reasons to appeal the decision.

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- If you are creating a new account.
  - After clicking on 'Create Account', enter your name and e-mail information and click 'Next'. Your e-mail information is very important.
  - Enter your institution and address information as appropriate, and then click 'Next.'
  - Enter a user ID and password of your choice (we recommend using your e-mail address as your user ID), and then select your area of expertise. Click 'Finish'.
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- Click the 'Next' button on each screen to save your work and advance to the next screen.
- You are required to upload your files.
  - Click on the 'Browse' button and locate the file on your computer.
  - Select the designation of each file in the drop-down menu next to the Browse button.
  - When you have selected all files you wish to upload, click the 'Upload Files' button.
- Review your submission (in HTML and PDF format) before sending to the Journal. Click the 'Submit' button when you are finished reviewing.

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in the file. Manuscripts should be formatted as described in the Author Guidelines below.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx file as .doc before uploading.

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Please upload:

- Your manuscript without title page under the file designation 'main document'
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After submission you will receive an e-mail to confirm receipt of your manuscript. If you do not receive the confirmation e-mail after 24 hours, please check your e-mail address carefully in the system. If the e-mail address is correct please contact your IT department. The error may be caused by spam filtering software on your e-mail server. Also, the e-mails should be received if the IT department adds our e-mail server (uranus.scholarone.com) to their whitelist.

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**Original Research Article** The main text should proceed through sections of Abstract, Introduction, Methods, Results, and Discussion.

**Full Reports** of up to 4,500 words are suitable for major studies, integrative reviews and presentation of related research projects or longitudinal enquiry of major theoretical and/or empirical conditions.

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Three main types of Annotations will be commissioned: 1. Authoritative reviews of empirical and theoretical literature. 2. Articles proposing a novel or modified theory or model. 3. Articles detailing a critical evaluation and summary of literature pertaining to the treatment of a specific disorder.

**A Hypothesis Paper** can be up to 2,500 words and no more than twenty key references. It aims to outline a significant advance in thinking that is testable and which challenges previously held concepts and theoretical perspectives.

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It is important that the term 'intellectual disabilities' is used when preparing manuscripts.

Please note that 'intellectual disability', as used in the Journal, includes those conditions labelled mental deficiency, mental handicap, learning disability and mental retardation in some countries.

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All manuscripts submitted to *The Journal of Intellectual Disability Research* should include: Title, Keywords, structured Abstract, Main Text (divided by appropriate sub headings) and References.

**Title Page:** Please remember that **peer-review is double-blind**, so that neither authors nor reviewers know each others' identity. Therefore, **no identifying details of the authors or their institutions must appear in the**

**submitted manuscript; author details should be entered as part of the online submission process.** However, a 'Title Page' must be submitted as part of the submission process as a 'Supplementary File Not for Review'. This should contain the title of the paper, names and qualifications of all authors, their affiliations and full mailing address, including e-mail addresses and fax and telephone numbers.

**Keywords:** The author should also provide up to six keywords to aid indexing.

**Abstracts: For full and brief reports a structured summary should be included at the beginning of each article, incorporating the following headings: Background, Method, Results, and Conclusions.** These should outline the questions investigated, the design, essential findings, and the main conclusions of the study.

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The Journal follows the Harvard reference style. 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.

The reference list should be in alphabetical order thus:

- Giblett E.R. (1969) Genetic Markers in Human Blood. Blackwell Scientific Publications, Oxford.
- Moss T.J. & Austin G.E. (1980) Preatherosclerotic lesions in Down's syndrome. *Journal of Mental Deficiency Research* **24**, 137- 41.
- Seltzer M. M. & Krauss M.W. (1994) Aging parents with co-resident adult children: the impact of lifelong caregiving. In: *Life Course Perspectives on Adulthood and Old Age* (eds M. M. Seltzer, M.W. Krauss & M. P. Janicki), pp. 3–18. American Association on Mental Retardation, Washington, DC.

Where more than six authors are listed for a reference please use the first six then 'et al.'

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We recommend the use of a tool such as [EndNote](#) or [Reference Manager](#) for reference management and formatting.

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### 5.4. Tables, Figures and Figure Legends

**Tables:** 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, Table 2, etc., and given a short caption.

**Figures:** All graphs, drawings and photographs are considered figures and should be numbered in sequence with Arabic numerals. All symbols and abbreviations should be clearly explained.

Tables and figures should be referred to in the text together with an indication of their approximate position recorded in the text margin.

## Preparation of Electronic Figures for Publication

Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size (see below). Please submit the data for figures in black and white or submit a Colour Work Agreement Form (see Colour Charges below). EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

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## Appendix B – Checklist of Challenging Behaviour (Harris et al., 1994)

Has this person exhibited any of the following behaviours during the last 3 months?

Key to rating scales

F = Frequency MD = Management difficulty S = Severity

Aggressive Behaviours	Enter Appropriate Numbers		
	F	MD	S
Pinching people?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Biting people?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Scratching people?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Hitting out at people? (i.e. punching or slapping)	<input type="text"/>	<input type="text"/>	<input type="text"/>
Grabbing, squeezing, pushing or pulling people?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Kicking people?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Head-butting people?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pulling people's hair?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Chocking or throttling people?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Using objects as weapons against people (eg knife or other hand held object)	<input type="text"/>	<input type="text"/>	<input type="text"/>
Throwing things at people?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Tearing other people's clothes?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Making unwanted sexual contact?	<input type="text"/>	<input type="text"/>	<input type="text"/>
Injuring self (eg head banging, eye poking/ gouging, biting, or scratching self)?	<input type="text"/>	<input type="text"/>	<input type="text"/>

Does this person exhibit any other type of aggressive behaviour?

Yes 1

No 2

If yes, please describe:

Other challenging behaviours (note: these behaviours are *not* rated for severity)

Enter Approximate Numbers

	F	MD
Damaging clothes, furniture or other objects?	<input type="text"/>	<input type="text"/>
Smashing windows?	<input type="text"/>	<input type="text"/>
Slamming doors?	<input type="text"/>	<input type="text"/>
Shouting and swearing at people?	<input type="text"/>	<input type="text"/>
Making loud noises (eg banging, screeching, screaming)?	<input type="text"/>	<input type="text"/>
Threatening to hurt others (either verbally or non-verbally)?	<input type="text"/>	<input type="text"/>
Taking food or drink from others?	<input type="text"/>	<input type="text"/>
Eating inappropriate things (eg. Rubbish, faeces, dangerous objects)?	<input type="text"/>	<input type="text"/>
Displaying ritualistic or repetitive behaviour (eg closing/opening doors, rearranging furniture, hoarding rubbish etc)?	<input type="text"/>	<input type="text"/>
Engaging in stereotyped behaviour (eg body-rocking, finger tapping, hand waving etc?)	<input type="text"/>	<input type="text"/>
Showing withdrawn behaviour (i.e. difficult to reach or contact)?	<input type="text"/>	<input type="text"/>
Spitting at people?	<input type="text"/>	<input type="text"/>
Deliberately soiling, wetting, or vomiting?	<input type="text"/>	<input type="text"/>
Smearing or flicking faeces (or anal probing)?	<input type="text"/>	<input type="text"/>
Exposing his or her body inappropriately (eg stripping, or masturbating in public)?	<input type="text"/>	<input type="text"/>
Refusing to do things (eg to eat or move)?	<input type="text"/>	<input type="text"/>
Absconding or trying to abscond from facility?	<input type="text"/>	<input type="text"/>
Causing night time disturbance?	<input type="text"/>	<input type="text"/>

Does this person exhibit any other type of challenging behaviour?

Yes 1      No 2

If yes, please describe:

#### FREQUENCY

How often has this behaviour occurred during the past 3 months?

- |                  |   |
|------------------|---|
| 1 = never        | This behaviour has not occurred during the past 3 months    |
| 2 = rarely       | Has occurred during the past 3 months but not in past month |
| 3 = occasionally | 1 – 4 times in past month                                   |
| 4 = often        | more than 4 times in past month                             |
| 5 = very often   | daily or more often   |

#### MANAGEMENT DIFFICULTY

How difficult do you find it to manage this situation?

- |                          |  |
|--------------------------|--|
| 1 = no problem           | I can usually manage this situation without any difficulty at all                  |
| 2 = slight problem       | I can manage this situation quite easily although it does cause me some difficulty |
| 3 = moderated problem    | I find this situation quite difficult to manage, but I feel confident that I can   |
| 4 = considerable problem | I find it very difficult to manage this situation on my own                        |
| 5 = extreme problem      | I simply cannot manage this situation without help                                 |

#### SEVERITY

What were the most serious injuries caused by this behaviour during the past 3 months?

- |                         |   |
|-------------------------|---|
| 1 = no injury           | did not appear to cause pain or tissue damage to other person   |
| 2 = minor injury        | Caused superficial scratching or reddening of the other person's skin (eg light slaps / hits, gentle pushes, hair pulling without force). First aid or medical attention was not needed |
| 3 = moderate injury     | caused moderate tissue damage to other person (eg bites/hits/kicks breaking the skin or resulting in bruising). First aid but not medical attention needed.                             |
| 4 = serious injury      | Caused serious tissue damage (eg cuts/wounds requiring stitching). Medical attention essential  |
| 5 = very serious injury | caused very serious tissues damage (eg bones broken, deep lacerations / wounds). Hospitalisation and / or certified absences from work necessary.                                       |

## Appendix C – Demographic Information Sheet

### PARTICIPANT DEMOGRAPHICS

**Participant number:**

**Age:**

**Gender:**

**Marital Status (please circle):**

Single

Married

Divorced

Separated

Widowed

**Relationship to the individual with a learning disability (please circle):**

Mother

Father

Sister

Brother

Aunt

Uncle

Grandmother

Grandfather

**Family Supports (please circle):**

Extended family

Voluntary Agencies

Social Work

Local CLDT

Other (please specify):

### RELATIVE WITH INTELLECTUAL DISABILITY DEMOGRAPHICS

**Age:**

**Gender:**

**Diagnosis (if known):**

**Severity of Learning Disability:**

## **Appendix D – Semi-Structured Interview**

*Confidentiality*

*Not an easy topic, but an important one*

*There is no right or wrong answers. Want you to talk about your experiences, your point of view.*

*You are the expert who cares for [relative]*

1. When was the last time X behaved aggressively when you were present?
2. Can you describe what happened?
3. At the time, why did you think X was [CB]?
4. What did you think of the behaviour (the CB X was doing) at the time?
5. How did you feel at the time?
6. What do you think made you feel like this?
7. At the time, what did you think of X as a person?
8. How did you feel X was treating you?
9. What did you want to do about X's behaviour at the time?
10. What stopped you from doing this?
11. What did you do about X's behaviour?
12. Why did you choose this form of response?

## Appendix E – Attributional Style Questionnaire and Other Rating Scales

Keeping in mind the incident you have just described, and how it made you feel and react, please complete the following questions:

### What is the most likely reason for X's behaviour?

**Thinking of this reason please show your agreement with the following statements by circling one number.**

1. Is this reason for X's behaviour due to X or due to other people or circumstances?

Is totally due to others 1      2      3      4      5      6      7      Totally due to X

2. If this behaviour happens over a long period of time will it be for the same reason?

Never for the same reason      1      2      3      4      5      6      7      Always for the same reason

3. Does this reason apply to just this situation or all situations in X's life?

Just this situation      1      2      3      4      5      6      7      All situations

4. Is the reason for X's behaviour under X's control?

Not under their control 1      2      3      4      5      6      7      Totally under X's control

### How did this behaviour make you feel? (Circle one number)

Not angry at all      1      2      3      4      5      6      7      Extremely angry

Not happy at all      1      2      3      4      5      6      7      Extremely happy

Not sad at all      1      2      3      4      5      6      7      Extremely sad

Not sympathetic at all 1      2      3      4      5      6      7      Extremely sympathetic

Not frightened at all      1      2      3      4      5      6      7      Extremely frightened

Not disgusted at all      1      2      3      4      5      6      7      Extremely disgusted

Not relaxed at all      1      2      3      4      5      6      7      Extremely relaxed

**How much do you agree with the following statements?**

All one can do for X is look after his basic physical needs

Strongly agree      1      2      3      4      5      6      7      Strongly Disagree

X will always have this behaviour now he has developed it

Strongly agree      1      2      3      4      5      6      7      Strongly Disagree

This type of behaviour is probably so well established that it will not respond to treatment programmes

Strongly agree      1      2      3      4      5      6      7      Strongly Disagree

*Still thinking of the behaviour you have described, can you answer the following questions.*

**Given your experience with this behaviour, how much extra effort would you be prepared to put in to help X**

As much extra effort as possible      1      2      3      4      5      6      7      No extra effort at all

**How bad is X's behaviour?**

It is not bad at all      1      2      3      4      5      6      7      It is totally bad

**How bad is X when he showed this behaviour?**

He is not bad at all      1      2      3      4      5      6      7      He is totally bad

**How responsible do you think X is for the development of this behaviour?**

Totally responsible      1      2      3      4      5      6      7      Not at all responsible

**How responsible do you think other people have been for the development of this behaviour?**

Others are totally responsible      1      2      3      4      5      6      7      Others are not responsible at all

**How responsible is X for any future change in his behaviour?**

He is totally responsible      1      2      3      4      5      6      7      He is not responsible at all

**How responsible are you for future change in this behaviour?**

I am totally responsible      1      2      3      4      5      6      7      I am not responsible at all

## Appendix F – Approval from the University of Glasgow



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

ST/LMcG

11<sup>th</sup> August 2011

Amy McMillan

Dear Amy,

**Doctorate in Clinical Psychology Major Research Project  
What is special about family relationships? Familial attributions and emotional responses to  
relatives who present with challenging behaviour**

The above project has been reviewed by your University Research supervisor and by a member of staff not involved in your project and has now been deemed fit to proceed to ethics.

Congratulations and good luck with the study.

Yours sincerely,

T M McMillan  
Professor of Clinical Neuropsychology  
Programme Director

Doctorate in Clinical Psychology  
Programme Director: Professor Tom McMillan

Academic Unit for Mental Health and Wellbeing  
Admin Building, Gartnavel Royal Hospital  
1055 Great Western Road  
GLASGOW G12 0XH  
Direct line: +44(0) 141 211 3920/0607 Fax: +44(0) 141 211 0356  
Email: [cphs-mentalhealth@glasgow.ac.uk](mailto:cphs-mentalhealth@glasgow.ac.uk)

## Appendix G – Research & Development approval from NHS Greater Glasgow & Clyde, Lanarkshire and Ayrshire & Arran



Coordinator/Administrator: Dr Erica Packard/Mrs Elaine O'Neill  
Telephone Number: 0141 211 6208  
E-Mail: [erica.packard@ggc.scot.nhs.uk](mailto:erica.packard@ggc.scot.nhs.uk)  
Website: [www.nhsggc.org.uk/r&d](http://www.nhsggc.org.uk/r&d)

R&D Management Office  
Western Infirmary  
Tennent Institute  
1st Floor 38 Church Street  
Glasgow, G11 6NT,

4 November 2011

Miss Amy McMillan  
Dept of Mental Health & Wellbeing  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow G12 0XH

### NHS GG&C Board Approval

Dear Miss McMillan,

**Study Title:** What is special about family relationships? Familial attributions and emotional responses to relatives who present with challenging behaviour  
**Principal Investigator:** Miss Amy McMillan  
**GG&C HB site:** NHS GG&C Community  
**Sponsor:** NHS Greater Glasgow and Clyde  
**R&D reference:** GN11CP319  
**REC reference:** 11/WS/0053  
**Protocol no:** V1; 12/08/11  
(including version and date)

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

#### Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
  - a. During the life span of the study GGHB requires the following information relating to this site
    - i. Notification of any potential serious breaches.
    - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy ([www.nhsggc.org.uk/content/default.asp?page=s1411](http://www.nhsggc.org.uk/content/default.asp?page=s1411)), evidence of such training to be filed in the site file.

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Page 1 of 2

R&D Approval GN11CP319

2. **For all studies** the following information is required during their lifespan.
  - a. Recruitment Numbers on a quarterly basis
  - b. Any change of staff named on the original SSI form
  - c. Any amendments – Substantial or Non Substantial
  - d. Notification of Trial/study end including final recruitment figures
  - e. Final Report & Copies of Publications/Abstracts

**Please add this approval to your study file as this letter may be subject to audit and monitoring.**

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Dr Erica Packard  
**Research Co-ordinator**



Dr Pamela MacMahon  
 Clinical Psychologist  
 NHS Greater Glasgow and Clyde  
 Department of Mental Health and  
 Wellbeing  
 Gartnavel Royal Hospital  
 1055 Great Western Road  
 Glasgow  
 G12 0XH

R&D Department  
 Corporate Services Building  
 Monklands Hospital  
 Monkscourt Avenue  
 AIRDRIE  
 ML6 0JS

Date 07 November 2011  
 Enquiries to Lorraine Windsor,  
 R&D Facilitator  
 Direct Line 01236 712459  
 Email Lorraine.Windsor@lanarkshire.scot.nhs.uk

Dear ~~Dr MacMahon~~ Miss McMillan

**PROJECT TITLE: What is special about family relationships? Familial attributions and emotional responses to relatives who present with challenging behaviour**

**R&D ID NUMBER: L11081**

**NRS ID NUMBER: NRS11/MH49**

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Miss Amy McMillan	Trainee Clinical Psychologist	Principal Investigator	Lanarkshire Learning Disability Service, Kirklands Hospital

For the study to be carried out you are subject to the conditions outlined overleaf:

Cont/...

### Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and the Data Protection Act 1998.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: <http://www.show.scot.nhs.uk/cso/> or the Research & Development Intranet site: <http://firstport/sites/randd/default.aspx>).
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.
- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the R&D Department if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire.
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

Cont/...

I trust these conditions are acceptable to you.

Yours sincerely,



**Raymond Hamill**  
**Research & Development Manager**

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Miss Amy McMillan	Trainee Clinical Psychologist	Academic Department of Mental Health & Wellbeing, Academic Centre Gartnavel Royal Hospital, 1055 Great Western Road Glasgow G12 0XH	Principal Investigator
Professor Andrew Jahoda	Clinical Psychologist/ Senior Lecturer	Academic Department of Mental Health & Wellbeing Gartnavel Royal Hospital, 1055 Great Western Road Glasgow G12 0XH	Named Contact
Dr Erica Packard	R&D Manager	Research & Development Management Office Tennent Institute, 38 Church Street Western Infirmary, Glasgow G11 6NT	Sponsor Contact
Dr Gillian Anderson	Consultant Psychologist	Kirklands Hospital Fallside Road Bothwell G71 8BB	Local Contact

c.c - (email)

[nhsr.nrscc@nhs.net](mailto:nhsr.nrscc@nhs.net)

Miss Amy McMillan  
Trainee Clinical Psychologist  
Academic Department of Mental  
Health and Wellbeing  
Academic Centre  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow  
G12 0XH

Tel: (01563) 825856  
Fax: (01563) 825806

Date: 4 November 2011  
Your Ref:  
Our Ref: CAW/KLB/NM R&D 2011AA058

Enquiries to: Karen Bell  
Extension: 25850  
Direct Line: 01563 825850  
Email: [Karen.bell@aaaht.scot.nhs.uk](mailto:Karen.bell@aaaht.scot.nhs.uk)

Dear Miss McMillan

***What is special about family relationships? Familial attributions and emotional responses to relatives who present with challenging behaviour***

I confirm that NHS Ayrshire and Arran have reviewed the undernoted documents and grant R&D Management approval for the above study.

**Approved documents:**

Document	Version	Date
SSI Form	Version 3.2	05/09/11 signed
R&D Form	Version 3.2	05/09/11 signed
Staff Information Sheet	Version 1.0	11/07/11
Participant Information Sheet	Version 2.0	10/10/11
Participant consent form	Version 2.0	10/10/11
Carer contact sheet	Version 1.0	28/07/11
Initial info sheet for staff	Version 1.0	28/07/11
Checklist of Challenging Behaviour	No version	12/08/11
Demographic Information	No version	12/08/11
Cognitive Behavioural Interview	No version	12/08/11
Exploring the applicability of Weiner's model	No version	12/08/11

The terms of approval state that the investigator authorised to undertake this study is: -

- Miss Amy McMillan, University of Glasgow

With no additional investigators.

The sponsors for this study are NHS Greater Glasgow and Clyde.

This approval letter is valid until 4 January 2013.

Regular reports of the study require to be submitted. Your first report should be submitted to Dr K Bell, Research & Development Manager in 12 months time and subsequently at yearly intervals until the work is completed.

Please note that as a requirement of this type of study your name, designation, work address, work telephone number, work e-mail address, work related qualifications and whole time equivalent will be held on the Scottish National Research Database so that NHS R&D staff in Scotland can access this information for purposes related to project management and report monitoring.

In addition approval is granted subject to the following conditions: -

- All research activity must comply with the standards detailed in the Research Governance Framework for Health and Community Care [www.cso.scot.nhs.uk/publications/ResGov/Framework/RGFEdTwo.pdf](http://www.cso.scot.nhs.uk/publications/ResGov/Framework/RGFEdTwo.pdf) and appropriate statutory legislation. It is your responsibility to ensure that you are familiar with these, however please do not hesitate to seek further advice if you are unsure.
- You are required to comply with Good Clinical Practice (ICH-GCP guidelines may be found at [www.ich.org/LOB/media/MEDIA482.pdf](http://www.ich.org/LOB/media/MEDIA482.pdf)), Ethics Guidelines, Health & Safety Act 1999 and Data Protection Act 1998.
- If any amendments are to be made to the study protocol and or the Research Team the Researcher must seek Ethical and Management Approval for the changes before they can be implemented.
- The Researcher and NHS Ayrshire and Arran must permit and assist with any monitoring, auditing or inspection of the project by the relevant authorities.
- The NHS Ayrshire and Arran Complaints Department should be informed if any complaints arise regarding the project and the R&D Department must be copied into this correspondence.
- The outcome and lessons learnt from complaints must be communicated to funders, sponsors and other partners associated with the project.
- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collated in line with NHS Scotland IT Security Policies, until the destruction of these data. Under no circumstances should personal data be stored on any unencrypted removable media e.g. laptop, USB or mobile device (for further information and guidance please contact the Information Governance Team based at Ailsa Hospital 01292 513693 or 513694).

If I can be of any further assistance please do not hesitate to contact me. On behalf of the department, I wish you every success with the project.

Yours sincerely



**Professor Craig A White**  
**Assistant Director (Healthcare Quality, Governance and Standards)**

- c.c. Erica Packard, R&D, NHS Greater Glasgow and Clyde (sponsor contact)  
Dr Helen Lynn, Clinical Director, Learning Disability Services, NHS A&A  
Professor Andrew Jahoda (Academic Supervisor)  
Dr Pamela MacMahon (Academic Supervisor)  
Lesley Douglas, Finance, Ailsa Hospital  
Information Governance, Ailsa Hospital  
NRS Coordinating Centre, Aberdeen

R&D 2011AA058

What is special about family relationships? Familial attributions and emotional responses to relatives who present with challenging behaviour

## Appendix H – Approval from West of Scotland Research Ethics Service

### **WoSRES**

#### **West of Scotland Research Ethics Service**

Dr Pamela MacMahon  
Clinical Psychologist  
NHS Greater Glasgow and Clyde  
Department of Mental Health and Wellbeing  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow  
G12 0XH

**West of Scotland REC 5**  
Ground Floor - Tennent Building  
Western Infirmary  
38 Church Street  
Glasgow  
G11 6NT

Date 03 November 2011

Direct line 0141 211 2102  
Fax 0141 211 1847  
E-mail sharon.macgregor@ggc.scot.nhs.uk

Dear Dr MacMahon

**Study title:** What is special about family relationships? Familial attributions and emotional responses to relatives who present with challenging behaviour  
**REC reference:** 11/WS/0053  
**Protocol number:** 1

Thank you for your letter of 31 October 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		05 September 2011
Evidence of insurance or indemnity (Glasgow City Council)		03 October 2011
Investigator CV	1	31 August 2011
Other: Additional Information re Charities		
Other: Carer Contact Sheet	1	28 July 2011
Other: University Approval letter		11 August 2011
Other: Evidence of Insurance (Quarriers)		01 April 2011
Other: Evidence of Insurance (ENABLE)		01 April 2011
Participant Consent Form	1	18 July 2011
Participant Consent Form	2	10 October 2011
Participant Information Sheet: Family Caregivers	1	11 July 2011
Participant Information Sheet: Staff	1	11 July 2011
Participant Information Sheet: Initial information sheet for staff	1	28 July 2011
Participant Information Sheet	2	10 October 2011
Protocol	1	12 August 2011
REC application	1	05 September 2011
Response to Request for Further Information		31 October 2011

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**11/WS/0053**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

**Dr Gregory Ofili  
Chair**

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments  
"After ethical review – guidance for researchers"

Copy to: Dr Erica Packard, NHS Greater Glasgow & Clyde

*Note – The above letter is addressed to Dr MacMahon, who was named as Chief Investigator for the study, following guidance to all Trainee Clinical Psychologists from the WOSRES*

## Appendix I – Approval from Glasgow Social Work Services

Ethics Approval

Page 1 of 1

### Ethics Approval

Mokrovich, Jason [Jason.Mokrovich@glasgow.gov.uk]

**Sent:** 12 July 2012 09:05

**To:** Amy McMillan

**Cc:** Melling, Chris [Chris.Melling@glasgow.gov.uk]; Cook, Glenda [Glenda.Cook@glasgow.gov.uk]; Maguire, Susan [Susan.Maguire@glasgow.gov.uk]

---

Good morning Amy,

**Research: What is special about family relationships? Familial attributions and emotional responses to relatives who present with challenging behaviour**  
**Researcher: Amy McMillan**

I am pleased to confirm that your ethics research application for the above piece of research has been approved to proceed by the Heads of Learning Disability.

I ask that participants are not contacted directly, but that SW managers/staff are the 'go between' for this research (e.g. disseminate information sheet on the research). You can contact the Heads of Learning Disability to progress this. I've copied them into this e-mail.

Kind regards,

Jason

---

**Dr. Jason T. Mokrovich**

Principal Officer Service Modernisation

The Research and Practice Development Team  
Service Modernisation  
Social Work Services  
Glasgow City Council  
Wheatley House, 25 Cochrane Street, G1 1HL  
Glasgow G2 4PF

Telephone 0141-287 8737

Email [jason.mokrovich@glasgow.gov.uk](mailto:jason.mokrovich@glasgow.gov.uk)

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<https://mail.student.gla.ac.uk/owa/?ae=Item&t=IPM.Note&id=RgAAAAB4%2fmgjU34p...> 7/16/2012

## Appendix J – Participant Information Sheet



### **What is special about family relationships? Familial attributions and emotional responses to relatives who present with challenging behaviour**

#### **Information Sheet for Family Caregivers**

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with friends or relatives if that would be helpful for you. I am also very happy to try and answer any questions that you might have or give you more information that you might want. My contact details are at the end of this document.

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

We know that supporting a relative who has a learning disability can be stressful. It can be particularly stressful when your relative also displays challenging behaviour. Research has found that the beliefs carers have about challenging behaviour can impact the level of stress they feel. However, research has mainly focused on paid care staff, and the experiences of familial carers has been largely neglected.

The point of this study is to find out about familial carers' beliefs and experiences of supporting a relative who has a learning disability and displays challenging behaviour.

#### **Why have I been chosen?**

You have been asked to take part in the study because the professional who supports you and / or your relative knows that you are a family carer of an adult with a mild – moderate learning disability who is aged 18 – 45, and who may also display frequent challenging behaviour.

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

You do not have to take part in this study. It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. If you do decide to take part you are still free to change your mind at any time without giving a reason.

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

The researcher, Amy McMillan, will initially speak to you over the phone to answer any questions you may have. If you want to take part, she will then ask you to return a signed consent form (in the freepost envelope). After this, Amy will complete a questionnaire with you about your relative's challenging behaviour. This is to check that you are eligible to take part in the study.

If you are eligible and still want to take part, Amy will arrange to meet with you at a local health & social work centre. If it suits you better, then she will arrange to speak to you over the telephone. When you meet with Amy, or speak to her over the telephone, she will complete an interview and a questionnaire with you. This will last between 60 – 90 minutes. With your agreement, Amy would like to record the interviews. This would mean that she won't have to write anything down and will allow her to talk more freely with you.

### **Will taking part in the study be kept confidential?**

Your identity and personal information will be completely confidential and known only to the researchers. All information will be kept strictly confidential and held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission. Anonymous quotations from your interview may be used in the publication of this research. No identifiable information will be included in any publication of this research. However, in the unlikely event that Amy was worried about your safety or the safety of your family member, she will help you obtain appropriate help.

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

We hope that the results will provide a greater understanding of families' experiences of caring for an adult with a learning disability who displays challenging behaviour. This understanding will help services to provide more sensitive and tailored support to families with regard to their family member's challenging behaviour.

### **What are the possible risks and benefits of taking part?**

Risks: There are no direct risks from taking part, although some people may feel uncomfortable talking about their experiences.

Benefits: It is hoped that by taking part in this research, you will be providing valuable information regarding your beliefs and experiences of challenging behaviour. This would be extremely helpful in planning future support for families caring for individuals who display challenging behaviour.

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

The study has been reviewed by the department of mental health and wellbeing at the University of Glasgow to ensure that it meets important standards of scientific conduct. It has also been reviewed by NHS Greater Glasgow and Clyde local research ethics committee to ensure that it meets important standards of ethical conduct.

## **Independent Contact**

The staff member who gave you this information pack is completely independent from this study. If you wish to discuss the study, or the possibility of taking part of the study, with someone who is not involved in the study itself, please contact the staff member who gave you this pack. Alternatively, Dr Jaycee Pownall, University Teacher, is also independent from this research and will be happy to discuss any queries you may have. Her telephone number is 0141 211 3917.

## **Further information**

If you have any further questions or are interested in taking part in the study, please contact Amy McMillan, Trainee Clinical Psychologist, at the following address:

Mental Health and Wellbeing  
1st Floor, Admin Building  
Gartnavel Royal Hospital  
**FREEPOST** SC03907  
Glasgow  
G12 0BR

Telephone: 0141 211 0690

Email: [a.mcmillan.1@research.gla.ac.uk](mailto:a.mcmillan.1@research.gla.ac.uk)

Alternatively you can return the consent form in the freepost envelope, with your contact details enclosed, and Amy will contact you.

## **If you have a complaint about any aspect of the study?**

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanisms are also available to you.

*Thank you very much for reading this and for any further involvement you may have with the study.*

## Appendix K - Participant Consent Form



Participant ID:

**What is special about family relationships? Familial attributions and emotional responses to relatives who present with challenging behaviour**

### CONSENT FORM

*Please tick the box*

I confirm that I have read and understand the participant information sheet (Version 2) for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

I understand that the face-to-face/telephone interview can be audio recorded.

I understand that all information will be kept confidential and that only the researcher and her academic supervisors will have access to that information.

I understand that anonymous, direct quotations may be used in the write up and publication of the research.

I agree to take part in the above study.

Name of Participant: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Contact Details (Preferred Telephone Number): \_\_\_\_\_

*Thank you for taking part in this study*

## **Appendix L- Major Research Project Proposal and Amendment**

**What is special about family relationships? Familial attributions and emotional responses to relatives who present with challenging behaviour.**

Amy Jenefer McMillan

**Affiliation:** University of Glasgow  
Academic Unit of Mental Health and Wellbeing  
Trust HQ, 1<sup>st</sup> Floor  
Administration Building  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow  
G12 0XH

## **Abstract**

**Background:** Despite the high numbers of adults with learning disabilities that are supported by familial caregivers, the majority of research into caregivers' attributions of an individual's challenging behaviour (CB) has focused upon paid care-staff. **Aims:** The present study aims to explore the nature of cognitive and emotional responses of familial caregivers towards adults who display CB. The applicability of Weiner's attributional model of helping behaviour (Weiner, 1980; 1986; 1992) to familial caregivers of individuals with learning disabilities who display CB will also be explored. **Methods:** Participants will complete an interpersonal interview aimed to help them to recall a recent incident of aggressive CB displayed by the adult they care for. They will also complete questionnaires relating to the incident of aggression and a more general view of the person and their behaviour. Data will be analysed to determine if Weiner's model is upheld, and to explore the nature of cognitive and emotional responses made by familial caregivers. **Practical Applications:** Findings from the study will potentially inform professionals' approaches when working with families who support individuals with learning disabilities who display aggressive CB.

## **Introduction**

Carers often play a significant role in supporting individuals with a learning disability (LD), particularly when the individual also displays challenging behaviour (CB). Research has shown that carer behaviour can have a significant role in both the development and maintenance of CB (e.g. Hastings and Remington, 1994). Researchers have attempted to conceptualise carers' responses to CB within a cognitive-behavioural framework, exploring the potential role of carer attributions regarding CB and, in turn, their emotional responses, in influencing their behavioural response.

Weiner's attributional model of helping behaviour (Weiner, 1980; 1986; 1992) has previously been applied to enhance our understanding of care staffs' responses to CB exhibited by individuals with LD (Dagnan et al., 1998; Hill & Dagnan, 2002; Jones & Hastings, 2003). This model highlights the importance of three attributional dimensions in governing an individual's helping behaviour: (i) locus of causality (whether the cause is internal or external to the individual); (ii) controllability (whether the behaviour is under the control of the individual) and (iii) stability (whether the cause of the behaviour is constant or likely to change). According to Weiner's model, these attributions influence the carer's emotional response to an event and, in turn, these emotions influence the likelihood of helping behaviour.

The evidence regarding the applicability of Weiner's model to this field appears to be inconsistent. Both limitations of the model and methodological limitations of studies have been suggested as a cause of variability within the research. In relation to the model itself, Weiner proposes the emotional response evoked by an individual's attributions of an event is either anger or sympathy (with sympathy making the individual more likely to engage in helping behaviours). However CB has been shown to evoke various emotions in individuals, including anger, fear, irritation and disgust (Bromley and Emerson, 1995). Thus it may be that, within the context of CB, assessing only anger and sympathy does not adequately capture the key emotions evoked in carers.

The context in which the behaviour occurs may also impact upon the adequacy of Weiner's model. Willner and Smith have previously highlighted that Weiner's attributional model of helping behaviour was intended to apply to low frequency behaviours (2008). However by its very definition, CB is a behaviour of "...intensity, frequency or duration" (McClellan and Grey, 2007). Thus carers are not only responding to one incident of CB in isolation. Rather they are responding to the latest in a series of incidents, for which they have already developed attributions. Furthermore, care staff responding to an individual's CB do so within the context of an interpersonal history (Jahoda and Wanless, 2005). Thus carers are not only responding to the behaviour, but to the individual as well. Dagnan et al. (1998) reported that staff who perceived the client to be in control of the behaviour, made negative evaluations not only of the observed behaviour, but also of the individual client. Thus Weiner's model may not fully account for the relationship between attributions and emotions, when occurring within an existing, interpersonal relationship.

Variation within the research outcomes may also relate to the use of vignettes, which have been relied upon by the majority of studies in this area (Armstrong and Dagnan, 2011; Dagnan and Cairns, 2005; Dagnan et al., 1998; Hill & Dagnan, 2002; Stanley and Standen, 2000). Vignettes are essentially abstract events, to which the participant has no relationship, and limited knowledge of. Therefore, the participant may struggle to make attributions regarding locus of causality, controllability and stability of the behaviour (Willner and Smith, 2008). It is unlikely that a carer's response to a vignette is representative of their response to real incidents of CB displayed by those they care for.

Wanless and Jahoda (2002) attempted to address some of the limitations of previous research. They tested the utility of Weiner's model in care staff responses' to CB in both vignettes and real incidents. In addition to utilising real life incidents, they also assessed and explored the emotional responses experienced by staff in greater detail than that specified by Weiner's model. Prior to completing the measures, a cognitive

behavioural interview was administered to both facilitate recall and elicit emotions associated with the incident. Staff perceptions of both the behaviour and the individual were also elicited, to account for the interpersonal context in which staff attributions occurred. Negative evaluations of the individual and their behaviour were associated with attributions of internality and control, and also with anger. Furthermore, the evaluations of the individual were stronger in response to real incidents, as opposed to vignettes. Thus suggesting emotionally 'hot' attributions, occurring in situations characterised by conflict, are essentially interpersonal.

The interpersonal context is even more relevant when considering the dynamics within a family relationship. Drysdale et al. (2009) assessed the utility of Weiner's model in understanding maternal attributions to self injurious behaviour. Although the attributions made by mothers were consistent with the attributional dimensions of locus of cause, stability and controllability, they were also "...contextual, dynamic and emotionally driven". Thus it may be, that an unmodified Weiner's model cannot fully account for the responses of familial caregivers to adults who display CB.

It is estimated that approximately 60% of adults with a LD live with, and are cared for, by their families (Department of Health, 2001). Family carers of adults with a LD have been reported to be at increased risk of stress, depression and poor physical health (Hatton et al., 2010). Families who support individuals with LD who display CB, are likely to experience additional difficulties, including restrictions of quality of life (Emerson, 2001) and distress for other family members (MacDonald et al., 2006). However, having a family member with LD who displays CB will not necessarily induce increased levels of stress in the family (Baxter et al., 2000). Several factors have been proposed as mediating the levels of stress experienced, including caregivers' attributions (Sloper and Turner, 1993). Despite the number of adults with LD who continue to live at home, and the impact this can have upon the whole family, the majority of research regarding carer attributions towards CB has focused upon paid care staff, with families' views being largely neglected.

In summary, research evidence therefore appears to support the development of a modified version of Weiner's model to enhance our understanding of carers' behavioural and emotional responses to an individual's CB, within the context of a complex and interpersonal relationship. However, research regarding causal attributions for CB has focused mainly on care staff, largely neglecting families' attributions (Hyman and Oliver, 2001). This study therefore intends to adapt the work of Wanless and Jahoda (2002), in order to explore the attributions made by familial caregivers of adults in response to CB displayed by their relative with LD. There are various types of CB, all of which elicit an emotional response from individuals involved. However aggression has been reported to be one of the most interpersonal forms of CB (Emerson and Bromely, 1995), and is therefore likely to impact upon the familial relationship. Therefore, this study aims to explore the attributions of familial caregivers of adults who display verbal or physical aggressive CB. In doing so, this may further develop our knowledge of how families support their relatives with CB, and how services can best provide support for these families, in both managing and coping with CB.

### **Aims, Research Questions and Hypotheses**

#### ***Aims***

The initial aim of this study is to explore the nature of cognitive and emotional responses of familial caregivers towards adults who display CB. In doing so, this study will also explore whether Weiner's attributional model of helping behaviour (Weiner, 1980; 1986; 1992) provides a framework for understanding the emotional, attributional and behavioural responses of familial caregivers to their adult relative's CB.

#### ***Research Questions***

Qualitative data collected during the cognitive behavioural interview will allow for the following questions to be explored:

1. What is the nature of the incidents that are recalled by caregivers?

2. What are the caregivers' inter-personal perceptions of the individual?
3. What are the caregivers' perceptions of the individual's behaviour?
4. What are the emotional responses experienced by caregivers to the incident?
5. What was the caregivers' behavioural response to the incident?

### ***Hypotheses***

Although there has been limited research into familial attributions, based upon the literature that is available it is anticipated that Weiner's attributional model of helping behaviour will be supported in so far as:

1. Caregivers who attribute challenging behaviour to a stable cause and as internal and controllable to the individual will report more negative emotions and will be less likely to offer help.
2. Caregivers who attribute challenging behaviour to an unstable cause and as external and uncontrollable to the individual will report experiencing more positive emotions (such as sympathy) and will be more likely to offer help.

### **Plan of Investigation**

#### *Design*

A mixed methods design will be adopted, gathering both qualitative and quantitative data. A semi-structured interview will be used to obtain qualitative data allowing the exploration of caregivers' emotional and cognitive responses to challenging behaviour. Quantitative measures will be used to obtain correlational data allowing the exploration of the applicability of Weiner's model.

### ***Participants Inclusion Criteria***

Participants will be familial caregivers (whose first language is English), including parents, adoptive parents, grandparents or siblings of individuals who:

- are aged 18 – 45 years old
- have a diagnosis of mild to moderate LD, as indicated by the referrer
- display frequent CB, as identified by the Checklist of Challenging Behaviours (Harris et al., 1994)

### ***Participants Exclusion Criteria***

Non-family carers (such as support workers) will be excluded. Familial carers will be excluded if the individual they are caring for:

- is aged under 18 years or over 45 years
- displays infrequent CB, as identified by the Checklist of Challenging Behaviours (Harris et al., 1994)
- presents with dementia
- presents with severe to profound LD

### ***Recruitment***

It is anticipated that participants will be recruited via local health, social work and voluntary services. Initially potential participants will be advised of the study by health, social care and voluntary agency staff. If they express interest, staff will provide them with an information pack regarding the study (which will include a participant information sheet, contact details for the researcher, a consent form, and a freepost envelope). When providing information packs, staff will also establish if the carer is prepared to be contacted by the researcher via telephone in two weeks time, to provide them with further information and answer any questions they may have. During this

telephone call, if the carer consents to participate in the study, s/he will be asked to return the consent form in the freepost envelope provided and arrangements will be made for the interview to take place.

### ***Research Procedures***

The measures will be piloted to ensure they are understandable to participants and that the procedure is of an acceptable duration. Adjustments will be made according to feedback from this process. Following recruitment and consent processes, the study will be conducted in the following order. Initially the Checklist of Challenging Behaviours (Harris et al., 1994) will be administered during the initial telephone conversation, in order to ensure participants suitability. Those who are established as caring for individuals who display frequent aggressive behaviours will be interviewed. Demographic information will be gathered, and the interpersonal interview conducted. Following this, participants will be supported in completing the Attributional Style Questionnaire and other rating scales. Participants who choose to be interviewed over the telephone, will receive a copy of the measures prior to the interview, and the measures will be completed during the telephone call. It is currently estimated that the process will last approximately 90 minutes.

### ***Measures***

Identification of Challenging behaviour: In order to establish participants' suitability for the study, they will be asked to complete the Checklist of Challenging Behaviours (Harris et al., 1994). This will serve as a means of identifying participants who care for individuals who displayed three or more incidents of aggression in the last 3 months.

Demographics: Participants' age, gender, marital status, supports available to the family (including other organisations and professions involved) and relationship to the individual with LD (eg mother) will be sought. Information on the age, gender and diagnosis (if known) of the participants' relative will also be gathered.

Exploration of cognitive and emotional responses to Challenging Behaviour using an interpersonal interview: All participants will engage in a brief cognitive behavioural interview adapted (by Wanless and Jahoda, 2002) from a rational emotive behaviour therapy format (Trower et al., 1988). The interview is designed to help participants recall a recent incident of aggressive CB, and elicit the emotions and interpersonal appraisals experienced during the incident. Participants will be asked to describe an incident of aggression displayed by their family member, and to discuss the feelings experienced during this incident. Once participants have identified the key emotions experienced, they will then be asked about their perceptions of the client and what they believed caused the individual to act as they did. This method was previously adopted by Wanless and Jahoda (2002).

Exploration of the applicability of Weiner's model to this population: Following the interview, participants will complete the modified form of the Attributional Style Questionnaire (ASQ; (Peterson et al., 1982) previously developed by (Dagnan et al., 1998). They will be asked to choose the most likely cause of the incident just discussed, and rate their attributions of this cause on a 7 point bipolar scale for causality, stability, globality and controllability. The modified ASQ has been shown to have adequate validity and good internal consistency for all four attributions: causality  $\alpha = 0.74$ , stability  $\alpha = 0.56$ , globality  $\alpha = 0.67$  and control  $\alpha = 0.81$  (Armstrong & Dagnan, 2011). A series of ratings will then be obtained for participants optimism for the possibility of change; their willingness to provide extra help; and their emotional response to the CB. Participants will also be asked to rate the behaviour of the individual during the incident, from 'completely neutral' to 'extremely bad'. The evaluation of the individual will be scored in a similar way. These measures have previously been used by Dagnan et al. (1998) and Wanless and Jahoda (2002). Where necessary, measures will be adapted for telephone interviews.

### ***Justification of Sample Size***

The Dagnan et al. (1998) study was selected to calculate the required sample size. This study was selected because of similarities with the current study, including use of the same measures. The effect size for the attribution of controllability and negative

emotion was selected (0.52). An estimation of sample size was produced using Gpower software, taking alpha as 0.05, with a power of 0.8. This gave a sample size of 21 participants.

### ***Settings and Equipment***

Caregivers will be interviewed in appropriate health and social care settings or over the telephone. Digital recording equipment, telephone recording equipment will be required, as will transcribing equipment. Access to an encrypted laptop, photocopier, printer and stationary will also be required.

### ***Data Analysis***

Qualitative data gathered from the interpersonal interview will be transcribed verbatim and analysed using content analysis. With regards to the quantitative data, if the data is normally distributed, parametric analysis will be used. Specifically Pearson product moment correlation coefficient will be used. If the data is not normally distributed, non parametric analysis (Spearman rho) will be used to identify any correlations.

### **Health and Safety Issues**

Participants will be met within health and social care facilities, or interviewed over the telephone. When using clinical rooms, local health and safety procedures will be followed.

### **Ethical Issues**

Care will be taken throughout the study to ensure that the participants are fully informed of the research procedures (transparency) and have the opportunity to refuse or withdraw consent at any stage. All data will be anonymised and a coding scheme will be used to identify participants. As participation in the study will involve discussing

intense and distressing incidents, and the emotions attached to these, participants will be given time after the interview for further discussion and debriefing. Participants will also be given the contact details for the researcher and following completion of the study, will be sent information regarding the study outcomes.

### **Financial Issues**

A digital recorder, telephone recorder and transcribing equipment will be obtained from the Department of Mental Health and Wellbeing. Access to an encrypted laptop and a photocopier will also be provided by the department. It is currently estimated that stationary costs will be £95.92, and travel costs approximately £90. It is hoped that approximately 10 participants will be interviewed over the telephone, and travel costs are therefore based on travel to local services (at 15 miles each, 23p per mile) to meet with 11 participants and 15 trips to liaise with services regarding recruitment.

### **Timescale**

May 2011 – Submit proposal to university

September 2011 – Apply for Research & Development, and ethical approval

Spring 2012 – Pilot phase

Summer 2012– Begin recruitment and data collection

Winter 2012 – Analysis and write up

January 2013– Submit research to university

### **Practical Applications**

Understanding the attributions that familial carers make about an individual's CB may allow professionals to tailor their approaches when working with families. There are implications when considering treatment acceptability and engagement in treatment, which is relevant given the number of individuals who are cared for by their family in the current financial climate.

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## **AMENDMENT – October 2012**

### **Recruitment Process**

Recruitment of participants began in spring 2012. As a first step, the researcher made contact with service and team leads of local health, social work and voluntary services in the following health boards:

- NHS Greater Glasgow Clyde (GG&C)
- NHS Ayrshire and Arran
- NHS Lanarkshire

This comprised of:

- 13 local Community Learning Disability Teams
- NHS GG&C Complex Needs Team
- NHS GG&C Adult Autism Team
- South Glasgow Social Work run services
  - Carer groups and 2 day services
- Quarriers
- Enable Glasgow
- Four local branches to the west of Scotland of Enable Scotland

The researcher attended team meetings and met with service leads to present a power point presentation regarding the study, and to answer any questions that staff may have had. Staff were provided with additional information on the study and each team were given 10 participant information packs. Staff were asked to consider their caseloads in order to identify any family carer who met criteria, and to provide them with information regarding the study. In order to be proactive with recruitment staff were also asked to establish if the carers whom they approached were happy to be contacted by the researcher in two weeks time. This enabled the researcher to prompt family carers about the study and answer any questions they may have had. In order to keep the study and the limited available time for recruitment in the minds of professionals, the researcher kept in regular contact (approximately twice monthly) with identified contacts at each team and service.

### **Difficulties Encountered During Recruitment**

During the initial months of recruitment, only 5 participants agreed to take part in the study. As a result of this, and through discussion with research supervisors, the inclusion and exclusion criteria were amended. The upper age limit for the individual with a learning disability was removed, thus participants could be family carers of individuals who were aged 18 years and over. However, to the author's knowledge, by winter 2012, only 13 potential participants (including the 5 mentioned above) had been provided with information regarding the study. From these individuals, 8 were successfully recruited. Of the remaining individuals, three had provided consent but withdrew from the study prior to interview due to various issues (including a bereavement and illness in the family). One potential participant was excluded upon initial contact when it became clear that their son had recently been diagnosed with dementia. The final potential participant, who had provided consent to be contacted after 2 weeks of receiving information about the study was un-contactable and did not return a consent form.

### **Reflections on the Difficulties with Recruitment of Participants**

Upon reflection, three issues come to mind which were possible barriers to the recruitment of participants. Firstly, from information provided by caregivers at the carer groups and from participants themselves, it appears that family carers may not view challenging behaviour as challenging when it occurs only within the family home. Many carers commented that their relative did not display any challenging behaviours in the community, but rather 'saved' them until they were home. Upon discussion, they felt that because their relative was not challenging for anyone else, that they would not meet criteria for the study. Although these individuals were assured that they did meet the inclusion criteria for the study, they appeared resigned to the idea that challenging behaviour was only deemed so when other people found their relative's behaviour difficult to manage.

Secondly, due to a lack of funding and health and safety issues, participants were not compensated for their time or travel, nor was the researcher allowed to interview participants outwith identified health, social work or voluntary service settings. It is

possible that some carers would have been happy to be interviewed at home but declined to take part in the study because they did not want to travel to another location to be interviewed. Furthermore it may have been that staff failed to notify possible participants who they did not think would have the time or resources to travel to meet with the researcher. A more general issue of 'gate keeping' by staff may have been another barrier to recruitment. From discussion with staff members in the services approached, it appears that when considering possible participants, staff held beliefs that certain carers would not participate, or that their situation was too challenging / difficult and participation in research would not be appropriate. Thus these carers were never advised about the study.

### **Amendment to the Study**

Unfortunately the data gathered from the small number of participants recruited did not lend itself to the original design and intended analysis, as detailed in the proposal. Thus it was not possible to utilise statistical analysis to explore whether Weiner's model provides a framework for understanding the emotional, attributional and behavioural responses of familial caregivers to their adult relative's CB, as originally intended. However, despite these difficulties, the 8 participants who were recruited offered rich and extensive accounts of their experiences of supporting their relative with challenging behaviour. It was therefore felt appropriate to recalibrate the objectives of the study and the approach to the analysis.

### **Aims & Research Questions**

The aim of the study is to explore the nature of cognitive and emotional responses of familial caregivers towards adults who display CB. In order to achieve this aim, the following research questions will be addressed:

1. What is the nature of the incidents that are recalled by caregivers?
2. What are the emotional responses experienced by caregivers?
3. What are carers' interpersonal appraisals?

4. What are carers' desired actions in response to the recalled incident?
5. What was the caregivers' behavioural responses to the incident?

### **Data Analysis**

In order to achieve the aims detailed above, the qualitative data gathered from the interpersonal interviews will be analysed using Conventional Content Analysis. This method of content analysis was selected because Hsieh and Shannon (2005) report that this method of analysis is the most appropriate method when limited research is available on a phenomenon, in this case, limited literature regarding family carers' experiences of CB. Therefore, relevant interview sections relating to participants' responses to the open ended questions asked as part of the interpersonal interview will be transcribed verbatim and coded from the transcripts.

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